



UNIVERSITY OF
STIRLING

Thesis submitted in partial fulfilment of the requirements of the Doctor of Applied Social Research degree.

By Carole Hunter BSc, BA, MSc, MRPharmS.

Title: Evaluation of Syringe Markers Distributed Through Community Pharmacy Needle Exchanges.

October 2012.

	Page Number
<u>INDEX</u>	ii
<u>Acknowledgements.</u>	iv
<u>Abbreviations</u>	v
<u>Abstract</u>	vi
<u>Chapters</u>	
1. <u>Literature Review</u>	
1.1 Introduction	1
1.2 HIV/AIDS	3
1.3 Hepatitis C	8
1.4 Harm Reduction and the Development of NEXs	12
1.5 Sharing and Re-Use of Injecting Equipment	18
1.6 Syringe Identification	24
1.7 Cost Effectiveness	28
1.8 Development of Community Pharmacy NEXs	30
1.9 Legal Issues	36
1.10 Public Attitudes and Needle Exchanges	39
1.11 Summary	43
2. <u>Methods and Methodology</u>	
2.1 Background	46
2.2 Theoretical Perspectives	51
2.3 Evaluation Design	56
2.4 Ethical Processes	65
2.5 Data Collection	67
2.6 Reflections on Design and Methodology	75
2.7 Analysis	78
3. <u>Peer Research Involvement</u>	
3.1 Background	81
3.2 Practical Aspects	94
3.3 Ethical Aspects	100
3.4 User Involvement Group Field Work Diary and Reflections	105
3.5 Field Work Diary Analysis	109
3.6 Summary	118
4. <u>Findings</u>	
4.1 Introduction	122
4.2 Refusal Rates	125

4.3	Questionnaire Responses	
4.3.1.	Personal Characteristics and Current Injecting Practices	128
4.3.2.	Use of the Markers	141
4.3.3.	Attitudes Towards the Markers	149
4.4	Feedback from Participating Community Pharmacists	153
4.5.	Discussion of Findings	155
5.	<u>Conclusions</u>	
5.1	Summary	162
5.2	Potential Options to Monitor Effectiveness of Syringe Marker Supply	165
5.3	Discussion of Findings and Proposed Areas of Further Work	168
5.4	Evaluation Limitations	179
5.5	Role of the Practitioner-Researcher in the Evaluation	181
5.6	Concluding Observations	182
6.	<u>References</u>	185
7.	<u>Appendices</u>	
Appendix 1	Media examples illustrating “moral panic” type Reporting	199
Appendix 2	Discarded Needle Article	201
Appendix 3	Safe Disposal Information	202
Appendix 4	Costs	203
Appendix 5	Participation Letter	204
Appendix 6	Markers and Instruction Leaflet	205
Appendix 7	Training Presentation	206
Appendix 8	Questionnaire	208
Appendix 9	Patient Information	211
Appendix 10	Field Work Diary Themes	212
Appendix 11	Commercially Produced Syringe and Paraphernalia Markers	213

Acknowledgements.

Thanks are due to my supervisors and examiners. I would also like to acknowledge the important part played by the peer researchers, service users and community pharmacy staff. Thanks are also due to my professional work colleagues and managers, past and current, for their support.

Special thanks are also due to my two wonderful daughters, Dr Donna Claire Hunter and Police Constable Amie Hunter, for their constant patience, support and encouragement.

Abbreviations

ACMD	Advisory Council on the Misuse of Drugs
AIDS	Acquired Immunodeficiency Syndrome
BBV	Blood Borne Virus
CMO	Chief Medical Officer
DMSS	Drug Misuse Statistics Scotland
DTOA	Drug Trafficking Offences Act
DV	Dependent Variable
EIU	Effective Interventions Unit
GP	General Practitioner (Medical)
HCAP	Hepatitis C Action Plan (Scotland)
HCV	Hepatitis C Virus
HIV	Human Immunodeficiency Virus
HPA	Health Protection Agency
HPS	Health Protection Scotland
IDU	Injecting Drug User(s)
IEP	Injecting Equipment Providers
IHRA	International Harm Reduction Association
ISD	Information Services Division
IV	Independent Variable
JUNP	Joint United Nations Programme
MDA	Misuse of Drugs Act
MEP	Medicines, Ethics and Practice Guidelines
NEX	Needle Exchange(s)
NTA	National Treatment Agency
IEP	Injecting Equipment Providers
NICE	National Institute for Health and Clinical Excellence
NSP	Needle and Syringe Programmes
REC	Research Ethics Committee
RPSGB	Royal Pharmaceutical Society of Great Britain
SCDEA	Scottish Crime and Drug Enforcement Agency
SDF	Scottish Drugs Forum
SHHD	Scottish Home and Health Department
SUIG	Service User Involvement Group
TQM	Total Quality Management
UIG	User Involvement Group
UN	United Nations
WHO	World Health Organisation

Title:

**Evaluation of Syringe Markers Distributed Through Community Pharmacy
Needle Exchanges.**

Abstract

The aim of this study is to evaluate the supply of markers for the identification of syringes distributed by pharmacy needle exchanges and to determine if this product and service delivery offers a feasible method of marking syringes to promote the reduction of accidental sharing of syringes and needles amongst injecting drug users (IDU) and thereby reduce the risk of transmission of blood borne viruses (BBVs) and other related infections. This study involves the assessment, implementation and evaluation of syringe markers as a pilot study within three community pharmacy sites in Glasgow. The secondary aims of the study were to identify whether the supply of syringe markers from community pharmacy needle exchanges was acceptable to IDU and if it enabled them to mark their syringes. The literature review demonstrates that providing a means of identification of personal injecting equipment has been proposed as a viable option that should be promoted to prevent the inadvertent accidental sharing of syringes within a group setting.

Needle exchanges (NEX) are important component parts of the harm reduction responses designed to reduce the physical health harms caused to individuals through injecting drug use. The literature is reviewed on BBV transmission and the historical, legal and policy context associated with the development of NEXs. Community

pharmacies act as a source of health advice and can help to facilitate access to treatment services for those attending the NEX. However the specific aim of this study is not to investigate the totality of the benefits of a NEX but to examine the supply of a potential means of reducing accidental and unintentional sharing of all injecting equipment and thereby contribute to minimising some of the health harms linked to injecting drug use.

Three established community pharmacies were identified as suitable sites to pilot the supply of syringe markers. A number of criteria were used to select the sites. These included an assessment of the geographic locations, staffing arrangements, NEX attendances and transactional activity and the availability of private consultation facilities. The health board central database which holds records on a range of factors including, the characteristics of those who attend NEX and detailed information on all transactions, was used to identify the most suitable sites to pilot the new intervention. This indicated that the characteristics of those who attended the three chosen sites were broadly similar to the wider NEX attending population.

The evaluation was conducted in two separate periods. The first 4 week period was the supply phase where markers were distributed over this period to all patients receiving NEX packs from the 3 pharmacies. The second data collection phase was undertaken in the following 4 week period. Data was collected by means of a structured questionnaire. In order to reduce the potential interviewer bias it was decided to incorporate the use of peer researchers in the administration of the questionnaire. The Scottish Drugs Forum (SDF) was approached and agreement was reached to use members of the Service User Involvement Group (SUIG) to assist with

the design and administration of the questionnaire. A submission was made to the health board Research Ethics Committee (REC) and approval was given to enable the study and the research evaluation to proceed. Before the start of the study, joint briefing and training sessions were held for pharmacy staff from the 3 sites and the 6 participating SUIG members.

A total of 177 questionnaires were completed during the second data collection phase of the evaluation. Information was collected on personal details and injecting behaviours (including deliberate and accidental sharing), any current means of syringe identification, use of the markers and on the usefulness of the instruction card. Most individuals (75%, n=132) had been supplied with the markers to trial during the first supply phase of the study with 63% of the 132 (n=83) of those individuals reporting use of the markers. The results of the evaluation and subsequent analysis of the findings indicated that the syringe marker supply could be successfully implemented using pharmacy NEXs. The product and the supply method were acceptable to both staff and service users. Initial bivariate analysis was conducted using a number of dependent and independent variables identified within the questionnaire. These findings highlighted a number of areas worthy of further exploration, including emerging differences between male and female respondents, and indicated specific target groups for future developments in syringe identification.

The contribution of the peer researchers was found to be a significant factor in successfully completing the evaluation. However it is not possible to make any definitive statements on how effective the intervention is in terms of reducing the transmission of BBVs and other related infections. The findings of the evaluation

indicated a number of potential areas of work that could be usefully explored to investigate the effectiveness of the markers in reducing the transmission of infections. The limitations of the evaluation became apparent during the course of the study and the implications of these limitations are discussed.

Chapter 1

Literature Review.

1.1 Introduction.

The supply of syringe markers is a proposed harm reduction intervention that was based on the emerging evidence on the identified risks associated with deliberate or accidental sharing of injecting equipment (Speed, 1998; Hunter, Stimson, Judd *et al*, 2000; Taylor, Fleming, Rutherford *et al*, 2004). This evaluation is aimed at investigating the practical application of one proposed solution to reducing accidental sharing and thereby promoting safer injecting practices. The intervention and evaluation was conducted in community pharmacy needle exchanges (NEXs).

In 1656, Sir Christopher Wren was the first person in Britain reported to use a form of intravenous injecting when he conducted experiments administering opium and other substances to dogs using this new method (Derricott, Preston and Hunt, 1999:8). The syringe attributed to Wren was described as a crude device which consisted of “a quill attached to a small bladder” (Derricott *et al*, 1999:8). According to Berridge, in the 19th Century, developments into finding an injectable means of drug delivery were associated with developments in the medical profession which, at the time, was attempting to differentiate itself from the “quacks, herbalists, patent-medicine vendors and manufacturers” who had predominated in providing medical remedies and advice (1999:140). Part of this search for a distinct scientific medical identity involved using injecting equipment as a new means of administering drugs and according to Berridge

this enabled the medical profession to use the injection of drugs as a “more scientific and exact” way of treating symptoms (1999:140). In an 1868 article, Dr Francis Anstie had promoted the hypodermic injection of remedies and claimed that the advantages of treating the patient by injecting morphine when compared with oral administration of the drug were substantial (Berridge, 1999:141).

Despite this historical background, widespread problematic injecting drug use is a relatively recent phenomenon. Early indications of illicit intravenous drug use were first reported in the UK in the 1920s (Derricott *et al*, 1999:25). It was recorded that this became established as a cultural phenomenon during the 1970s and 80s when illicit drug injecting drug established itself in Western societies and rapidly spread globally (Rhodes, Greenwood and Robertson, 2001:6).

Addiction, including drug injecting, has evolved into a global phenomenon and according to Alexander has become “endemic in western free-market society” (2000:501). Alexander’s premise is that social dislocation caused by free markets is the “precursor of addiction” (2000:504). This is only one of a number of theories of the origin and causes of addiction. While a full review of the range of theories is out with the scope of this study, there is no doubt that whatever the cause(s) of addiction, the problems associated with injecting drugs are not solely local but have national and international dimensions. It is therefore inevitable that injecting equipment supply schemes are now found world wide in response to widespread addiction and the health problems related to injecting drug use. Different models of delivery have developed that are dependent on the existence of national differences in both legal and policy contexts.

Two of the current major problems related to increasing injecting drug use, both in the UK and world wide, are the continuing health problems associated with the Human Immunodeficiency Virus (HIV) and with the transmission of Hepatitis C (HCV).

1.2 HIV /AIDS.

Acquired immunodeficiency syndrome (AIDS) is defined as a cluster of related medical conditions resulting from infection by the human immunodeficiency virus (HIV), which results in severe weakening of the immune system and HIV is spread through contamination of paraphernalia used to inject drugs and through a variety of other means including sexual transmission, blood transfusions, and from mother to child (Piot and Cherney, 2001). The major problem for those who inject illicit drugs is that AIDS can be transmitted through the injecting drug using population mainly by sharing of any of the items of paraphernalia used to prepare and inject illicit drugs (Battjes and Pickens, 1988:1).

The syndrome was first identified in Los Angeles in 1981 and a description of the HIV responsible for causing AIDS was first recorded in 1983 (Oxford Medical Dictionary, 2007). Due to the development of new treatment therapies the progression of the disease from infection with the HIV to AIDS has dramatically changed and it is now possible to delay the onset, improve survival rates and at the same time improve the overall quality of life of sufferers by treatment with new drug therapies including combinations of protease inhibitors and reverse transcriptase inhibitors (Piot and Cherney, 2001). However, although the progression of the disease can be slowed, there is still no cure for HIV infection. The primary means of prevention of the transmission of HIV in IDU remains rooted in the health services along with a

combination of educational and harm reduction methods including the increased provision of sterile injection equipment (Piot and Cherney 2001). As a result of the global scale of the problem a major monitoring programme entitled, “The Joint United Nations Programme (JUNP) on HIV/AIDS”, has been initiated under the direct control of the United Nations (UN) Secretary General (Last, 2007, Oxford Ref Online). This UN body is responsible for collection, analysis and production of reports from data on AIDS and HIV infection and for the international co-ordination and advocacy for improved public health programmes to prevent and control the spread of AIDS. In January 2006 the JUNP reported that HIV/AIDS was responsible for infecting in excess of 42 million people and that this had resulted in an estimated 12 million deaths (Last, 2007).

The recent 2009 “Shooting Up” report from the UK Health Protection Agencies (HPA) claims that, apart from the outbreak in Edinburgh in the 1980s, HIV infection is relatively uncommon in injecting drug users (IDUs) and proposed that this low incidence is due in part to effective community based interventions (HPA(s), 2009:7). Despite the obvious dangers and risks of HIV transmission through injecting drug use the “Shooting Up” report claims that there has been no recorded episode of a specific outbreak in the United Kingdom similar to outbreaks that have happened in other parts of the world (HPS(s), 2009:7).

In Britain the levels of HIV infection amongst the IDU population remains low by international standards (Stimson, 1995:700). Whilst acknowledging the difficulties inherent in linking social interventions and the prevention of an epidemic Stimson argues that there is *prima facie* evidence to demonstrate the success of syringe exchanges and that the range of different interventions introduced in the UK has

affected the behaviour of IDU to an extent that an epidemic of HIV infection in this group has been prevented (Stimson, 1995:699). The UK experience is only one example that illustrates the prime importance of introducing interventions quickly to encourage the changes in behaviour that are required to reduce the spread of HIV infection (Stimson, 1995:699).

The first major report on the relationship between HIV / AIDS and injecting drug misuse was published by the Advisory Council on the Misuse of Drugs (ACMD) in 1988. The report concluded that “HIV is a greater threat to public health and individual health than drug misuse” (ACMD, 1988:75). As a result, the fear generated by the concerns relating to the spread of HIV was a major contributory factor that resulted in the early development of needle and syringe exchange programmes (NSP) in the UK.

Scotland was at the forefront in identifying the relationship between injecting drug use and HIV infection. In 1985, Dr Roy Robertson and his colleagues in a general practice in Edinburgh had identified, within one GP practice, that 51% of the injecting drug users were HIV positive (Robertson, Bucknall, Welsby *et al*, 1986:528). Robertson and his colleagues advocated that a “rapid and aggressive intervention” was required to limit the spread of infection (1986: 527). The authors were unable to identify the origin of the virus within the local population. However, they claimed that the rapid spread of infection had resulted from a combination of a number of interrelated factors including injection of heroin and sharing of injecting equipment due to lack of access to sterile equipment. They concluded that this combination of factors resulted in an increased risk of contracting HIV (1986:529). This effectively resulted in the establishment of a service that was a precursor to the subsequent

development of NEX schemes where the two GPs within the practice introduced an exchange policy for needles and syringes to those patients they had identified as being most at risk (Robertson *et al*, 1986:529).

A 1986 report published by the Scottish Home and Health Department (SHHD) was the first United Kingdom Government paper to recognise the existence of HIV infection within the population of IDUs. This report stated that,

“There is a need to contain the spread of HIV infection among drug users, not only to limit the harm caused to drug misusers themselves but also to protect the health of the general public. The gravity of the problem is such that on balance the containment of the spread of the virus is a higher priority in management than the prevention of drug misuse” (SHHD, 1986:5).

This mirrored the later conclusions of the 1988 ACMD report where prevention of harm by minimising the spread of HIV became the primary priority for intervention. It has been reported that the changes which took place at this time were effectively a “paradigm shift” which had radically changed the focus of attention away from the addiction itself onto the impact that injecting behaviours were having on the physical health of drug users (Jones, Pickering , Sumnall *et al*, 2008:11).

It is clear from this brief summary that the introduction of NSPs and related policy developments in the United Kingdom have had a major impact in reducing injecting associated risks resulting in, what Stimson described as, the UK’s “low and stable prevalence of HIV infection” (Stimson, 1995:712). Australia adopted an approach similar to that of the UK which incorporated harm reduction interventions including drug treatment programmes, prescription of substitution therapies and education about

safer injecting practices that became a core part of their early national HIV/AIDS policies (Loxley, 2000:407). In Europe by 1987 NSPs had been adopted by Denmark, the Netherlands, Malta, Spain and the UK as public health measures and by 2001, 26 of the European Union countries had NSPs in place (Hedrich, Pirona and Wiessing, 2008:508).

This picture is not replicated in other parts of the world where different policy approaches to the risks of intravenous drug use have been adopted. Despite the fact that the HIV was first identified in the USA there was no parallel introduction of NSP similar to those established in Europe and Australia. Lurie and Drucker claimed that this was a major public health failure and that the USA federal government's lack of support and funding for any national NEX schemes, contrary to a number of government funded reports that had supported the introduction of NEXs, could have been responsible for high levels of HIV infection among "thousands of IDUs, their sexual partners and their children" (1997:604). As a result of this ban, Lurie and Drucker claim that the absence of a national NEX in the USA has contributed to an estimated "4,000-10,000 preventable HIV infections" and that the associated social costs attached to providing treatment for these infections are estimated at between "a quarter and half a billion dollars" (1997:600). These estimates were arrived at by comparison with the Australian schemes where the estimated figures were based on the assumption of the position that would have existed if, in 1987, the USA had implemented and developed a NEX programme following the Australian model (Laurie and Drucker, 1997:606).

1.3 Hepatitis C Virus (HCV)

HCV is described as a “blood-borne virus that can seriously damage the liver and affect its ability to function” (Scottish Executive, 2006:1). This virus was first identified in 1989 (Health Protection Scotland (HPS), 2010). HPS reported on the differences in routes of transmission of HCV in countries that are termed either resource-rich or resource-poor. In resource-rich countries, including the UK, sharing of injecting drug equipment has been identified as the main route of transmission and in resource-poor areas the main cause of infection is deficiencies in the healthcare system including use of infected blood products and of non-sterile equipment (HPS, 2010). It has been estimated that approximately 70 to 75% of people infected with HCV will progress to developing chronic hepatitis infections with a high risk of the infection leading to serious liver disease including liver cancer (HPS, 2010). If these estimates are accurate then this will inevitably lead to increased demands on the resources of both health and social care services in Scotland, throughout the UK and in other countries.

HCV has been declared a global health problem and the World Health Organisation (WHO) estimates that 3% of the world’s population is infected (Wright, Millson and Tompkins, 2005:5). The evidence from a review of the worldwide HCV prevalence among IDU recorded reported data from 57 countries and that for 49 of those countries the HCV prevalence rates among IDU was reported to be more than 50% (Aceijas and Rhodes, 2007:352). The authors also identified evidence to show that in 16 countries, IDUs were infected with both HCV and HIV. At the end of 2008 it was estimated that 1% of the population in Scotland, which equates to approximately

50,000 people, had been infected with HCV (HPA, 2009:10). The majority of these infections were as the result of injecting drug use (Hutchison, Roy, Wadd *et al*, 2006:8). As testing for HCV is ongoing, not all of the estimated numbers of those infected have yet been diagnosed as HCV positive. By the end of 2008 the total number of diagnosed HCV positive people in Scotland was 25,355 (HPA, 2009:11).

Scotland's Health Minister in 2004 stated that the HCV "is one of the most serious and significant public health risks of our generation" (Hutchison, Roy *et al*, 2006:8). As already described this is a worldwide problem and in a review of the global epidemiology of HCV infection, Shepard and colleagues estimated that approximately 123 million people may be infected with HCV (Shepard, Finelli and Alter, 2005:558). They concluded that for the developed world, injecting drug use is the main causative factor responsible for the high rates of HCV infection (Shepard *et al*, 2005:559).

In an examination of the trends in HCV prevalence in Glasgow and Edinburgh amongst IDUs, at a time when needle and syringe exchange schemes were expanding, it was found that amongst young injectors in the 1990s there was a decrease in the incidence of HCV that coincided with the introduction of NEX schemes and related treatment interventions, however the authors claimed that the number of those infected were still at unacceptably high levels (Goldberg, Burns, Taylor *et al*, 2001:457). This indicated that the basic NEX schemes had only been partially successful in controlling the spread of HCV and the authors recommended the need for expanded prevention work and further research (Goldberg *et al*, 2001:457).

A review of the epidemiological evidence in Scotland has demonstrated that in Glasgow, from the period 1990 to 1996, there had been a reduction in HCV prevalence from 79% to 66% (Hutchison, Roy *et al*, 2006:11). The authors suggested that this decline was due to the fact that in the period from the late 1980's and throughout the 1990's a number of interventions had been implemented. These interventions, aimed at reducing the transmission of BBVs among IDUs, included schemes to provide sterile injecting equipment and prescribing opioid substitution treatment programmes (Hutchison, Roy *at al*, 2006:11). As no further significant reductions in HCV prevalence after 1997 were noted the authors concluded that the findings demonstrated that although it was accepted that the current harm reduction measures were recognised as reducing the spread of HCV among IDUs, in isolation these strategies were not sufficient to fully control the epidemic (Hutchison, Roy *at al*, 2006:11). One of the aims of the study described here includes the evaluation of a novel method of syringe identification that may have the potential to contribute to the reduction of HCV transmission in the drug using population through providing a method to promote a reduction in accidental sharing.

Inevitably, due to the interrelated physical, social and cultural factors linked to intravenous drug use, it is difficult to definitively isolate the effects of NEXs from other harm reduction, treatment, education and other preventative initiatives. According to Ashton the argument relating to the critical role that NEX plays in containing the spread of HCV when compared with HIV is less apparent. He claims that the evidence to support the effectiveness of NEXs in reducing the incidence of HCV in IDUs is far less convincing and “rests partly on eliminating the alternatives” (Ashton, 2003:4). However the inherent difficulties should not deter the search for

alternative prevention strategies to reduce the spread of HCV. This is particularly important when the scale and urgency of the current and potential future problems outlined above have been identified as a major issue that can no longer be ignored (Scottish Executive, 2006:3).

There appears to be evidence to show that the effects of NEX have not had the same impact on HCV as with HIV. Despite this, results from a modelling study assessing the impact of existing and of “hypothesised” prevention initiatives on HCV transmission among IDUs in Glasgow concluded that during the period 1988-2000 an estimated 45,000 HCV infections had potentially been prevented as a result of these harm reduction strategies (Hutchison, Bird, Taylor *et al*, 2006:211). The authors claim that, in terms of public health, this model has the potential to indicate strategies that are effective in reducing the incidence of HCV infection (Hutchison, Bird, et al, 2006:219). These conclusions have been supported elsewhere and a previous Australian study had concluded that control of an HCV epidemic required different approaches with a greater emphasis on reducing needle and syringe sharing from those employed to reduce the impact of HIV transmission and that “more intense concentration” was required to develop effective HCV harm reduction strategies (Crofts, Aitken and Kalder 1999:221).

In 2002 the Effective Interventions Unit (EIU) in Scotland reviewed the current research evidence on the HCV risks and prevention strategies in IDUs. This review concluded that no single strategy was likely to be effective and that any new strategy should incorporate a range of different interventions (Morrison, Duff, Taylor *et al*, 2002:5). Phase 1 of Scotland’s Hepatitis C Action Plan (HCAP) was published in

2006. In a foreword to the document the Chief Medical Officer (CMO) noted that “Prevention is as important and necessary as treatment and care” and that “in order to meet the needs of people who have been infected with Hepatitis C, existing services may need to change the way they do things” (Scottish Executive, 2006:v). In Scotland, and internationally, existing strategies have not yet controlled the epidemic and reducing HCV and Hepatitis B incidence in the IDU population continues to be a “major challenge” (Loxley, 2000:407). For this reason the prevention aims of Scotland’s national Hepatitis C Action Plan incorporate specific actions where the anticipated outcomes include reducing sharing of injecting paraphernalia and reducing HCV transmission among IDUs (Scottish Government, 2008:19).

1.4 Harm Reduction and the Development of Needle Exchanges.

Harm reduction has been defined as,

“Policies, programmes and practices that aim primarily to reduce the adverse health, social and economic consequences of the use of legal and illegal psychoactive drugs without necessarily reducing drug consumption. Harm reduction benefits people who use drugs, their families and the community” (IHRA, 2009:1).

The supply of syringe markers through community pharmacy NEXs is a harm reduction initiative that focuses solely on reducing the adverse health consequences caused by continued injection of illegal drugs. Essentially the aim of any NEX is to reduce the harms caused by injecting drug use. The harm reduction term is wider than NEXs and covers a wide range of programmes and policies including:

1. Advocacy for changes in drug policies, including legalisation and changes in drug paraphernalia laws.
2. HIV/AIDS-related interventions, including needle/syringe exchange programmes.
3. Broader drug treatment options, including methadone maintenance prescribing.
4. Drug abuse management for those who wish to continue using drugs, including promoting safer and more responsible drug use.
5. Ancillary interventions, including housing and advocacy groups.”

(Extract from Inciardi and Harrison, 2000:viii).

According to Inciardi and Harrison, although the term harm reduction covers a range of areas described above, there is no single universally accepted definition (2000:vii). It appears obvious that the ultimate harm reduction initiative would be a total cessation of injecting drug use. Despite there being a number of different perceptions as to the exact definition of harm reduction they claimed that the essential feature of harm reduction is the “attempt to ameliorate the adverse health, social or economic consequences associated with the mood altering substances without necessarily requiring a reduction in the consumption of these substances” (Inciardi and Harrison, 2000:viii). As mentioned above this evaluation is confined to the one specific health aspect of harm reduction within the NEX context and that is to evaluate the supply of markers and acceptability of this method of syringe identification as a potential means of minimising the harms caused by sharing of injecting equipment. Whilst the complete cessation of drug use inevitably remains the ultimate goal for patients and treatment services, the evaluation that has been undertaken into the distribution of syringe markers from community pharmacies attempts to investigate a potential method of ameliorating harms within the context of the period of a patient’s life

where they are continuing to participate in potentially dangerous injecting drug use practices.

Early harm reduction initiatives originated in the Netherlands where the first NEX programme was established in 1984 (van Haastrecht, 1997:57). This programme was established in an attempt to reduce the spread of hepatitis in the injecting population. As these programmes predated the identification and understanding of the transmission mechanism of HIV/AIDS it is postulated that this is the reason why the incidence and prevalence of HIV infection in the Netherlands remained at a relatively low level when compared with the “epidemic levels” that emerged in other countries. (van Haastrecht, 1997: 59). In the UK, NEX schemes were initiated as a policy response to the emergence of HIV/AIDS. According to Stimson, there is evidence from a review of this policy change and its subsequent implementation that IDU can alter their behaviour and that this, in turn, led to improved health by reducing risks of HIV infection (1995:699).

The policy of providing drug users with sterile injecting equipment did not have universal acceptance in the early stages of development. For example, in 1987, Ghodse and colleagues commented in the debate that due to the fact that there was minimum information available on existing injecting practices it was not possible to assess whether equipment supply schemes and increased knowledge of AIDS and HIV transmission had caused any behaviour changes (Ghodse, Treganza and Li, 1987:698). Farid pointed out that those in treatment represented only a small fraction of the population at risk. Despite this observation he questioned the emerging policy on NEX schemes and claimed that screening facilities from drug treatment services

offered a more effective way of “combating the spread of AIDS” (1988:376). However, this appears to have been a logical argument for extending the schemes to those in the target population who are outside the treatment services rather than a sound reason for restricting the supply of clean injecting equipment.

Similar harm reduction initiatives were also adopted in others areas outside Western Europe. The prevalence of HIV infection among injecting drug users in Australia is approximately 2% (Loxley, 2000:407). According to Loxley harm reduction has been the major response to reducing the spread of HIV in Australia and she claims that there is evidence to show that this approach has led to a decrease in needle sharing (2000:407). An Australian report published in 2002 claims that NSP, established in 1988, have been responsible for reducing the rates of HIV infection (Commonwealth of Australia, 2002:10). The report claims that by the year 2000, approximately 25,000 HIV infections had been prevented and estimated that by 2010 approximately 4,500 deaths would have been prevented as a result of the implementation of these programmes (2002:10).

The situation in the United States is different as the government there has remained opposed to the widespread introduction of NEX. It has been claimed that no other country has reported a similar ban on funding into NEX programs or related research on effectiveness (Vlahov, Des Jarlais, Goosby *et al*, 2001:S72). In 1998, although the federal ban remained, the USA government finally concluded that, despite evidence to support the fact that NEX programs did not promote injecting drug use and were effective in reducing HIV infection, federal funds would still not be made available. However, they allowed local communities to make unilateral decisions on establishing

NSPs within their existing resources (Vlahovy *et al*, 2001:S72). By 2007 it was reported that local funds had been made available to establish approximately 200 NEX programs across 36 states (Johnson, 2008/09:1).

NEX schemes that distribute sterile injecting equipment to IDUs and provide safe storage facilities have become an accepted component of the harm reduction strategy in the UK (Strang and Gossop, 2005:145). NEXs operate from a variety of different sites and can adopt varying methods of supply. These have been reported to include “drug agencies, drug treatment clinics, accident and emergency departments, mobile units, voluntary agencies, outreach services” (Strang and Gossop, 2005: 146). The range of services available offers access to sterile injecting equipment to a wide range of IDU including those who are not in contact with the mainstream drug treatment services. Having injecting equipment supplied from various locations means that there is increased access in terms of geography and in the hours that the service is accessible.

The 1987 the UK Government sponsored experimental schemes that were designed to provide

- “a) injecting equipment on an exchange basis to drug abusers who were already injecting and unable or unwilling to stop;
 - b) assessment of and counselling for clients’ drug problems;
 - c) advice on safer sex and counselling on HIV testing”
- (Stimson, Allritt, Dolan *et al*, 1988:1717).

The findings from the initial monitoring of the schemes in England and Scotland showed that the schemes had been successful in attracting clients who had no other access to treatment services. The schemes were found to have been “reasonably

successful” and provided evidence that this was an effective means of supplying equipment using exchanges (Stimson *et al*, 1988:1717). This means that clean injecting equipment was supplied free of charge when used, and therefore potentially contaminated equipment was returned for safe disposal.

In the European context, Hedrich and colleagues examined the developments and shifts in policy and attitudes and claim that there is data to support a European trend of recognising harm reduction as an essential and widespread element in public health and social policies designed to deal with problem drug use (Hedrich, Pirona and Weissing, 2008:512). These authors maintain that despite the reported differential approaches to the extent and existence of both abstinence based, and harm reduction strategies that have been reported across Europe, the reality is that both coexist (Hedrich *et al*, 2008:512). It is clear that NEXs have become a core element of any harm reduction strategy.

Referring to the initial starting point of the 1988 ACMD report Yates has outlined that the underlying theme of the report remains one where “the goal is abstinence” (2002:119). He describes two sets of circumstances where the goal of abstinence can be legitimately delayed; these are “where circumstances dictate that it cannot be immediately achieved and where to attempt an abstinence intervention may undermine risk reduction initiatives already underway” (Yates, 2002: 119). Initially the goal of abstinence and any harm reduction strategies may appear to be mutually incompatible. However it is possible to implement strategies to maximise protection of the health of an individual where circumstances exist that have resulted in a delay in attaining the goal of abstinence.

1.5 Sharing and the Re-Use of Injecting Equipment.

An early review of needle sharing among intravenous drug users in 1987 had shown that those involved in injecting illicit drugs shared a range of equipment paraphernalia in addition to needles and syringes including “cookers” and cotton filters (Battjes and Pickens, 1988:2). This review of the international situation in 1987 concluded that the term “needle sharing” should be used in a wider context to refer to the sharing of all equipment used in the preparation and administration of drugs for injection (Battjes and Pickens, 1988:2). In Scotland the “McClelland Report” had indicated that the shortage of needles and syringes in Edinburgh, due to active local police enforcement policies, had resulted in injection equipment being widely shared (Scottish Home and Health Department (SHHD), 1986:7).

An early ethnographic study of drug users in Scotland by McKeganey and Barnard was undertaken to investigate the interrelationship between the behaviours of IDUs and the transmission of HIV infection (1992:xvii). This work was conducted as there was minimal existing knowledge of the reasons for sharing and the practical aspects of the drug injecting situations that resulted in sharing and also the extent and relationships amongst those who shared injecting equipment (McKeganey and Barnard, 1992:25). The results of this study showed that sharing was not merely due to lack of availability, information or access to injecting equipment, but that there was a complex interplay of social factors directly affecting levels of sharing. This was particularly evident in the sharing that was identified amongst “sexual partners, close friends and family members” (1992:51). Whilst acknowledging the need for the provision of clean injecting equipment and for continued health education messages,

the authors claimed that it was probable that some level of sharing would be likely to remain despite the implementation of campaigns to promote safer injecting and highlighting risk related behaviours (McKeganey and Barnard, 1992:52). There is evidence from other countries to demonstrate that the social element influencing sharing amongst drug injectors also occurs outside the UK. Field studies in Rotterdam and New York had shown that despite differences in the types of equipment used, injecting practices and the drugs injected, “syringe-mediated drug sharing (SMDS)” was affected by an IDU’s social network and by the injection setting (Grund, Kaplan, Adriaans *et al*, 1991:701).

One of the early studies in Australia by Crofts *et al* had pointed out the emerging evidence on how blood contact was possible outside the recognised sharing of needles and syringes but could also occur through injecting practices and sharing of related paraphernalia (Crofts, Aitken and Kalder, 1999:220). This study involved ethnographic work videotaping groups of drug users and revealed that there were many varied instances where the individuals could become exposed to the transmission of a range of infections through blood contaminated equipment other than the needles and syringes. This work showed the possibilities for transmission through a range of items including “swabs, spoons, water vials and tourniquets, as well as fingers, other body parts and surfaces in the immediate environment” (Crofts *et al*, 1999:220). On the basis of this evidence the authors concluded that for any measures to be effective in controlling the spread of HCV, greater efforts would have to be targeted towards reducing needle and syringe sharing and the other identified risk related behaviours (Crofts *et al*, 1999:221). In addition to the sharing of needles and syringes, the indirect sharing of other paraphernalia, including filters, spoons,

water and drug division processes were illustrated in a number of later studies that highlighted that even when needles and syringes were not being shared it was possible for transmission of HIV and Hepatitis B and C to occur through other means (Gossop, Griffiths, Powis *et al*, 1997, Hunter, Stimson, Jones *et al* 1998). According to Hunter and colleagues, HIV rates in the UK have remained comparatively low due to the existence of NEXs and other HIV harm reduction work, however they cautioned against complacency as there was evidence to show that despite these actions the potential remains for BBV transmission to continue (1998:46).

The Hunter *et al* study in 1998 measured the level of sharing of syringes and other injecting equipment among IDUs. This work was carried out on a population of drug users in England who were not in current contact with treatment services (Hunter *et al*, 1998:5). This showed that when asked detailed questions about injecting behaviour and sharing practices in the previous four weeks 78 % reported some form of sharing behaviour (Hunter *et al*: 1998: 24).

Some of the early work by Grund and colleagues in Rotterdam and Koester and colleagues in Denver was based on a series of observations of how IDUs actually mix, divide and distribute the prepared drug solutions for injecting (Grund, Kaplan, Adrians *et al*, 1991, Koester, Booth and Wiebel 1990). Koester outlines 9 distinct means of injection equipment sharing, shown in Table 1.1. These are in addition to directly sharing a previously used needle or syringe and can be summarised as, shared use of water, cookers, mixers, cotton filters, “front loading”, and “back loading” (Koester, 1996:1350).

Table 1.1

Indirect Sharing.

“INDIRECT SHARING”: AN ETHNOGRAPHIC TYPOLOGY.
1. Rinsing previously used syringes(s) in a shared water container prior to drug preparation and injection.
2. Using one participant’s syringe to draw up water for dissolving the drug.
3. Using the rubber internal end of a participant’s syringe plunger to mix water with the drug.
4. Using one participant’s syringe to measure and distribute a share of the drug solution to each participant (distribution then occurs through “back-loading” or “front-loading”).
5. Drawing each share of the drug through a common cotton filter.
6. Returning the drug solution to the common cooker, or directly to another injector’s syringe when an injector inadvertently draws up more than his/her share.
7. Returning the drug solution to the cooker or directly into another’s syringe to “kick them out a taste”
8. “Beating a cotton” that others have placed their needles in to draw up their dose.
9. Rinsing a used syringe in water in which others have previously used for mixing and rinsing.

Source: Koester, 1996: 135.

The terms “front loading” and “back loading” included in the typology are sociological terms that were first used to describe the practices observed by Grund in 1993 (Derricott *et al*, 1999: 48). These terms are used to describe practices where a single syringe is used as a measuring device in the preparation of a batch of drugs. The prepared solution is then redistributed to other syringes either by “frontloading” where the “recipient” syringe has no needle attached or by “backloading” where the drug solution is inserted to the recipient syringe through the plunger end as the needle is non detachable (Derricott *et al*, 1999:48). These are inherently unsafe injecting practices and according to Smythe *et al* there is a clear and demonstrable association between these practices and the transmission of HCV infection (Smythe, Barry and Keenan, 2005:167).

Smythe and colleagues conducted a cross-sectional study of IDUs in Dublin in 2004 using structured interviews. HCV tests were also performed on participants and 61% were found to be antibody positive (Smythe *et al*, 2005:166). This study was aimed at exploring the social context of drug injecting and the results suggested that unplanned sharing through accident and inadvertent sharing of equipment was potentially an important contributory factor in the spread of HCV infection and of increasing an individual's risk of contracting this virus over time (Smythe *et al*, 2005:167). In Scotland a direct observational study of the practices of injecting drug users was published in 2004 (Taylor, Fleming, Rutherford *et al*, 2004). This research incorporated the use of video taping of actual injecting events supplemented by detailed field notes and the aim was to examine in detail the practicalities of the injecting processes to an extent that had not previously been done in the UK (2004). This work provided definitive evidence from direct observations that there were a number of points in the preparation process where deliberate or accidental sharing of equipment occurred. In observations where groups of injectors were involved it was found that in 44 out of 47 observed episodes, a range of injecting paraphernalia was shared by those observed (Taylor *et al*, 2004:2). This illustrates the high level of sharing that existed and the observations demonstrated how the social aspects of the situation often led to unsafe and "sub-optimal practices" (2004:3).

In Scotland, the NHS Information Services Division (ISD) publishes an annual report that provides information on a range of drug misuse statistics (Drug Misuse Statistics Scotland (DMSS)). This publication incorporates data from a wide range of relevant sources. These sources include services and agencies from primary, secondary, paediatric and mental health agencies and incorporate prescription related and hospital

discharge information. An illustration of the existing data available on sharing from individuals who have reported to have injected in the past month has been extracted and summarised below in Table 1.2.

Table 1.2. Extracted Injecting Sharing Data 2003-07 (DMSS).

Scotland	Current Sharing of needles/syringes (%)	Current sharing of spoons/water/filters/solutions (%)
2003/4	34	50
2004/5	31	47
2005/6	27	42
2006/7	29	36

(source: Drug Misuse Statistics Scotland, ISD publications)

Table 1.2 gives a summary of figures on sharing behaviours from 2003 to 2007 for Scotland. This data is also collected on a health board and local authority basis and it is therefore possible to use this data for local monitoring purposes. The use of the data as a monitoring tool and how to incorporate this into an assessment of the impact of any intervention on sharing practices is discussed further in Chapter 5. Although there may appear to be an indication of reduced levels of sharing, the figures illustrate that sharing remains at an unacceptably high level. It is important to note that the figures in Table 1.2 are likely to be an underestimate of the full extent of sharing behaviours as they only record information from patients already in contact with treatment services. For example, there is no record of any information from those attending NEXs and therefore the information will not capture sharing data from the IDUs who are most likely to be involved in unsafe and risk taking injecting practices. This group contains some of the most hard to reach injecting drug users who may have no other formal contact with any health or social service and are likely to be a group that will have a significant effect on the levels of sharing of injecting equipment and the

resultant transmission of BBVs, related bacterial and other infections. Work by Scott in 2008 explored the risks attached to the use of injecting paraphernalia other than needles and syringes. This study included a qualitative element in addition to laboratory investigations of injecting equipment and methods of drug preparation (Scott, 2008:2). The results of the Scott study showed evidence of bacterial and fungal infections and vascular damage that was attributable to the circumstances surrounding injection preparation and to the re-use and sharing of equipment.

The evidence demonstrated by existing research that utilised a variety of different methods and from the Scottish Government annual drug misuse statistics all indicate that sharing and re-use of injecting equipment is a real and significant health problem for IDUs that requires further investigation.

1.6 Syringe Identification

Following from the work described in section 1.5 that had successfully shown the existence, and some of the characteristics, of both planned and accidental sharing, proposals emerged for the introduction of a method of syringe identification. One of the recommendations from the observational work carried out in Scotland was that injecting equipment should be produced in a range of colours so that drug users who lived together would be able to easily recognise their own equipment when it was stored in a central shared space (Taylor *et al*, 2004:38). The subsequent practical development of different methods of syringe identification and their relevance to the syringe marker supply evaluation are discussed in Chapter 2.

The National Institute for Health and Clinical Excellence (NICE) has promoted the introduction of syringe identification schemes (NICE, 2009:8). The 2009 NICE public health report also highlighted that there was an ongoing need for more extensive research to assess the most effective and cost effective types of injecting equipment that could be used to minimise harms and also recommended that drug users should be involved with this type of research and development (2009:22). The syringe marker evaluation study described here is designed to address some of the practical aspects associated with the introduction of a supply of one type of injecting equipment identification and its acceptability to services and service users.

The study of the distribution and use of syringe markers in community pharmacies was conducted against a background policy context that included the emerging development of the National Hepatitis C Plans for Scotland. Phase 1 of Scotland's National Hepatitis C Action Plan was published in 2006. Following extensive consultation the Action Plan concluded that this needed to be tackled on several fronts and that the actions should be "focussed and co-ordinated" (Scottish Executive, 2006:3). The plan was divided into 6 main sections. These covered "Co-ordination, Prevention, Testing, Treatment, Care and Support, Education, Training and Awareness-raising and Surveillance and Monitoring" (Scottish Executive, 2006:3). This evaluation is confined to the action points detailed in Section 2: Prevention. The Action Plan highlighted that the main means of transmission of HCV in Scottish IDUs was through sharing and reusing of equipment (Scottish Executive, 2006:7). Recommendations from the Action Plan included advice to Health Boards that consideration should be given to using a proportion of the funds allocated to them to improve prevention services for HCV with particular reference to enhancing NEX

services (Scottish Executive, 2006:10). More specifically, NHS Boards were asked to assess if the extent and nature of the interventions they currently offered were sufficient to promote safer injecting within this group (Scottish Executive, 2006). The Action Plan was explicit that in order to assist IDUs to identify their own equipment, these interventions should include “labelling or colour-coding” of injecting equipment (Scottish Executive, 2006:10).

The aim of Phase 1 of the Hepatitis C Action Plan was to generate the evidence base for the actions detailed in Phase 2 (Scottish Government, 2008: 8). The main action relevant to the syringe marker evaluation is Action 15 which states that:

“Services providing injecting equipment (needles/syringes and other injection paraphernalia) will be improved in accordance with the Guidelines referred to in Action 14 above. Improvements will be made in terms of the i) quantity (increasing access and uptake of equipment through innovative, including outreach, approaches). ii) quality (e.g. the colour coding of equipment to avoid sharing) and, iii) nature (e.g. the provision of equipment other than needles/syringes), of provision (Action 15)”
(Scottish Government, 2008: 19).

It is clear that the service development and evaluation that is the subject of this study has direct relevance to the evolving Scottish HCV policy initiatives and recommendations.

The ACMD produced an extensive report for the UK Government on the “Primary Prevention of Hepatitis C among Injecting Drug Users” (ACMD, 2009). This report

made a number of policy recommendations with major implications for HCV prevention and other harm reduction services. This report noted the innovative nature of a number of UK prevention initiatives including reference to “coloured syringes” (ACMD, 2009:29). The report, however, recorded a note of caution as it recommended that innovation in this field should be supported but that more attention needs to be given to evaluating innovative interventions and that this should include attempts to model the “potential impact and cost-effectiveness” of any innovation (ACMD, 2009:29). Section 1.7 below discusses the potential cost effectiveness of the intervention described in this evaluation and the likely financial impact for the health board of expansion of the supply.

NEXs, including pharmacy based exchanges, have been extensively developed over the last 25 years and are now an integral part of UK and international prevention policies. There has been long established involvement in Glasgow and it has been claimed that the development of the Glasgow pharmacy based services has had a major impact on service developments in other parts of the United Kingdom (Roberts and Hunter, 2004:6). In 1996, Greater Glasgow Health Board (GGHB) published a joint planning strategy for HIV and AIDS (GGHB, 1996). This strategy recognised that an essential element in tackling the health harms associated with drug misuse was to prevent the spread of HIV within the population and that the developing role of community pharmacists was becoming an increasingly important element in this strategy (Roberts, Gilchrist, Cameron *et al*, 2002:4).

The Scottish and the UK policy strategies are broadly similar in relation to reducing the sharing of injecting equipment by using syringe identification methods. The 2009

NICE public health report promotes the optimal provision of needle and syringe programmes for injecting drug users. One of the actions recommended to providers of this type of service is that they should “encourage people who inject drugs to mark their syringes and other injecting equipment or to use easily identifiable equipment to prevent mix-ups” (2009:18).

1.7 Cost Effectiveness

Although a full cost benefit analysis was outside the scope of this evaluation, the findings described in Chapter 4 and 5 would indicate that this is an area worthy of further examination. Intuitively the supply of syringe markers appears to be a relatively inexpensive intervention. A full cost benefit analysis would ideally include the costs of the intervention and the wider benefits shown to be associated with reduced transmission of BBVs and other related infections. For an intervention designed to reduce the harms to IDUs any potential cost benefit is a difficult factor to isolate and to quantify. This difficulty was acknowledged in the Scottish Hepatitis C Action Plan. The Action Plan recommends the supply of colour coded injecting equipment to reduce sharing and transmission of HCV but notes that even if these benefits were achieved, attributing the benefits with any degree of certainty to specific interventions would be problematic (Scottish Government, 2008:19). This is largely due to the fact that the influences on drug users are multifactorial and include the interplay of biological, social, psychological, cultural and practical influences.

In an English study into the factors and the costs that could be attributed to injection site infections caused by illicit drug injecting it was found that were significant costs

for the health services (Hope, Kimber, Vickerman *et al*, 2008:1). In this study in England over 75% of those who attended hospital for treatment of injecting infections required hospital admission and the authors estimated that the associated costs were in the region of £19.2 to £30.5 million annually (Hope *et al*, 2008:3). The authors claimed that a large proportion of these infections were caused by the reuse of syringes (Hope *et al*, 2008:6). Therefore any intervention, such as the supply of syringe markers, which has the potential to reduce the level of deliberate or accidental sharing, is likely to have a consequential positive impact on the associated health costs. It should be noted that the Hope *et al* study refers only to injection site infections which were defined as “abscess (pus filled swelling) or open wound/sore” and excludes any costs attributed to the contraction of HIV or HCV through injecting drug use (2008:2). The annual individual patient costs associated with HIV and HCV treatment range from £14,000 to £20,000 annually (Y Gourlay, 2008: personal communication). Therefore the estimated costs quoted by Hope *et al* only reflect a fraction of the potential costs associated with the totality of the BBVs and associated infections that can be acquired through the use, re-use and sharing of contaminated injecting equipment. A full analysis would require further work to include all associated costs and ideally the incorporation of a statistical model that could definitively establish an association between the supply of markers and reduced levels of equipment sharing leading to a subsequent reduction in the transmission of BBVs and other related infections.

1.8 Development of Community Pharmacy Based Needle Exchanges.

It has been reported that the first recorded provision of sterile injecting equipment worldwide was made by a pharmacist in the early 1980's in Edinburgh (Wodak and Cooney, 2005: S31). As mentioned previously there are many different types of exchanges. The variety of service delivery locations and staffing complements determines the range and type of service available. These are provided from different settings and in addition to community pharmacies include specialist drug treatment services, outreach and mobile services, supplies from police custody suites and hospital based accident and emergency units (National Treatment Agency (NTA), 2007). This evaluation is concerned exclusively with one aspect of the NEX service provided from community pharmacies. In 1982 the Royal Pharmaceutical Society of Great Britain (RPSGB) issued a directive, which prohibited pharmacists from selling needles and syringes (RPSGB, 1982). In 1986, due to the emerging concerns around the transmission of HIV, this was reversed and pharmacists were then allowed by their professional body to supply injecting equipment to IDUs (RPSGB, 1986). This referred to the sale of injecting equipment and not to the free provision of injecting equipment through a NEX service. According to Sheridan the reversal of the 1982 advice in 1986 "paved the way for pharmacists to become major players" in the supply of injecting equipment and enabled the profession to be included in exchange schemes (in Strang and Gossop, 2005:147).

Of the first British schemes established in 1986, only Sheffield had any pharmacy involvement. Unlike the current situation where injecting equipment is supplied free of charge, this was a scheme that allowed clients to purchase equipment and provided

a safe disposal facility. Based on the results from the initial monitoring of the early pilot schemes different models of service began to evolve. In addition to offering supplies of clean injecting equipment and providing safe disposal facilities there was an expansion of the range and type of services offered by NEXs. The evolution increased the diversity and accessibility of services available from different sites and increased the range of interventions offered to include “condoms, referrals, hepatitis B vaccination, HIV and hepatitis testing” (Jones, Pickering, Sumnall *et al*, 2008:12). A survey conducted in 2005 in Scotland identified that NEXs existed across the full range of different services (Greisbach, Abdulrahim, Gordon *et al*, 2006). The services and types of intervention that can be provided were, and still are, largely dependent on the premises and the type of staff involved. Vaccinations, for example, can only be provided by appropriately qualified professional staff. The pharmacy based NEX schemes also changed to the type of free exchange with additional health advice that is familiar today. The aim of pharmacy-based schemes was described by Shorrock and services included providing, free of charge, a range of injecting equipment, condoms and related health information materials aimed at reducing the transmission of HIV (2003:114). Important aspects of this local community service are to provide easy access to safe disposal facilities, to maintain patient confidentiality and for staff to have a “non-judgemental attitude” (Shorrock, 2003:114).

The ACMD report in 1993 recommended an increased role for pharmacists in providing injecting equipment to intravenous drug users. This report advised that there was untapped potential within the pharmacy network that could be used to expand the existing needle and syringe provision (ACMD, 1993:34). This early report identified the training and support needs of pharmacists that required to be addressed

in order to provide this type of enhanced service. The training and support service run by a pharmacist employed by the Leicestershire Community Drug Service was commended as an example of good practice that could be reproduced in other areas (1993:34). An independent review by the Department of Health (DOH) of drug treatment services in England in 1996, recommended an extension of the role of the pharmacy based NEXs. In this review community pharmacies were viewed as sites where there was the opportunity to incorporate health promotion advice and other services alongside supplies of injecting equipment in a setting that could be described as a “neutral space” (DOH, 1996:32). Despite being impressed by the existing commitment demonstrated by pharmacists the review noted that there was scope to realise untapped potential that existed due to unique accessibility of pharmacies for IDUs who were not currently in contact with treatment services. The review continued to advise that not only should geographic coverage via community pharmacies be extended but that there should be an expansion of the range of services available (1996:33).

According to Shorrock, pharmacy-based schemes have a number of advantages that should be utilised. There is a network of approximately 12,000 community pharmacies in the UK. For IDUs these provide relatively easy local accessibility with associated longer opening hours and she also claims that there is reduced stigma associated with entering a community pharmacy as opposed to a dedicated drug treatment service (Shorrock, 2003:115). Many of these perceived advantages are due to the presence of the pharmacist who is a health care professional who can provide health information, interventions and advice and where consultations can occur on an opportunistic basis with no need for pre-planned appointments (Shorrock, 2003: 115).

Research indicated that more effort should be made to maximise the potential contribution of locally based community pharmacists in providing this type of intervention as it had been demonstrated that there were high levels of contact with “hard to reach” drug misusers (Sheridan, Strang, Barbour *et al*, 1996:272). This was confirmed later in an investigation into the profile of service users in community pharmacies and other settings where it was found that pharmacy NEXs could attract large numbers of injectors and that this was associated with high return rates of the needles and syringes that had been supplied (Cameron, Gilchrist and Roberts, 2004:211).

In 1988, 3% of community pharmacies in England and Wales provided a NEX service and by 1995 this had risen to 19% (Sheridan *et al*, 1996: 272). This situation was not mirrored in Scotland where only 9% provided the service in 1995. It has been suggested that this discrepancy may possibly be due to the fact that the first pharmacy based NEXs were not established in Scotland until four years later in 1992 and that participation was therefore inevitably slower to increase than in England (Cameron *et al*, 2004:211). It is also possible to speculate that the relatively slower involvement of Scottish pharmacists may also have been due, in part, to the existence in Scotland of the criminal offence of “reckless conduct”. Unlike England and Wales, in Scotland common law crimes, including reckless conduct, are relevant when considering injecting equipment supply and this may possibly have acted as a deterrent to the parallel expansion of the schemes in Scotland. In Scotland, unlike England, it is technically possible for pharmacists to be prosecuted using the law of reckless conduct and there is anecdotal evidence from NEX co-ordinators that this may have deterred some pharmacists from participating in exchange programmes despite

reassurances that prosecution under this statute would be an extremely unlikely action if supplies were made as part of a health board approved exchange scheme (Roberts K, 2004: personal communication).

It should be noted that between 1988 and 1992 in Scotland pharmacies only supplied injecting equipment on a sale and not an exchange basis. In 1988, the office of the Lord Advocate had issued a statement that said.

“The existence of the common law crime of reckless conduct makes it impossible to say that the supply of needles and syringes to be used for injecting controlled drugs could never amount to the commission of a criminal offence. The Lord Advocate’s view is that the crime of reckless conduct would only arise very exceptionally as regards the supply of needles and syringes by doctors and pharmacists and he would wish to retain discretion to prosecute only in such exceptional cases. While the Lord Advocate will not give any general and unqualified undertaking of immunity, he would not authorise the prosecution of any pharmacist in respect of the sale by the pharmacist of needles and syringes to drug misusers, provided they acted in accordance with the conditions and procedures set out in Annex 1”

(SHHD, 1988).

The Scottish Department of the Royal Pharmaceutical Society (RPS) was instructed to make arrangements for the guidance to be communicated to pharmacists in Scotland (SHHD, 1988). Despite the fact that this common law offence was not used to prosecute any pharmacists, Stimson claimed that “ it is clear that police in some parts of Scotland have been active in dissuading pharmacists from selling syringes” (1988:

91). It is reasonable to assume that this could have had an adverse effect on the sale of syringes and the development of pharmacy based NEXs in Scotland. This was not an issue that had to be addressed by pharmacists involved in the sale or supply of injecting equipment to drug users in England. For this reason it is possible to speculate that the cross border legal differences may have been a contributory factor in the identified slower increase in pharmacies willing to participate in exchange schemes in Scotland.

By 1995 the participation of community pharmacies in Glasgow was below the English, Welsh and Scottish averages at only 5% of the eligible pharmacies within the Health Board area participating (Cameron *et al*, 2004:211). Recognition of this fact and the need for a full scale examination of the existing ad hoc arrangements for injecting equipment provision across the Health Board led in 2001 to a full scale review (Gruer, 2001).

Despite the fact that there is evidence to indicate that pharmacy NEXs have positively contributed to promoting safer injecting behaviours and reducing sharing of used equipment, the number of pharmacies involved in providing this service in Glasgow remained low (Cameron *et al*, 2004:212). The 2001 comprehensive review concluded that local drug injectors were at “high risk of infection with HIV, hepatitis B and C viruses and other micro-organisms through sharing and other unhygienic uses of injection equipment” (Roberts, Gilchrist, Cameron *et al*, 2002:6). The review recommended that more community pharmacies should participate in the NEX scheme with a target of increasing participating sites from 15 to 30 by 2005 (Gruer, 2001:2). This recommendation was accepted and implemented and the target of 30

participating pharmacies was eventually reached in 2005. Since then there has been a continued increase in the number of sites, improvements in service delivery and staff training in response to the Action Points contained in Phases 1 and 2 of Scotland's National Hepatitis C Action Plan (Scottish Government, 2006, 2008). By 2009 the numbers had risen and there are now 62 community pharmacies providing NEX services across the Greater Glasgow and Clyde health board. This constitutes 20% of the total of 312 pharmacies and has now reached a par with service provision in England.

1.9 Legal Issues

The discussion above has focussed on the supply of needles and syringes through the development of community pharmacy based services. Before 1986 it was not an offence to supply other pieces of equipment that could potentially be used in preparing illicit drugs for injection. According to Bucknell and Ghodse changes in legislation relating to the types of equipment that could be supplied were in response to the fact that some shops in Soho, London, were selling articles "which in themselves appeared innocent, but when put together they formed cocaine sniffing kits" (1989:2). In 1986 the Drug Trafficking Offences Act (DTOA) inserted Section 9A into the Misuse of Drugs Act. The Drug Trafficking Offences Act introduced the term "drug administration kits". This resulted in the "prohibition of supply etc of articles for administering or preparing controlled drugs". Section 34 of the DTOA reinforced that "it is not an offence to supply or offer to supply a hypodermic syringe or any part of one". Section 9A of the Misuse of Drugs Act created a new summary offence, with a maximum penalty of six months imprisonment, for the supply of any

articles that could be used or adapted for the administration of controlled drugs. This meant that any supplier, including pharmacists, was committing an offence if they knowingly supplied any article where “the supplier believes it may be used by the recipient to administer an unlawful drug or prepare an unlawful drug for administration”. The insertion of Section 9A into the MDA was as a direct result of a visit, in 1985, by the UK Home Affairs Select Committee Office to the United States. Following this visit the committee described problematic drug use as the “most serious peacetime threat to our national well being” (Roberts, 2009:2). At this time there was an acknowledgement of the health benefits to be gained from the supply of sterile needles and syringes, in terms of reducing the transmission of HIV.

This remained the situation with the supply of injecting equipment until 2003 when the Misuse of Drugs Act was amended (Statutory Instrument (SI), 2003, 1653). This followed a Home Office consultation in 2002 into the proposed amendments to Section 9A of the MDA. These amendments made legal the supply to drug users of five specific items, by practitioners, pharmacists and persons employed or engaged in lawful provision of drug treatment services. The five items which could now be legally supplied under the Section 9A amendment were ampoules of water for injection (subject to the requirements of the Medicines Act), swabs, utensils for the preparation of a controlled drug (spoons, bowls, cups, and dishes), citric acid and filters.

Before embarking on the syringe marker study, an assessment had to be made of the legal aspects of this supply with reference to Section 9A of the MDA and the Scottish common law crime of reckless conduct. As outlined above, Section 9A permits the

supply of specific items of injecting paraphernalia by pharmacists and other professionals as part of NEX services. Syringe markers are not mentioned as an exempted item in this section, however Section 9A relates to items used in the “preparation” and “administration” of illicit drugs. It can be seen that all of the current 5 exempted items are intimately involved in the preparation and administration and have direct contact with illicit controlled drugs. Syringe markers appear to be one step removed from involvement in direct preparation and administration and therefore not affected by the restrictions of Section 9A. Further advice was sought from the NHS legal department who supported this interpretation. As noted above, blanket immunity for NEXs from prosecution under the common law crime of reckless conduct is not possible. This power is retained for use in exceptional circumstances only, and would not apply to NHS or other approved services. Confirmation was received from the Scottish Crime and Drug Enforcement Agency (SCDEA) who supported the view that any prosecution was “highly unlikely” in the settings and circumstances described.

In England there were no restrictions on the quantities of needles, syringes and associated paraphernalia that could be supplied. However in Scotland the Lord Advocate set restrictions on the quantities that could be supplied. This was limited to only 5 sets of equipment to be supplied on a first visit and up to a maximum of 15 sets thereafter. As a direct response to the growing problem of HCV transmission these limits were revised in 2002 to a maximum of 20 needles and syringes on a first visit with a limit of 60 for subsequent visits and an exceptional upper limit to account for holiday or other similar periods of 120 sets (NHSHDL No.(2002)90). As a direct response to the accepted public health benefits of NEXs these restrictions were finally eliminated in 2010. To coincide with the introduction of the national Injecting

Equipment Providers (IEP) guidelines the Lord Advocate lifted restrictions on the maximum number of sets of needles and syringes that could be supplied and removed the return of used equipment as a prerequisite for increased supplies (Scottish Government, 2010: 31)

1.10 Public Attitudes and Needle Exchanges

It is clear from the review of the evidence on the development of needle and syringe exchange programmes that there is almost universal agreement on their effectiveness in reducing the spread of BBVs and other related infections and on the associated potential cost savings. However it should not be assumed that there is also universal acceptance of the principle of making such schemes freely available. There is often a tension between the proponents of the evidence based research and a media fuelled “moral panic” response. In 1971, Young first introduced the term “moral panic” in an examination of statistics that appeared to indicate an alarming increase in the levels of drug abuse and the public concern that this generated (Young, 1971). He noted that the “moral panic over drug-taking results in the setting up of drug squads” (Young, 1971:10). According to Thompson this observation by Young highlights the effect produced by the interaction of the media, public opinion, interest groups and the authorities and a combination of these influences and effects results in the phenomenon described as moral panic (Thompson, 1998:7). Thompson identifies five key elements or stages that describe the development of moral panic. These are:

- “1. Something or someone is defined as a threat to values or interests.
2. This threat is depicted in an easily recognisable form by the media.
3. There is a rapid build up of public concern.

4. There is a response from authorities or opinion-makers.
 5. The panic recedes or results in social changes”
- (Thompson, 1998: 8).

There are numerous current local examples where the media and public reaction to new NEXs and advances in the type and range of equipment supplied appear to have evoked a reaction which follows precisely the stages identified above and could be legitimately labelled as examples of moral panic. Appendix 1 illustrates some local examples of this type of media reporting. Similarly, Cohen’s “Model of Deviancy Amplification” can be summarised as a process that exhibits a number of stepwise stages. These are:

- “Initial problem
 - Initial Solution
 - Societal Reaction
 - Operation of Control Culture, Exploitation and Creation of Stereotypes
 - Increased Deviance, Polarisation
 - Confirmation of Stereotypes”
- (Cohen, 1980: 199).

This can be related to the subject under discussion here where, the “initial problem” is the emergence of HIV/AIDs and the recognition that this virus can be spread through the IDU population by the sharing of injecting equipment. The “initial solution” is the development and the introduction of NEXs. The involvement of the media is essential in the evolution of stereotypes of deviancy in relation to those who use NEXs. It is rare to find any media recognition that the use of NEXs can be a positive health step for an individual and that the existence of NEXs protects both the health of the individual and promotes public health benefits for the wider community. This type of adverse media reporting has inevitably shaped “societal reaction”. In turn this has led to “polarisation” and further “confirmation of stereotypes” resulting in public

opposition to establishment of NEXs and the “dramatisation” of reports of single discarded needles (Illustrated in Appendix 2).

It has been claimed that concentrated media attention confers the status of high public concern on issues which are highlighted; these generally become understood by everyone as the “pressing issues of the day” (Hall, Critcher, Jefferson *et al* 1978:62). When the media acts in this way it effectively sets an agenda and by the act of further reporting it then establishes what has been termed a “reality-confirming effect” (Hall, Critcher, Jefferson *et al* 1978:62). Thomson explains how this can lead to a state where the media assumes a campaigning role claiming that their reports articulate what the ‘moral majority think” (1998:61). When this set of circumstances exists with controversial issues, including NEXs, where a single dominant viewpoint is consistently presented, it becomes very difficult to discuss the wider context and to propose alternative opposing viewpoints (Thomson 1998:61). This partly explains some of the inherent underlying difficulties for professional treatment services of promoting evidence to support both the health and the cost effective benefits of NEXs to the wider community.

An analysis of the politics of NEXs demonstrated that there is compelling evidence to support the public health benefits of syringe exchange programmes (Buchanan, Shaw, Ford *et al*, 2003:427). These authors highlighted the existence of evidence in support of NEXs as part of the public health interventions to prevent the spread of HIV and also noted that supplying injecting equipment in this way did not promote or increase the use of illegal drugs (Buchanan *et al*, 2003:427). This view is supported by the first comprehensive international review of the evidence for needle syringe programmes

where it was shown that the findings demonstrated that needle syringe programmes were able to reduce HIV transmission “effectively, safely and cost effectively” and that these are benefits are significant (Wodak and Cooney 2005:31).

Despite the existence of a large body of empirical scientific evidence to support the benefits of NEXs, these programmes do not always benefit from full public and professional support (Buchanan *et al*, 2003:427). Attempts were made to analyse why this situation existed and the authors highlighted the problems associated with resorting solely to the scientific evidence in NEX policy development (Buchanan *et al*, 2003:431). They advise the proponents of NEX that scientific evidence on its own will never be sufficient to gain public support for public policies but that the underlying “moral values” need to be used to counter the opponents expressed ethical concerns (Buchanan *et al*, 2003:432). Rather than promoting the use of scientific evidence alone on the transmission of BBVs, it should be claimed that these schemes are best viewed from a wider social and fiscal viewpoint as they help to prevent the most disadvantaged groups in society from suffering further preventable harms (Buchanan *et al* 2003:439). These authors claimed that in any public debate the most effective position to adopt to gain acceptance of the NEX was to remove the debate away from the benefits to individual IDUs and to demonstrate the security that the exchange affords to protect, those they termed, “innocent” victims as the risk of HIV affecting the wider non-drug using population is reduced by IDUs having access to sterile injecting equipment (Buchanan *et al*, 2003: 440). The authors concluded that in order to build greater public support the “interpretive framework” of the policy is the aspect that needs to change. (2003:440). Although the work by Buchanan and colleagues outlined above is centred in an American analysis of NEX policies, there

are general parallels with the existing situation in the UK and in Scotland as shown by the examples in Appendix 1 and 2 of similar distorted reporting that inevitably serves to inflame local communities and debates. According to Stone, when communities and officials debate policy issues the decisions are rarely based exclusively on matters of “fact and science” but are based on the meanings attributed to the subject (2001: 232). She further claims that the disputes in relation to NEX become disputes about “core values” and this is the reason why reference to the scientific evidence is never solely sufficient (Stone, 2001:233). This clearly identifies the problem as one that cannot be resolved purely by reference to the existing body of scientific evidence or by the promotion of the proven public health benefits of NEXs. Although this is an American analysis of factors affecting policy decisions, the external factors and meanings and the role of scientific evidence associated with NEXs are equally relevant for UK and Scottish policies. This reflects the context for the development and funding of any new intervention including syringe markers.

1.11 Summary

It is clear that there has been a change over time and that the protection of public health, through provision of NEXs and opiate substitute prescribing, has become the predominant public health imperative both locally and nationally for drug treatment services over the last 25 years. Stimson concluded that IDUs were able to change their behaviours resulting in reduced risks of HIV infection (1995:699). Based on the previous experiences with HIV and extensive evidence of changes in behaviour, it is possible to conclude that changes in behaviour that reduce the risk of HCV are also potentially achievable. This will be dependent on the existence of effective training

and information programmes for service users and professionals and on an effective means of reducing sharing of all injecting paraphernalia becoming more widely available. For any intervention to be completely effective there needs to be an understanding of the social context and meanings that surround all aspects of injecting drug use in addition to the mechanics of drug preparation and injection.

The initial aims of NEXs were to reduce the sharing of needles and syringes. There is evidence to support the effectiveness, across a range of factors, of sterile needle and syringe programmes. Wodak and Cooney's review of the current international evidence of the effectiveness of sterile needle and syringe programmes demonstrated the existence of proven and substantial benefits (2005:31). In examining the perception of risk behaviour and risk reduction in the context of personal experiences and lifestyles it was highlighted that there is a need for interventions to incorporate experience as well as theory (Rhodes, Greenwood and Robertson, 2001:84). For this reason, although it may appear axiomatic that reducing sharing and reuse of injecting equipment will reduce the spread of HCV, it is essential that any new policy developments are informed directly by IDUs experiences. These authors outlined the benefits to be gained from linking interventions and evaluation (Rhodes *et al*, 2001, 87).

The intervention outlined in this syringe marker study evolved from the range of qualitative and quantitative research in the area of injecting drug use and risk behaviours. The aim of this intervention under evaluation is to implement the supply of syringe markers, to assess the acceptability to IDUs and to provide one possible aid to reduce re-use and sharing of injecting equipment and thereby offer a potential

means of reducing the transmission of HCV. Scotland's Hepatitis C Action plan proposed a number of specific action points. This included asking NHS boards to:

“Consider whether they have the full range of interventions in place to reduce re-using and sharing of needles, syringes and injecting paraphernalia to promote safer injecting. These interventions should include: more outreach and mobile exchange services; distributing a wide range of paraphernalia (in addition to needles and syringes) in needle exchanges and labelling or colour-coding of injecting equipment to help drug users identify their own”

(Scottish Executive, 2006:10).

In Scotland, an early review of the research concluded that strategies to prevent the spread of HCV should not be based on a single approach but should tackle the problem in different ways using a range of interventions (Morrison, Duff, Taylor *et al*, 2002:12). The syringe marker supply is only one intervention that may potentially have a part to play in reducing the spread of HCV. The aim of the study described here is to contribute to the evidence base on the introduction and supply of colour-coding of injecting equipment from NEXs by evaluating the syringe marker supply implementation. As the management of the NEX programme is the responsibility of the investigator, this work forms an integral and ongoing part of the investigator's professional work role.

Chapter 2

Methods and Methodology

2.1 Background

An examination of the injecting practices of injecting drug users in Scotland demonstrated that some users had difficulty identifying their own syringes when injecting in a group situation (Taylor *et al*, 2004:7). As outlined in the literature review, this is a recently identified problem with particular relevance being attributed to the role of shared items of injecting paraphernalia, in addition to needles and syringes, in the spread of infections, notably of HCV. This risk is irrespective of whether the sharing is deliberate or accidental.

The growing body of work into transmission of HCV has shown that current prevention strategies are insufficient to adequately deal with the problem (Hutchison *et al*, 2006:8). Taylor *et al* highlighted the potential for transmission through other paraphernalia and made recommendations regarding the desirability of introducing a means of syringe identification (2004:4). Based on an examination of real life injecting practices, it was recommended that the current supplies of fixed 1ml needles and syringes should be produced in a range of different colours to enable IDUs who lived together to distinguish each other's equipment (Taylor *et al*, 2004:38).

Little previous work, however, has been done to either establish the practicalities of this type of intervention, to investigate service users' views on the acceptability or of any potential problems of introducing syringe identifier supplies from existing services. In 2005, Exchange Supplies reacted to the emerging evidence on the risks

associated with sharing of injecting equipment and developed and marketed a new product range named *syringe id plunger caps* (Exchange Supplies). Although the rationale behind the introduction of these caps was strongly centred in the emerging evidence base, as previously noted, there was a lack of research evidence into the implementation and subsequent evaluation of the impact and applicability of markers or identifiers in real life situations. The *syringe id plunger caps* became the precursors to a further innovation from Exchange Supplies of the Nevershare® syringe. (Exchange Supplies, 2010). This is a coloured syringe that has a built in advantage over the previous *id plunger caps* as the IDU is not required to physically attach an additional part or alter the coloured syringe. The advantage is that it is ready for immediate use.

As the author of this study manages the operational aspects of the Health Board NEX programme, the implications for services of the emerging research and the recommendations on syringe identification were identified as an appropriate subject for combined professional and educational investigation. Initially a decision was made to undertake a comparative study of the commercially produced *syringe id plunger caps* produced by Exchange Supplies and of sheets of coloured stickers (syringe markers) as a possible alternative means of syringe identification. The proposal to use sheets of coloured stickers as an alternative had emerged through informal discussions with staff and service user involvement groups as potentially being a cost effective alternative to the newly available id caps. As the community pharmacy based NEXs are the largest suppliers of sterile injecting equipment to IDUs it was decided to use this scheme to undertake a comparative study of the two potential options for syringe identification.

As part of the background preparatory work the local Health Board Risk Assessment Department was consulted for advice. They advised that, in their professional opinion, the syringe *id plunger caps* could potentially pose a choking hazard to children (Green J, 2006: personal communication). This was based on an examination of the design of the caps which are of a solid plastic material and are small enough to be attached onto the plunger end of a syringe. These are also produced in a wide range of attractive bright colours. Although it appears intrinsically obvious that a needle and syringe poses a hazard for a child, the view of the senior staff from the Risk Assessment Department of the health board was that supplies of separate plastic caps which are not attached to the syringe introduces another additional hazard if left in areas where children may be present. There are numerous health and safety messages available relating to safe storage and disposal of injecting equipment but it was advised that this material did not provide sufficient information on the risks associated with items other than the needle and syringe (Appendix 3). Based on this assessment the advice received was that there was an unacceptable extra risk and that these *id caps* could not be supplied through any health board funded NEXs. It was therefore not possible to continue with the initial planned comparative study.

At this point the comparative study was reviewed and a decision taken to continue with an evaluation of the sheets of coloured stickers (referred to as syringe markers) as a means of syringe identification. As noted above the evidence had demonstrated the need for syringe identification; however the gap in the evidence base related to the practical applications of supply and acceptability of the different proposed options for syringe identification. The evaluation was designed to study the distribution of the markers from pharmacy NEXs, to identify whether this was acceptable to IDUs and to

determine if this offered a feasible method of reducing the accidental sharing of syringes by providing a potential means of identifying injecting equipment for personal use and therefore preventing the inadvertent accidental sharing of syringes within a group setting.

The proposed study utilised the principles of evaluation research. This type of research is embedded in the social world and investigates “real-life interventions” (Bryman, 2004:539). This is distinct from basic or applied research designs in that it allows the assessment of “the outcomes of treatments applied to social problems” (Miller and Salkind, 2002:3). It does not involve seeking out new knowledge in relation to social phenomena or how this knowledge could be used to address a problem but is concerned with decisions relating to the “value or merit” of individual interventions or programmes (Miller and Salkind, 2002:3). According to Rossi and Wright, evaluation research came to prominence as an applied social scientific activity in the mid 1960’s where they identified the distinctive feature as the recognition, amongst decision makers, that the principles of social science research could be applied to evaluations and that this was likely to yield more valid results than the previous “judgemental approaches” that had been employed (2002:79). This was re-enforced by Clark, who claims that the distinguishing factor for evaluation research is the ability to make recommendations for change based on an “action oriented” investigation into the outcomes of specific policies, programmes or service interventions (2005:vi). The essential features of evaluation research described above appeared to fit the requirements of this study where the objectives were to make judgements on the implementation of an intervention (syringe markers) within a

service setting (community pharmacy NEX) and to systematically examine the potential value of the intervention.

This evaluation is distinct from a clinical audit of the intervention. Although audit and evaluation may both adhere to systematic procedures and have the same ultimate aim of quality improvement, there remains a clear distinction (Clarke, 2005:5). Clinical Audit has been defined as a:

“Quality improvement process that seeks to improve patient care and outcomes through systematic review of care against explicit criteria and the implementation of change. Aspects of the structure, processes, and outcomes of care are selected and systematically evaluated against explicit criteria. Where indicated, changes are implemented at an individual, team or service level and further monitoring is used to confirm improvement in healthcare delivery”

(National Institute for Clinical Excellence (NICE),2002:1)

Essentially a clinical audit is a cyclical process whereby standards are set, practice is observed, comparison is made between standards and observed practice and change is then implemented. According to Clarke, for an evaluation, there is greater consideration of the underlying theory and the impact of a specific programme which enables evaluations to predict the direction of future developments (2005:5). Audit is described as being less ambitious than evaluation (Clarke, 2005:5). One of the main aims of the evaluation described here is to obtain information that will help to structure and expand future developments and for this reason a clinical audit would not have been sufficient as there is no predictive or transferable element to the audit process that would direct future developments.

With the pilot study of syringe markers it would have been relatively straightforward to audit the practical operational aspects of the programme, including numbers supplied at each transaction, records of advice provided and requests for re-supplies, against a predetermined set of standards. However this would not have enabled an investigation of the feasibility of the markers as a method of reducing the accidental sharing of needles amongst IDU nor of their acceptability or of any practical problems associated with this method of supply. A basic clinical audit approach would not allow judgements to be made on the “value and merit” of the intervention as described previously (Miller and Salkind, 2002:3).

2.2 Theoretical Perspectives

The core of evaluation research is to investigate the effectiveness of social programmes or planned interventions. Claims are frequently made that the theory behind an evaluation is often ignored resulting in evaluation being portrayed as “an atheoretical, methods-oriented enterprise” (Clarke, 2005:30). However, although the role of theory may not be as immediately obvious or as relevant when compared with other forms of research methodology, it has an important role to play as it provides the evaluating researcher with the basis for the choice of specific research methods and methodological design (Clarke, 2005:30).

According to McLaughlin there are four competing epistemologies that appear to have relevance to the theoretical basis of evaluation research. These are positivism, constructionism, pragmatism and advocacy / participatory knowledge claims (2009:67). Positivism is associated with quantitative methods and refers to the use of

natural science methods to study social reality (Bryman, 2004:11). Constructionist knowledge claims are associated with a qualitative approach and are at the opposite end of the spectrum to positivism where meaning and human agency are the core elements (McLaughlin, 2009:70). Advocacy / participatory knowledge claims promote a social model perspective where the emphasis is on the disabling effect that society has on individuals (McLaughlin, 2009:72). According to the latter approach research cannot be justified solely by the search for new knowledge but can only be legitimised when it leads to change (Glasby and Beresford, 2006:268).

These approaches all have elements that are relevant to the current study particularly as service users were involved as research participants. The syringe marker evaluation is set within a defined setting where the aim is to extrapolate findings to the wider population necessitating a positivist approach to design. Due to the setting and nature of the patient group, other elements inevitably become involved in the design that require consideration from a constructionist position as the actions and interactions may be governed by potentially unknown meanings. The role of service users in research is discussed in Chapter 3 and considers the implications of using peer researchers in detail. However it is reasonable to assume that included in the benefits to service users participating in research is the opportunity to participate and advocate for change and thereby positively affect services they currently use or have used in the past (McLaughlin, 2009:34). However, despite the relevance of the three approaches mentioned above, the main theoretical perspective underpinning the syringe marker evaluation is one of pragmatism. The driving force behind modern pragmatism has been defined as the notion that “belief in the truth on one hand must have a close connection with success in action on the other” (Blackburn, 2008, Oxford Reference

Online). According to Misak one of the central claims of pragmatism is that “epistemological and moral theory should try to preserve our deeply held convictions and our ways of inquiring into various subject matters” (1999:6). The relationship of pragmatism to the syringe marker evaluation is that the study is conducted within the framework of a harm reduction model. The development of the harm reduction model was outlined in Chapter 1. Essentially this is a belief system where the compelling need to reduce harm is deemed to outweigh any other ethical or legal considerations. Harm reduction, in the form of providing clean injecting equipment, does not have universal acceptance, including within the pharmacy profession. However this study is set within a harm reduction setting and investigates a specific intervention in this context. The harm reduction model can be viewed as an ethical belief system where the value of the action is determined by the resulting beneficial consequences for individuals and the wider public. A constituent part of modern pragmatism is claimed to be “doxastic inertia” where any inquiry is carried out in a context where there is no need to justify the existing belief (Misak, 1999:179). This reflects the conduct of the evaluation within a harm reduction service setting.

Although McLaughlin claimed that the four epistemologies mentioned above were “competing” it is clear that the syringe marker evaluation demonstrates elements of all four. Despite the evaluation demonstrating elements of different theoretical perspectives, it is primarily conducted within the paradigm of a harm reduction model where the core component of pragmatism is demonstrated by the belief in the efficacy and moral legitimacy of this model.

In addition to the theory of the evaluation, it is relevant to examine the theoretical perspective aligned with IDU and NEX itself. Health and illness are now increasingly agreed to be the result of complex interplay of actions amongst biological, psychological and social factors (Alonso, 2004:239). According to Engel, sole reliance on the previously accepted biomedical model of disease which involved identifying and treating causative factors in illness, ultimately leads to inadequate patient care (1977:131). In 1977 he proposed a bio-psychosocial model of disease that incorporated human experiences and interactions. He proposed that, in addition to the biological factors, social, psychological and behavioural considerations are also essential for effective patient care in real life settings (1977:135). Although there may be legitimate debate about whether problematic drug use can be deemed as an illness or as a social construct there is no doubt that, for the majority, the health of an IDU is adversely affected. The role of NEXs can also be viewed from this perspective as its positive impact on the health of an IDU, and the wider community, is the result of a complex interplay of biological, psychological and social factors. This was demonstrated in Chapter 1 where the biological aspects of HIV and HCV transmission were discussed along with behavioural elements attached to injecting, including sharing. Use of NEX services is associated with illegal behaviours and is set within communities and for these reasons is affected by numerous social factors including adverse public perceptions and attitudes along with the perceived barriers that often makes access difficult for IDUs. Taking these factors into account the bio-psychosocial model appears to be the most apt theoretical perspective for complex public health interventions, like NEXs, that aim to promote health through behavioural change.

The term pragmatism is used in everyday language to convey a range of different meanings. According to Webb the term can be used in ways that can be vague and confusing (2007:1064). Care needs to be taken to distinguish between pragmatism, as a theoretical basis discussed above, and a pragmatic approach to the choice of methods employed in the evaluation. The key feature of the pragmatic approach is to focus primarily on the problem rather than the methods used. According to McLaughlin it is legitimate for the researcher to use whatever methods are required to address specific issues (2009). Creswell has identified the key features of a pragmatic approach as the “freedom to choose the methods, techniques and procedures” that best fit the aims of a particular study (2003:12). McLaughlin (2009) sums up the pragmatist methodological approach to research by claiming that no one method is inherently better than another as the choice is dependent on the question being asked. Irrespective of the theoretical basis, a pragmatic approach offers the option of using a variety of different methods at different times. This is relevant to evaluation research where the main aim is to evaluate the effects of interventions where the researcher requires methodological flexibility as they may have little or no control over some elements but still needs to strive to maintain an objective scientific rigour in the design, despite any practical contextual constraints.

A pragmatic methodological approach to the syringe marker evaluation with pragmatism as the theoretical underpinning is the approach that best describes the evaluation set within community pharmacy NEXs. The service is best described with reference to the bio-psychosocial model which incorporates the various theoretical elements that constitute the totality of the NEX settings, professional participants, service users and wider community involvement. In addition to establishing the

underlying theoretical perspectives there were also a number of inherent practical difficulties involved in designing and implementing an evaluation of the syringe markers. These, along with the identified solutions, are considered below.

2.3 Evaluation Design

The study aimed to evaluate the distribution of syringe markers and to survey those who were supplied with markers to obtain feedback about their use. The final design and methods used in the evaluation were constrained by a number of factors including the limited funding available to conduct the study (Appendix 4). Due to the volume of supplies made and the extended opening hours of community pharmacy based NEXs a decision was made to use these outlets as the evaluation sites. This was based on information routinely recorded on the NEX database. The database contains recorded details of all individual transactions from 2003 onwards and is used to monitor activity and identify emerging trends. Although individuals using a NEX remain anonymous, a limited amount of basic transactional, drug and demographic information is collected to enable effective monitoring of the scheme and to identify new and emerging trends and patterns in injecting drug use. The centrally held comprehensive database records details of all individual transactions, supplies, returns of used equipment, information on drugs injected and other basic demographic information. Data monitoring has been described as a “process of keeping track of what is happening; watching what is happening and documenting this in some way” (Everitt and Hardiker, 1996:20). The data that is created through this monitoring process can be used to help to design practice evaluations (Everitt and Hardiker, 1996). However as Clarke observed, any routine process involving auditing,

monitoring and inspection can generate data that may be useful in an evaluation, but these do not necessarily constitute evaluations in themselves (2005:7). Therefore the data that was generated from the NEX database was informative in assisting the design of the evaluation but was not an element of the evaluation itself. This database was also a useful resource to assess the representative nature of the sample of people interviewed on the days when interviewers were present in each pharmacy.

According to Clarke designing a “perfect evaluative study” does not follow set guidelines (2005:16). He further outlines the difficulties facing researchers that must be considered. These include all the practical, technical and methodological aspects that have to be considered and incorporated into the design before it is possible to implement an evaluation in an existing operational setting. This highlights that the researcher has to be prepared to deal with any of the multitude of practical challenges that will inevitably occur in real life settings (Clark, 2005:16). In designing this evaluation attempts were made, where possible, to identify and address in advance, any potential practical difficulties. This was largely based on background knowledge of the day to day operational aspects of community pharmacies and the delivery of a NEX service within this context. The anticipated and the actual practical difficulties encountered in the design and implementation of this evaluation are discussed below.

The database information was used as the main source to select 3 sites in different geographic locations in Glasgow that were shown to be most likely to have the highest number of daily attendances and therefore offer the maximum opportunity for distribution of the markers. There were further practical considerations that restricted the choice of sites. These included identifying sites that had an internal area where

service users could complete the questionnaire in privacy and that this was an area that could be used throughout the day by the researchers without adversely impacting on the other pharmaceutical services being provided. In order to ensure consistency, only pharmacies with a permanent manager and not different temporary locums were used as sites to trial the markers. The reason for this was to ensure that, following the briefing session, the pharmacist was fully informed about the research and the background evidence and was therefore able to respond consistently to any questions that arose when supplying the markers during a NEX transaction. Using a pharmacy that was being managed by a series of locums would introduce additional uncontrolled variables that could potentially lead to unpredictable effects on the supply and inconsistent advice being given to those supplied with syringe markers when collecting their normal injecting equipment supplies.

Pharmacy based NEX services operate with no appointment system over extended opening hours and it is therefore difficult to predict who will attend and at what times of the day. For this reason it was essential to explore, in advance, any potential problems that the subsequent onsite data collection could cause for pharmacy staff, service users, the researcher and other pharmacy customers and patients. The aim was to have procedures in place to minimise any potential difficulties when administering the questionnaire. This included adjusting the data collection process to the daily pattern of routine work within a busy community pharmacy by establishing relationships with regular staff, attempting to identify patterns of NEX attendance and making optimum use of consultation and private areas to administer the questionnaire confidentially with minimal disruption.

Based on the above criteria, 3 sites were selected that best met the identified requirements. These were situated in separate locations and were identified as Pharmacy 1, 2 and 3. Pharmacy 2 was part of a large multiple pharmacy chain and the other two were members of two smaller independent groups. All sites were established NEX pharmacies that had been assessed as fitting the inclusion criteria and were based in different geographical locations in the city. These pharmacies were then invited to take part in the pilot supply of syringe markers (Appendix 5).

The fieldwork took place in 2 separate 4 week periods. In the first 4 week period the pharmacy staff were responsible for supplying syringe markers and giving directions on use to those attending the NEX. In the second 4 week period the peer researchers from the Scottish Drugs Forum (SDF), Service User Involvement Group (SUIG) * identified participants and administered the questionnaire in the 3 pharmacy sites. The type and brand of stickers to be used as markers were selected and a commercial source of supply was identified. Stocks were obtained and distributed. Specific tailored instructions for use were developed and produced (Appendix 6).

Before the intervention could be implemented it was necessary to ensure that the pharmacists and relevant staff had received additional training to enable them to make the supply appropriately and to explain the purpose and use of markers to patients in

* *The work of the SDF SUIG involves, identifying the views of service users, (peer research and service evaluation), representing the views of service users (planning forums, advisory groups, and media work) participation at conferences/seminars (participant or facilitator), training (peer education, drug worker training, emergency first aid) development and dissemination of drug awareness material (drug prevention and harm reduction material). <http://www.sdf.org.uk/sdf/429.200.321.html#involving>*

a consistent manner across the 3 sites (Appendix 7). The training session was also attended by 6 members of the SUIG and their support co-ordinator. The SUIG members would be responsible for administering the questionnaire in the pharmacies. This allowed the pharmacy staff to meet with members of the SUIG in advance to help facilitate effective working relationships and establish clarity on the roles and responsibilities of all groups involved in the evaluation. The first 4 week period of syringe marker supply was initiated on the Monday following completion of the training sessions.

The next identified step was to design a questionnaire to be administered at each site during the second 4 week period of the fieldwork. The questionnaire consisted mainly of closed questions with a number of fixed response answers. This was administered to respondents by the peer researchers responsible for conducting the structured interviews. The questionnaire was subdivided into 4 sections. These were Personal Information and Injecting pattern, Supply of Syringe Markers, Use of Syringe Markers and the Instruction Card. Details of the questionnaire are shown in Appendix 8. The practicalities of administration of the questionnaire are described in detail below. This second period was the data collection phase of the evaluation.

The time periods for marker distribution and questionnaire data collection were selected following interrogation of the daily log sheets and the database, as this showed evidence of a definite regular pattern of repeat attendances. This indicated that 4 weeks was an appropriate duration so that the first 4 week syringe marker supply period was likely to achieve maximum coverage of people attending the pharmacy for injecting equipment. Although, as mentioned above, the pre-existing

NEX data is collected anonymously, basic information including date of birth and initials are collected. Details of gender and ethnicity are also recorded. No confirmatory checks are made on the data supplied by individuals and it is not possible to identify individual patients on the system but it is possible to make estimates of numbers attending, repeat visits and new attendees. Examination of the database showed that extending past the 4 week period was likely to result in repeat attendances of the same people. The database information indicated that using the two separate 4 week periods (first period for syringe marker supply and second for data collection) was the most likely to achieve the maximum possible distribution to individuals from the pharmacy site and to maximise the likelihood that during the second stage of administration of the questionnaire that those attending the NEX would have previously been supplied with the markers. At this stage this was an important unknown factor. In order to have any meaningful results, it was essential that those interviewed had been exposed to the intervention and had had the opportunity to use the markers in practice. The information contained on the database combined with anecdotal information available from pharmacy staff and the SUIG were essential at this stage in the design of the evaluation. The choice and timing of the two 4 week periods was therefore based on a combination of information obtained from scrutiny of the database, background knowledge of the service provided by staff and knowledge of the patterns of behaviour of those attending a NEX provided by the SUIG.

It has been noted that for this type of evaluation research the options for using particular data collection methods are strongly influenced by the practical constraints of the evaluation setting (Clarke, 2005:64). In this situation the anonymity of the

participants and the community pharmacy based operational conditions placed inevitable constraints on the data collection methods available. Interrogation of the NEX database indicated that the time scales chosen for the questionnaire administration were most likely to enable capture of information from a subgroup of the population attending the NEX that had previously been exposed to the intervention of syringe marker supply. This inevitably involved an element of judgement and was partly due to the essential feature of the NEX, which is the anonymity of those attending. Effectively this means that it is not possible to track specific individuals who have received the intervention. This problem had not been tackled before as previous evaluations conducted in the pharmacies and other NEX settings concerned the totality of the service and therefore anyone attending would have been eligible to complete a survey or questionnaire. One of the main issues to be solved in the evaluation design was that only a small subgroup of those attending would be eligible to complete the questionnaire as the original supply of markers took place over a restricted time period of 4 weeks. There were an unknown number of factors that may have influenced the data collection and the methods chosen needed to be sufficiently flexible to react to any emerging issues throughout the course of the trial.

“Judgement sampling” was used as this allows existing information to be used to select a subgroup of the population that is presumed to be representative of the wider population (Miller and Salkind, 2002:55). There was no randomisation of the intervention at the pharmacies nor was there any non-intervention group as all attendees were offered the markers during the first 4 week (supply) period. This was due to the setting, as the intervention was carried out in an existing treatment service

and there were limitations on the number of variables that could be controlled in this type of research. To assist the design and to investigate whether these 3 sites were attended by a group with similar characteristics to other sites, the demographic data from the 3 pharmacy sites chosen was examined. This allowed a judgement to be made and indicated that for the three chosen sites there were no significant differences when compared with other sites in respect of gender, age, ethnicity or in recorded illicit drug use that would be likely to cause any idiosyncratic results. The relevant details for the 3 chosen sites and the combined information for all sites in Greater Glasgow and Clyde are shown in Table 2.1. This indicated that the overall demographic pattern and the information collected on the types of drugs injected were consistent across the 3 research sites and were in line with the aggregated information from all sites in the health board area. The information contained on the main database allowed comparison to be made of the characteristics of the sample likely to be interviewed in each pharmacy and the wider NEX attending population. Data was collected by the SUIG interviewers on the number and reasons for refusal to participate.

Table 2.1.
Recorded Information From Central Database on Characteristics of NEX Attendees and Transactions

% based on transactions	Pharmacy 1	Pharmacy 2	Pharmacy 3	All Health Board Sites
Most common Age Range : 35-39 (%)	23.7	26.7	31	24.8
Female (%)	23.7	20.4	22.1	21.9
Male (%)	76.3	79.6	77.9	78.1
Ethnicity (%) White British	92.3	94.4	98.4	95.7
Drugs Injected				
1. Heroin (Opiate)	84.9	88.3	86.8	85.1
2. Cocaine (Stimulant)	6.9	8.9	10.1	9.4

Source : NHS Greater Glasgow and Clyde Needle Exchange Database(2003-2007).

Judgment sampling has a number of advantages for this type of evaluation as it reduces costs associated with identifying the sample and the subsequent fieldwork (Miller and Salkind, 2002:55). The main disadvantages are that it is difficult to control any bias and requires extensive knowledge of the population and subgroup identified (Miller and Salkind, 2002:55). It is recognised that there are inherent difficulties in attempting to exercise control over the range of factors that may potentially confound the final results. Based on knowledge and experience of the service and with the added experience of the peer researchers of the population under study, the evaluation was designed to overcome the practical difficulties that research in this type of service environment poses. The final design was mainly achieved through a process of continual refinement and consultation.

2.4 Ethical Processes.

Research and evaluation in a health care setting that has a direct effect on patients can take a number of forms. These include clinical audit, service evaluation and research. Normally only research that involves new treatments, random allocation to different groups and the direct involvement of patients requires ethical approval (National Patient Safety Agency (NPSA), 2006). Audit and evaluation are normally considered to be routine parts of service delivery that do not require ethical approval. However there were two main factors in this evaluation, discussed below, that prompted the decision to seek advice from the local research ethics committee (REC).

Firstly, the decision to involve the SUIG, and not existing staff members, to administer the questionnaire introduced an additional ethical dimension that needed to be considered. For example there are potential implications in allowing external groups access to patients as maintaining patient confidentiality is a key principle for any health care professional. For pharmacists there are seven governing principles in their code of ethics. These include “making care of patients your first concern” and “exercising your professional judgement in the interests of patients and the public” (Royal Pharmaceutical Society of Great Britain (RPSGB), 2010:4). Pharmacists are directed to “take all reasonable steps to prevent accidental disclosure or unauthorised access to confidential information and ensure that you do not disclose confidential information without consent” (RPSGB, 2010:8). This applies to all aspects of the NEX programme. Also the introduction of the SUIG members into the evaluation meant that there was an ethical responsibility on the principle researcher to ensure that their participation would have no adverse effects on the individual peer researcher.

Research has shown that when individuals are exposed to environmental triggers associated with their previous drug use there is a risk that this can precipitate relapse (Crombag, Bossert, Koya *et al*, 2008: 3233). In this evaluation the peer researchers were required to enter and spend time in the physical environment of the NEX resulting in exposure to both the physical environment and the injecting paraphernalia closely associated with their personal previous drug use. It was therefore essential to provide full support for the peer researchers to avoid involvement in the research resulting in relapse in their own personal recovery. The wider role of peer researchers is discussed separately in Chapter 3.

Secondly, the National Patient Safety Agency (NPSA) has issued guidance on governance arrangements for service evaluations and has stated that:

“If it is intended that the results of the service evaluation are to be used to influence practices or processes outside the immediate setting and the work was not managed within the Research Governance Framework, there would be a risk of the public being exposed to changes without a sound evidence base. Where it is intended to publish the results of an evaluation in a form that aims to generalise the results to others situations, the evaluation should therefore be managed within the Research Governance Framework”

(NPSA 2006:2)

If the results of the evaluation were positive there was a clear intention to extend the scope of the service intervention outside the immediate setting of the three research sites. Potentially this could affect thousands of individuals who access local NEXS on a regular basis. For these reasons this evaluation was submitted to the NHS Research

Ethics Committee for ethical approval. This had the added advantage that the REC provided independent scrutiny of the design of the evaluation as the practical difficulties associated with any evaluation research design have been outlined above. RECs are required to assess a number of factors for any application including the “scientific design, conduct of the study and the recruitment of research participants” (Department of Health (DoH), 2001:24). Before a favourable opinion is given to any application, the REC must be content that the study design is appropriate to the aims of the study (DoH, 2001).

Following an informal approach for advice a formal submission of the evaluation was made to the NHS Research Ethics Committee. Ethical approval was granted subject to the following three minor amendments,

“a) Researcher to ensure that there is a sufficient range of colours available for the syringes. Care should also be taken to ensure that people who could be colour blind cannot be misled.

b) Researcher requires to ensure that use of quotes is entirely anonymous and does not compromise confidentiality and

c) The terminology of Q2 of the service user questionnaire should be altered to “street” terminology as the participant possibly might not understand the original phrases”

(REC Reference Number 06/S0701/80).

2.5 Data Collection

According to Clarke (2005) evaluation studies routinely incorporate several different methods of data collection. Different strategies were involved in the design of this evaluation but the main method used to collect data was a questionnaire that generated

quantitative data. However qualitative data was also generated by the decision to use peers to administer the questionnaire. According to Patton researchers are described as the “instruments of data collection” which means there must be reflection and understanding of any resulting potential bias (2002:51). The research diary created during the fieldwork by the SUIG members assisted in the reflection process and generated relevant qualitative data. The reflexive observations from the SUIG and the researcher contributed to the final overall evaluation. At the end of the study the views of staff from the three participating pharmacies were sought and included in the overall reflection. The use of peer researchers and their involvement and impact on this work is considered separately in Chapter 3.

The aim was for the 3 pharmacies to distribute the markers over a 4 week period to all patients receiving NEX packs. These were distributed along with an instruction card on the correct use of the markers (Appendix 6). This was accompanied by a brief consistent explanation from the staff on the nature of the supply and instructions on how to use the markers. It should be noted that this constituted a service development in an existing service and the evaluation was not discussed with service users at this point.

Before ethical approval was sought a final version of the questionnaire was developed. This was devised in the planning stages by the researcher based on comments and advice from the SUIG. The main aim of the questionnaire was to assess the views of those who had been supplied with the markers. The SUIG were relatively inexperienced with this type of research work and this was a consideration in the design and length of the questionnaire. Members of the SUIG all had previous

personal experience of use of NEX services and piloting was undertaken by members of the SUIG amongst the group. With hindsight it would have been more informative to have piloted the questionnaire in one of the pharmacy based NEXs with current NEX attendees. This is explored further in Chapter 5 in discussion of the evaluation limitations. The questionnaire was divided into four sections and employed mainly closed questions. Closed questions have the advantage that they are easier and quicker for both interviewers and respondents to complete and help to reduce the variability in recording responses (Bryman, 2004:148). Further amendments were made following advice from the local REC. The final version employed is shown in Appendix 8. Members of the SUIG were responsible for introducing themselves to potential interviewees attending the NEX. This was followed by a brief introduction to the study. A copy of the patient information provided to respondents is shown in Appendix 9. The questionnaire forms were colour coded for the three pharmacy sites to aid the peer researchers' recording procedures. This meant that the location did not have to be recorded each time as there was the possibility that the interviewers would relocate amongst the sites depending on the pharmacy operational requirements and the availability of those attending the NEX to interview. The questionnaire was administered in the second phase, four weeks after the initial marker distribution.

Completion of a questionnaire can utilise different methods. When dealing with illegal behaviours such as injecting illicit drugs there are inevitably added difficulties in collecting the data through use of questionnaires. However, self completion questionnaires have the advantage that this method reduces adverse interviewer effects (Bryman, 2004:133). These adverse interviewer effects have been identified as including characteristics such as ethnicity, gender, and the social background of

interviewers which may individually or in combination affect the responses that are given (Bryman, 2004:133). This is relevant to the syringe marker evaluation as Bryman reports that “social desirability bias”, where the respondent provides the answer that presents them in the most favourable way, is often exhibited when the interviewer assists with completion (2004:134). He demonstrates that this effect is particularly relevant when investigating drug and alcohol issues as self completion results in higher reported rates of use than when the interviewer is present (2004:134). For the syringe marker study this highlights the possibility that answers to questions on whether syringes have been mixed up with some one else’s may be under-reported and the use and usefulness of the markers supplied could be over-reported. It is reasonable to assume that the combination of perceived interviewer effects and socially desirable responses are likely to be heightened when dealing with illegal, harmful and less socially acceptable types of behaviour. Previous work in Australia using peer workers in a participatory action research project had produced results that indicated that data quality was improved by involving peers in this way to offset biases experienced with other data collection methods (Coupland, Maher, Enriquez *et al*, 2005:191).

In work investigating sharing behaviours, researchers claimed that this often relied on self reporting due to the difficulty of “ethically validating” alternative methods of data collection (White, Day and Mather, 2007:441). They observed that the behaviours which placed people at greatest risk were also the most likely to be considered stigmatised and therefore the most susceptible to effects of biased under reporting (White *et al*, 2007:441). This would suggest that the potential existed to over report use of the markers due to a desire to present any information on their implied injecting

behaviour in the most positive light. This was an issue for the syringe markers evaluation as the supply of markers to potentially promote safer injecting practices was the reason for the intervention. The study conducted by White and colleagues in Australia compared results obtained where the participants were needle and syringe programme (NSP) attendees with self completed questionnaires and those where an interviewer assisted with completion (2007:441). These results showed that when participants received assistance in the completion of the questionnaire they were less likely to report that they had shared or re-used a syringe previously known to have been used by someone else. As this evaluation related to questions on the use of syringe markers to identify individual syringes there may be potential challenges in addressing this type of sensitive topic and obtaining accurate responses.

Despite the effects of interviewer bias described above and the findings of the Australian study, which recommended that questionnaires involving risk behaviours should be self completed rather than administered by the interviewer to improve the accuracy of the reports, a decision was taken to administer the questionnaire using an interviewer and not to offer it for self completion. Self completion may have initially appeared to be the most relevant method of investigating any sensitive and potentially stigmatising behaviour of those attending NEXs. However this was not considered to be appropriate for this particular evaluation due to the nature of the subject and the group. For example, initial contact with interviewees is essential to establish that the questions are being answered by those who have previously used the markers and are therefore eligible to complete the questionnaire. Facilities for self completion within the pharmacy environment would have been practically very difficult to arrange. The sensitivity of the subject matter and the influence of the interviewer on the accuracy

of responses were considered in the evaluation design. In this context, self completion was assessed and then dismissed as a workable option due to operational difficulties and the need to ensure that only those eligible completed the questionnaire. The use of peer researchers rather than staff to pose the questions is an attempt to address these potential sources of bias. Essentially the use of peer group interviewers was a practical compromise designed to reduce the impact of any potential interviewer bias effects and to improve the quality of data collected by minimising the need for respondents to provide socially acceptable responses.

The SUIG were consulted and a decision was made for them to operate in pairs while attending each of the 3 pharmacy sites. This was due partly to the fact that although all of the members had received specific training they were all relatively inexperienced in this type of data collection. There were advantages to working in pairs in the initial stages as this provided their own peer support while they gained experience in an unfamiliar role. Following joint discussions between the researcher and the SUIG a decision was made to attempt to administer 150 questionnaires over the second 4 week (data collection) period. There were six members of the SUIG available to participate in the work and the figure of 150 was considered to be realistic within the timeframe available. This arrangement required to have flexibility due to the difficulties associated with the unpredictability of NEX attendances and the personal commitments and availability of the peer researchers. Planning was problematic as it was not possible to identify specified appointment times to interview respondents and the NEX service is available for extended periods during the full opening hours of the pharmacy. The SUIG members identified the perceived optimal time periods to attend each pharmacy and matched this with their own personal

circumstances that affected their availability. This was inevitably an evolving process and the SUIG members needed to be flexible to be able to react and alter their attendances to try and maximise contact with potential respondents.

The SUIG field work diary was a contemporaneous record of their personal observations of the evaluation process during the time spent in each pharmacy. Along with personal observations, details were recorded of the pharmacy site, total length of time spent in the pharmacy, number of completed questionnaires and the number of refusals. The field work diary also recorded details of interactions with and comments made by pharmacy staff and respondents. This allowed the capture of a range of valuable qualitative information that was not recorded by the structured questionnaire or elsewhere.

The methodological procedures described above illustrate a common feature of evaluation research where there are no set guidelines on methods to follow which means that the evaluator has to devise and have strategies in place that anticipate and deal with the inevitable practical challenges that will occur in this type of research (Clarke, 2005:16). It is impossible to separate any evaluation from its setting. In the early stages of evaluation theory and methodological development Patton had noted that due to the diverse nature of the settings where evaluations took place it was inevitable that “methodological flexibility and creativity” had become essential components (Patton, 1981:272). The social context influencing the design of the syringe marker evaluation has many elements and includes the requirement to respond, in a public place, to questions on normally hidden illegal and harmful behaviours. This inevitably introduced other social and political factors to the

evaluation, including public and staff perceptions of harm reduction and public health and the need to protect the rights and privacy of patients, staff and the wider public using the pharmacy premises. In practical terms the methods used in this evaluation research were designed to be feasible and also to maintain the integrity of the research methodology within a busy public healthcare and commercial environment. The phased steps in the design and implementation of the evaluation are summarised in Table 2.2.

Table 2.2. Summary of Design and Implementation Steps.

Phased Activity	Comments
1. Design comparative evaluation of <i>id caps</i> and markers.	Advice from Risk Dept prevents distribution of <i>id caps</i> .
2. Reconsider design and plan new evaluation.	Obtain funding
3. Markers and Advice card	Design refined following wider consultation with staff and SUIG.
4. Questionnaire design	Consult and pilot final version with SUIG
5. Questionnaire administration	Agree method of administration and use of Field Diary with SUIG
6. Interrogation of existing database.	To identify pilot sites and any anomalies or sites with unrepresentative activity data, likely to affect results. Identify sample.
7. Choose Sites	Contact 3 sites identified to agree participation.
8. Ethical Approval	Approval granted with minor amendments suggested and incorporated.
9. Brief staff and peer researchers	Arrange training sessions and follow up for those unable to attend.
10. Phase 1. Distribute supplies.	Arrange distribution to 3 pilot sites.
11. Phase 2. Administer Questionnaire	177 forms completed by SDF SUIG.
12. Phase 3. Analyse Results	Included quantitative data from questionnaire and qualitative data from SUIG Field Diary. Analysis of questionnaire results and secondary thematic analysis of field work diary.

2.6 Reflections on Design and Methodology

The author of this evaluation holds dual roles. These include the role of academic researcher and one of professional management responsibility for all aspects of the NEX programme in NHS Greater Glasgow and Clyde. This is an extensive programme that supplies in excess of one million sets of injecting equipment annually and is delivered by approximately 450 staff across a range of disciplines and agencies, to thousands of IDUs. It has been claimed that this is the largest provision, from a single organisation, of clean injecting equipment to IDUs in Europe (Roberts, 2007: personal communication). Prevalence data estimates that the number of IDUs in NHS Greater Glasgow and Clyde is in the range of 7,091 to 11,330 (Hay, Gannon, Casey *et al*, 2009:32).

The role of a manager consists of a number of different component roles. These have been identified and listed as “communicator, leader, group leader and team builder, conflict handler and negotiator, communications manager, accountant, budget-holder, quality coordinator and evaluator” (Whitely, Ellis and Broomfield, 1996: vii). This placed the researcher in a position of power where the need to negotiate access for the service user research participants was removed as the role of management gatekeeper was an existing element of the researcher’s professional role. For any manager in the public sector the core of their service is governed by the “end benefit to the public” rather than with generating profit (Haynes, 2003:17). However they are required to manage within a defined budget and, according to Haynes, this can be as influential as the need to generate profits within the private sector (2003:17). Any resources allocated to the syringe marker evaluation had to viewed in the context of the budget

for the overall service and the potential wider benefits to be gained from the evaluation and associated expenditure. This was an additional reason why approval through the independent ethical processes outlined above was deemed to be essential to give an external objective opinion on the research proposals.

The potential for conflict between the roles of manager and researcher is one that had to be considered and reflected upon throughout the design and implementation of this evaluation. According to Handy it is essential for anyone in a position of influence to “reflect upon the source of their power” (1993:125). He identified a variety of potential sources of power that affect the ability to influence others. These are listed as “physical, resource, position, expert and personal power” (Handy, 1993:125). For the researcher in this study, one of the additional sources of power not routinely available in the research setting was one of “resource power” where resources were available that could be re-directed to facilitate the research (Handy,1993:127). As the manager of the service there is also an element of “expert power” where this is defined as having specific relevant “acknowledged expertise” (Handy, 1993:130). In the management of the NEX programme, the researcher and other senior management colleagues routinely exercise “expert power” and act as sources of expert advice to a range of other professional health and social care colleagues on all practical and legal operational aspects of NEX provision. However, when examining the mechanics and the situational realities of the processes involved in the preparation and injection of illicit drugs, it was recognised that for the researcher, any knowledge in this area was purely theoretical. This gap was recognised and filled by the distinctive “expert by experience” knowledge that service user involvement contributed to the evaluation (McLaughlin, 2009:17).

A key component of this evaluation was to examine the acceptability of the syringe markers to IDUs and to ascertain if they would be useful as a means of identifying syringes. An audit of supplies made would not give any information on the use of these markers in real life situations and for this reason service users' views and the assistance of the members of the SUIG in the design and analysis were essential to the validity of the evaluation. Irrespective of what the evidence base indicates, ultimately, any changes to types of injecting equipment or methods of supply will only result in improvements to health if the changes and the equipment supplied are acceptable to service users. According to Harris "Not only should health research be valid science, but also it should be deemed to be valuable by those who live with the medical condition or use the services of interest" (in Lowes and Hulatt, 2005:190). This is particularly relevant for those attending NEXs as, despite the increasing evidence on ranges of equipment and the types of behaviour that will prevent the transmission of BBVs and related infections, successful harm reduction will only be achieved if the equipment offered and the routes of supply are acceptable to those using the service. The design of the syringe marker evaluation aimed to employ methods that were scientifically valid to assess the syringe marker supply, despite the practical constraints of the setting and the limitations on the variables that could be manipulated. Despite the use of the questionnaire being more likely to provide relevant information on use than an audit of supplies there are still limitations to this approach. This relies on self reporting of behaviour and does not involve any direct observational evidence. This aspect is further explored in Chapter 5.

Details of the questionnaire are shown in Appendix 8. According to Moser and Kalton it is presumed that the length of the questionnaire affects the morale of interviewer

and respondent, refusal rates and the quality of the data collected (1989:309). The design of the questionnaire had to take account of the setting, the relative inexperience of the interviewers and the nature of the group attending a NEX. Taking these factors into account it was essential to minimise the time taken to complete the questionnaire in order to reduce any practical difficulties and to attempt to increase the number of responses. The data in this evaluation was collected within the setting of an ongoing service delivery environment of a community pharmacy based NEX. This inevitably restricted the data collection methods and data available for analysis.

There are obvious competing priorities and potential conflicts for the researcher who had different roles to undertake during the period of this evaluation. However the roles should not be viewed as incompatible as Cooper and Schindler noted that “good researchers and good managers alike, practice habits of thought that reflect sound reasoning” (2003:32). In this evaluation of the syringe marker supply it was not possible to separate the roles, leading to the final evaluation design and the methods employed being an inevitable amalgamation of management and research requirements.

2.7 Analysis.

The analysis of the data has two main components. This involves analysis of the quantitative data from the questionnaire and of the qualitative data provided by the peer researchers’ fieldwork diaries and recommendations. The views of the researcher and the participating pharmacy staff were incorporated in the final reflection on the evaluation.

According to Blaikie there are a number of different methods of data analysis that can be used to describe the characteristics of social phenomena and to investigate their interrelationships (2003:29). The data generated in the evaluation was investigated to uncover any underlying patterns of association. Statistical analysis of the questionnaire results involved identifying three variables to be used as potential independent variables (IV) to investigate relationships amongst a range of dependent variables (DV). The variables identified as potentially relevant independent variables were gender, length of time injecting and housing status. Cross tabulations of these three variables were undertaken with five identified potential dependent variables to look for differences between groups. These were, current syringe identification, mixing up of syringes, use of the markers, reported usefulness of the markers and reported usefulness of the instruction leaflet. SPSS version 12 and Excel were used.

The characteristics of those attending the three pharmacy sites were compared with each other and with the characteristics of the aggregated data contained in the health board wide database and these were found to be broadly similar with no major apparent differences. Therefore, based on a combination of the questionnaire responses, knowledge of the service and the observations of the SUIG it may be possible to infer whether the characteristics of the information gathered can be extrapolated to the wider population who use NEXs.

The qualitative element of the evaluation involved secondary analysis of the field work diaries completed by the peer researchers during the data collection phase of the evaluation. The categories and themes that emerged from thematic analysis of the

field work diaries are shown in Appendix 10. Feedback was also sought from staff in the participating pharmacy sites.

Chapter 3 is devoted to the background and the role played by the peer researchers in the evaluation and includes findings from the secondary analysis. The results of the quantitative analysis, including descriptive statistics and cross tabulations are discussed in Chapter 4. The combined results and the implications for the syringe marker evaluation and the future implications and identified areas that require further investigation are discussed in Chapter 5.

Chapter 3

Peer Research Involvement

3.1 Background

De Winter and Noom have defined peer research as a form of research where “people from a particular target group act as fellow researchers of problems that occur within the same target group” (2003:327). In this evaluation the peer researchers involved were volunteers drawn from members of the Scottish Drugs Forum (SDF), Service User Involvement Group (SUIG). The peer researchers were responsible for the data collection using a structured questionnaire. The questionnaire used to collect data and the reasons for involving service users as peer researchers in this evaluation were described in Chapter 2. The ethical and practical issues for the research that the participation of peer researchers raised are explored in this chapter.

According to McLaughlin in order to understand any involvement of service users in research there is a need to look at and understand “user involvement more generally” (2009:2). In 1969 Arnstein had identified a “ladder of citizen participation” that was used to describe user involvement in policy making (1969:216). Within this model the only means of assessing the level of involvement is to examine the extent of the individual’s “power to make decisions” and that a determination of the level of control is an accurate measure of the extent and the final aim of full engagement (Tritter and McCallum, 2006:157). The main problem identified with this model as a description of user involvement is that there is no differentiation amongst “method, category of user and outcome” (Tritter and McCallum, 2006:161). Within the health

services recent developments have placed a greater emphasis on the relevance of “public and patient involvement” (Tritter and McCallum, 2006:156).

The origins of any type of consumer or service user involvement in the development of health policy were contained in the “Griffith’s Report” of 1983 (Department of Health and Social Security, 1983). This report had argued that the “NHS had to recognise and respond to the needs of its “customers” ” (Boote, Barber and Cooper, 2002:218). The syringe marker evaluation involved peer researchers at various stages throughout the evaluation. The link between NHS “consumers”, those who attend a NEX and the use of peer researchers in a NEX setting are not immediately obvious and are examined in more detail below. This evaluation research involves an NHS commissioned service; however the population under investigation is one which is involved with illegal activities and where their anonymity is protected as a core component of the service provided. In the UK, in this context, “consumers” have been defined as “patients, potential patients, informal (unpaid) carers, people who use health and social services and members of the public who may be potential recipients of health promotion plans” (Boote *et al*, 2006:280). Despite the fact that attendance at a NEX service is on an anonymous basis, injecting drug users who access a pharmacy exchange can be legitimately be considered as “consumers” of a specific public health service.

Despite the unique nature of a NEX service, its management follows the same principles as the management of any other type of organisation where a product or a service is provided. Total Quality Management (TQM) is a generic approach to management underpinned by a number of principles defined as “Customer

Orientation, Process Orientation and Continuous Improvement” (Wilkinson, Redman, Snape *et al*, 1998:12). According to Wilkinson *et al* within TQM, quality means being able to “meet customer requirements” (1988:12). Although the final product (injecting paraphernalia) is not purchased, but provided as a service, the principles of meeting the customer requirements remain the same. The final customer is the drug user and it can be argued that customer satisfaction with the provided product is particularly essential as the correct use of the product potentially results in reducing the pool of serious infections within communities. This therefore can provide potentially life saving health benefits for the individual user and for local populations. Ultimately any changes made in the equipment supplied will only result in positive improvements if the changes are acceptable and if drug users continue to access the service and to use the equipment supplied. For these reasons it was considered essential for the evaluation to use the peer researchers to attempt to reflect accurately the drug users’ responses and views on the supply and use of syringe markers. There is no doubt that there are difficulties and barriers associated with peer researcher involvement but for an evaluation of a service development associated with the illegal activities of illicit drug use, the potential benefits outweigh any perceived difficulties.

This type of consumerist approach to service user involvement in research has been described by Hulatt and Lowes as essentially “a passive process by service users, who were consulted regarding services but saw no real place for their input in the process of shaping those services” and that this sense of “frustration about being consulted in a tokenistic manner extended further into the arena of research” (2005:1). From this early involvement as consumers of services there has been a continuous progression from the 1990’s to incorporate a range of different strategies and innovative levels of

participation. Kemshall and Littlechild have described how this form of service user and peer research involvement has extended into areas of “health, social care and criminal justice” and they have drawn together and described the range of research and evaluation strategies that can promote user participation and involvement in research (2000:8).

As discussed in Chapter 2, any research involving direct contact with injecting drug users has additional ethical and practical dimensions as, due to the nature of the activity, this is traditionally a marginalised and therefore a hard to reach group. In 1996 the NHS Central Research and Development Committee established a group entitled “Consumers in NHS Research” which was designed to advise them on “how best to involve members of the public in the research and development process” (Caton and Hanley, 2001:195). In 2001 the Policy Research Programme of the Department of Health was given an expanded remit and in 2003 the programme group was renamed “INVOLVE” and was specifically re-designed to promote “public involvement in NHS, public health and social care research” (INVOLVE, 2003).

In 2004 INVOLVE produced a consultation document entitled “Involving Marginalised and Vulnerable People in Research”. This document has relevance for the syringe marker evaluation as it gives examples of groups of people that can be viewed by themselves or by others as “vulnerable or marginalised”. These groups included “homeless people, people whose voices cannot be heard, drug addicts, people in poverty, people who need, but are not receiving health or social care services” (INVOLVE, 2004:2). It is clear that those attending a needle exchange are a multifaceted group who may fall into more than one of the categories of vulnerable

and marginalised groups listed above. In addition to their injecting drug use other complex factors can contribute to their marginalisation and social isolation. For these reasons the design and implementation of the syringe marker evaluation benefited from the contributions of the previous personal experiences of the SUIG members. For example, their experiences were utilised in ensuring that the content and language of the questionnaire was appropriate and understandable to the study participants and their networks of contacts could be used to disseminate results.

Despite the difficulties and challenges associated with engaging marginalised and hard to reach groups in the research process there are many examples from a range of related disciplines where this has been conducted successfully. For example, in the field of mental health research, service user and peer involvement has been shown to have numerous benefits including:

“increasing relevance of the research (for example, by enriching researcher’s understanding of the illness, ensuring the questions being asked are meaningful, improving the design of a study, choosing appropriate outcome measures, and generally preserving a focus on the meanings of the research for those with the illness); better recruitment to studies and better, more open responses from research participants who are more likely to feel their interests are being addressed, and with less likelihood of dropouts; fresh insights in interpreting results; service user support may assist dissemination and implementation of research findings;”

(Szmukler, 2009:87).

This has resonance with the main purpose of incorporating service user involvement into the syringe marker evaluation and identifies many of the anticipated benefits for the evaluation.

“Children in general, children in care and young carers” have also been identified as hard to reach, vulnerable and marginalised groups (INVOLVE, 2004:2). Even with children, where the challenges of involving them in the research process may be considered even more problematic, it has still been possible to use children to make positive contributions to research and for them to participate as full research group members. In 2006 in Scotland, a mapping exercise was conducted to review literature around children carrying out research. This work included interviews with policy makers, researchers, research managers and young researchers (Brownlie, Anderson and Ormston, 2006:2). Many of the key issues identified in this review were similar to the issues that were explored in Chapter 2 when the justification for using peer researchers in the syringe marker evaluation was explored. These identified issues included “ethical issues around confidentiality, risk of harm, payments and power in research partnerships; and balancing young people's involvement with the need for high quality, reliable data” (Brownlie *et al*, 2006:3).

In 2005 a study was initiated to examine the experiences of homeless people who were attempting to find and sustain employment whilst being homeless (Butcher, 2005:30). The methodology of this project involved using peer interviewers to conduct the interviews. The benefits of using peer interviewers were found to be twofold. Firstly the peer researchers “provided important input into the methodology and development of the questions used in interviews, surveys and focus groups” and secondly for those interviewed some reported that they felt that the “the peer researchers were role models, inspiring them to get more involved in shaping homelessness services” (Butcher, 2005:31). This is an example of where peer

researchers from an identified marginalised group were successful participants in the research process.

This indicates that the problems associated with the incorporation of members of the injecting drug using community as co-researchers are not unique to this group and that there are close parallels, particularly from research experiences with other hard to reach groups including those who use mental health services and with populations of children and the homeless.

A project conducted in 2002 was designed to explore the views and experiences of one of the groups that would be considered as particularly hard to reach, namely, parents who use illegal drugs (Elliot, Watson and Harries, 2002:172). This was a qualitative study and the methodology involved the use of peer interviewers. This study concluded that “the involvement of peer interviewers in research can be a valuable means of enhancing our knowledge and understanding of a variety of population groups who tend to live beyond the gaze of more orthodox researchers” (Elliot *et al*, 2002:172). However, the authors did acknowledge that there were both positive and negative aspects to using peer interviewers as co researchers in this type of setting. They identified that this methodology posed a number of challenges related to the difficulties associated with the need to support interviewers who were not trained researchers, the inevitable tensions that arose due to the researcher being removed from the immediate interaction involved in data collection and the associated “difficulties of gaining from the skills and experiences of peer interviewers without exploiting their labour” (Elliot *et al*, 2002:172). This was reflected in the practical experiences of the syringe marker evaluation where on-going support for the peer

interviewers had been identified in the early stages as a crucial factor to ensure, as far as possible, full and safe participation by the group members. The ethical issues linked to the use of peer researchers are explored in more detail below in section 3.3. The possibility that the use of peer researchers may result in a sense of distance from the raw data was considered in Chapter 2 in the discussion on the reasons for the choice of specific methods.

The UK Government has been described as “keen to promote service user and carer involvement” (McLaughlin, 2009:3). This is a very wide generic statement. The term user involvement can cover a wide spectrum and promoting service user and care involvement in service delivery may involve simple consultation, with minimal involvement, on various aspects of services but does not necessarily involve service users further in service and service delivery research. There are now statutory requirements set down in the National Health Service Reform (Scotland) Act where, for new policy developments, there is a “duty to encourage public involvement” (2004:6). More detail is outlined in the paper, “Patient Focus and Public Involvement” which states that services should be developed where “people are respected, treated as individuals and involved in their own care” (2001:2). It is claimed that this improves the “quality of service provided” for patients and for staff (2001:16). This establishes the principle of service user involvement in helping to develop quality services but gives little or no guidance on service user participation in research. For this reason, it is important to note that there is no clear indication as to the extent of the level of service user involvement or peer research that is necessary for improved service quality to be achieved. This document also identifies that patient and public involvement is often seen as a “low priority issue” (2001:10). It is possible to

speculate that involving hard to reach groups, including IDUs, is likely to be even less of a priority for those developing services due to the many barriers associated with involving those involved with illegal activities.

Service user involvement can incorporate a range of potential roles across the spectrum from consultation with no direct effect on service development to full service user controlled research. There needs to be recognition and acknowledgement of the different roles that service users are able to perform and that this may be extensive in some health and social care areas. In reviewing the impact of service user involvement in research and evaluation Beresford notes that there is “growing political and research interest in user involvement” which is specifically relevant to the public and social sphere particularly in the fields of health and social care (2002:95). Despite this, service user participation as peer researchers is far less common than other types of service user involvement in services. According to Hulatt and Lowes this can be viewed as a “continuum model” that incorporates varying levels of service user consultation, peer research participation, through to research that is designed and controlled by service user involvement groups that have been responsible for designing and undertaking the research (2005:2).

For the syringe marker evaluation the views of service users were considered to be essential in helping to shape and develop the service. The reason for using peer researchers in this evaluation was to utilise their unique expertise, as previous users of the needle exchange service under study, to assist with the development of the original design of the syringe marker evaluation and in the data collection phase to facilitate contact with a recognised hard to reach group. It can be seen that this level

of involvement for the peer researchers incorporates elements of consultation, collaboration and participation in the research process whilst the ultimate control of the research remains with the principle researcher.

As this type of service user involvement and interaction has evolved a number of terms have been used to describe the various layers of service user involvement. These include “patient, client, expert by experience and service user” (McLaughlin, 2009:10). The most relevant descriptive term for the form of service user involvement in the syringe marker evaluation is “expert by experience”. This has been defined and includes “people who use services now or have done in the past; people who need services but haven’t been offered them; people who need services but haven’t been offered any that are appropriate” (McLaughlin, 2009:16). All of the six members of the SUIG had used NEX services in the past and had a range of both positive and negative experiences of various types of NEX service provision. Their major contribution to the evaluation was based on the premise that they had unique expertise from their previous experiences as intravenous drug users and that they were familiar with and had used the services offered by NEXs. The term “expert by experience” aptly describes their role. The main aim was to utilise this experience to support the researcher in the design and implementation of the evaluation to ensure that the intervention and any proposed expansion was of practical, not theoretical, relevance in promoting safer injecting practices.

The field of service user involvement has moved from one of consultation to the position where service user led research is now possible. The area has not remained static and the focus is now on assessing the quality and the impact on research and

outcomes of incorporating service user researchers into research processes. There have been major advances and developments in the involvement of service users in all aspects of health orientated research, to the extent that Wright and colleagues have claimed that “involving service users is now seen as a core component of good research practice for all forms of health research” (2010:359). Wright and colleagues have developed critical appraisal guidelines for assessing the quality and impact of user involvement in research (2010:359). According to this appraisal the quality of any research involving service users should include an assessment of the following criteria, summarised below:

1. Is the rationale for involving users clearly demonstrated?
2. Is the level of user involvement appropriate?
3. Is the recruitment strategy appropriate?
4. Is the nature of the training provided appropriate?
5. Has sufficient attention been given to the ethical considerations of user involvement and how were these managed?
6. Has sufficient attention been given to the methodological considerations of user involvement and how were these managed?
7. Has there been any attempt to involve users in the dissemination of findings?
8. Has the “added-value” of user involvement been demonstrated clearly?
9. Have attempts been made to evaluate the user involvement component of the research? ”

(Adapted from Wright et al, 2010:364-366).

Although initially the use of the service user involvement group as peer researchers was aimed solely at assisting with targeting a hard to reach population there are many aspects of the criteria documented by Wright that became central to the assessment of

the role that the peer researchers played. The practical and ethical aspects are discussed below and user involvement component became a separate issue for discussion in the analysis of the findings where it became apparent that the peer researchers had “added-value” to the evaluation.

The Wright criteria are in line with the work of Morrow *et al* who claim that for any level of service user involvement in research there is now a pressing need “for more critical and consistent assessment of what constitutes quality improvement” (Morrow, Ross, Grocott, 2010:532). The model and measure developed by Morrow and colleagues is aimed directly at research teams and is designed to assist with evaluating “dimensions of quality service user involvement in the contexts they are working within” (2010:538). This work proposes a model for a “Quality Involvement Framework” that would enable both researchers and service users to assess the quality element of service user involvement and to promote a more reflexive account of the process (2010:532). The main benefit of this type of formal framework model is that it allows consideration of the impact of “personal factors” to be considered along with the research context and setting. One of the personal factors identified by Morrow *et al* was the concept of payment for participation where for peer researchers this was shown to be associated with a “sense of empowerment” (2010:534). For the syringe marker evaluation the financing issue has two separate aspects, both of which have the potential to affect the quality of the evaluation. Firstly the SUIG members were not paid to conduct the research although full expenses were provided. The issue of financial and other types of benefit are explored further in section 3.3 on the ethical aspects of peer research. Secondly the participants who completed the questionnaire were a distinct group from the SUIG who acted as peer researchers. The participants

who responded were current service users of the pharmacy NEXs. There are conflicting views on the ethics of payment to current injecting drug users for participation in research and the potential this has to influence results. According to Ritter *et al* it is normal practice to pay any research participants as a reimbursement for their time and experience (Ritter, Fry and Swan, 2003:2). In Australia this extends to all research in the public health domain involving IDUs (Ritter *et al*, 2003:2). The difficulties arise when the payment can be deemed an inducement to participation, particularly in the field of illicit drug use. It has been claimed that payment to service users who are IDUs is ethical as long as value is not so great that it makes “informed consent questionable” (Ritter *et al*, 2003:4). These authors go further in that they claim it would be unethical to withhold any payment from this group as it would be “unfair and prejudicial” to a group that is already marginalised from society (2003:2). For the syringe marker evaluation no payments were made to the service user respondents. This was not an option for consideration as no funds were available for this purpose. However there was no element of discrimination or judgement involved as it is not routine practice to make payments to participants for any type of service evaluation in a community pharmacy. Reasons for refusal to participate are explored further in Chapter 4 however it should be noted that lack of a payment was never reported as a reason for non participation.

Elements of the service user involvement as peer researchers and their role in improving the quality of the syringe marker evaluation are discussed in Chapter 4. Involvement of service users in research is an area that is continuing to evolve, not only for the health services but in other public services. Minogue and Girdlestone have noted many examples of increasing public involvement in research in “NHS,

Higher Education Institutes (HEIs) and social care organisations across the UK” and they claim that there are numerous examples of work that “presents a very positive picture in terms of the level of interest, energy, and volume of work being undertaken” (2010:432). However they record a note of caution as they claim that despite this being an emerging area that is continually evolving fragmentation exists in developments that can be the result of lack of both direction and resources (2010:433). Despite this caution there remains the possibility of major potential benefits for services, research, researchers, policy development, evaluation and users of services from the continued more structured development of service user involvement that extends to include the involvement of peer researchers.

The practical and ethical aspects of the peer research involvement in the syringe markers evaluation are detailed below and a further examination of the relevance of service user involvement in the evaluation analysis is discussed in Chapter 4.

3.2 Practical Aspects

Hanley and colleagues identified a number of points along a continuum to describe the extent of the involvement of external groups in health and social care research. These progress through “tokenism, consultation, and collaboration” and ultimately to research which is wholly “service user controlled” (Hanley, Bradburn, Barnes *et al*, 2004:26). The extent of the involvement in the syringe markers evaluation was an evolving aspect of the research and had elements of both “consultation” and “collaboration”. Although the initial aim had been to use SUIG members to collect data to reduce interviewer bias, the role and the nature of their involvement changed

and increased throughout the various stages of the evaluation. The initial role involved consultation as the SUIG members were consulted on the design and the practical implementation of the questionnaire. However their role evolved during the course of the evaluation to take on a more collaborative aspect. According to McLaughlin, collaboration requires the lead researcher to be “more participative than is required for consultation as they are sharing their power to control the research as a means to ensure a more collaborative research process and a better quality product” (2009:28). Within the syringe marker evaluation the move from consultation to collaboration emerged as the researcher devolved control of the data collection to the SUIG. This aspect of the evaluation became controlled by the interviewers as, for example, they took responsibility for identifying those to be interviewed, ensuring that respondents were properly informed of the nature of the research and that informed consent was in place and in identifying and recording accurately any additional relevant information.

This collaborative approach is in line with the views of Godfrey who, when examining the use of user interviewers in research in a social care setting, concluded that “asking users for their views is not enough” (2004:223). He argued that for any real change to take place the “balance of power has to be shifted, and it is only by agencies releasing some control that this will happen” (Godfrey 2004:223). Although the peer researchers in this evaluation did not have sole control over the evaluation their involvement was extensive and continually evolving. Godfrey noted that when undertaking research in evaluating services “user researchers bring a new and different perspective, which generates new ideas and constructs” (2004:229). For this evaluation the use of peer researchers supported the conclusions reached by Godfrey

that their involvement could help to improve the quality of the research process in unanticipated ways (2004:229).

The peer researchers contributed during all stages in a number of ways to the overall evaluation including, for example, maintaining their own field work diaries. The diaries were initially intended to be used to record details of the numbers of people approached, refusals and reasons for refusal to participate and the time spent in each pharmacy. However the use of the diaries as a tool expanded as the research progressed. There were six peer researchers, however the diaries did not record who had made which comment or observation. As noted in Chapter 2 the peer researchers worked in pairs and completed the field work diary to reflect their agreed comments on the research experiences of the day. During the debriefing sessions and discussions with the six group members it was clear that the observations recorded had been discussed and agreed together before being recorded. From this it is reasonable to assume that the views expressed represented a consensus from the group. As the peer researchers experienced the practical difficulties of fieldwork, the diaries were used to record more subjective information on the process and their role and observations. In effect the use of the diaries developed over time and rather than being simply a record of contacts they increasingly functioned as field notes. Field notes have been defined as a “detailed chronicle by an ethnographer of events, conversations and behaviour, and the researcher’s initial reflections on them” (Bryman, 2004:539). This reflects the unanticipated evolution of the peer researchers’ role from solely administering the questionnaire to one that incorporated elements of the participant observer role where they recorded observations and reflected on situations not directly related to questionnaire but relevant to the wider context of the research setting. Due to this

unexpected development with the field work diaries it appeared that it was possible these could be subjected to thematic analysis by the researcher and the results of this analysis are discussed in further detail in Chapter 4. The main theme that emerged centred on the role and identity of the peer researchers and how this changed over the course of the research. A number of related strands emerged around the main theme and these are illustrated by the following quotes:

1) *“Staff gave us a key for the store room which made us feel really trusted”*

2) *“Staff were nice and came over to ask me how things were going and if I would like a cup of tea, felt included”*

3) *“Really struggling hanging about the shop waiting for people to come in”*

4) *“Chemist even quieter today, really disheartening”*

5) *“I feel the methadone users are getting someone to come in for a pack then they are sharing it out as they don’t want to ask for it because they collect their methadone there. I have observed a few people getting their meth and then waiting about or coming back later with someone else who uses the needle exchange. They then leave and hang about outside for a few minutes before going in separate directions”*

(Research Diary of Field Work 2006, SUIG)

Quotes 1 and 2 relate to the identity of the SUIG members as individuals involved in the process as researchers. This is the result of a social interaction and interpretation. According to Morrow the term “service user” and by implication, service user or peer researcher is a “professionally generated concept” that is the subject of personal negotiations and allocation of power (2003:536). This type of interaction can be “potentially sensitive” but according to Morrow et al it is essential to understand the

roles and identities of all involved to help to improve the relationships and interactions of service user involvement in any type of health research (2003:537). There are clear indications from the quotes above that the peer researchers' interactions with pharmacy staff were positive and therefore likely to add to the quality of the evaluation as a whole. Quotes 3 and 4 are directly related to the peer researchers role and identity as researchers where they are directly responding and recording their reactions to the research setting and where they demonstrate that they are experiencing the realities of practical research field work which is often tedious and at times boring. Quotation 5 demonstrates a degree of initiative in that they have extended their researcher role into recording observations that are not directly related to the syringe marker evaluation but that are relevant to the wider area of injecting equipment distribution and sharing. It is possible to speculate that this extension into making observations on the wider aspects of the NEX and pharmacy functioning could be as a direct result of the reactions to the restrictions of the research setting and process shown in quotes 3 and 4. These three examples of Identity, Reaction to Research Setting and Observations can all be viewed as different strands in the change and development of the role and identity of the peer researchers during the conduct of the evaluation.

At the end of the data collection period the SUIG collectively reflected on the process and produced a set of recommendations that had been agreed by the group, for consideration to inform future decisions on the extension of syringe markers supply to the other needle exchange sites. The positive contribution that this made to the final recommendations is discussed further in the analysis section in Chapter 4. The recommendations were based on a combination of their experience, observations and

reflections on the fieldwork phase and their previous “expert experiences”. This was not a requirement that had been originally sought by the researcher from the group but reflected the extent to which the peer researchers had become involved in the evaluation and the way the role and confidence of the peer researchers had evolved and expanded. This mirrors the experience of peer researchers in other addiction related settings where the role evolves and where it becomes necessary for the lead researcher to understand and to “appreciate the dynamics of role evolution” (Jason *et al*, 2006:9). At the start of this evaluation the identified role of the peer researchers was to collect data using the structured questionnaire. However this expanded into recording reflections on perceptions of their involvement in the research process and proposing and recording the group’s views on the usefulness of syringe markers. This extended to recording the group’s views on how the design of the markers and any proposed wider supply system could be improved.

As this evaluation investigated the behaviours of individuals involved in illicit drug use there was an added extra dimension that is not normally a factor in mainstream health related research. The involvement of service user participants in the research therefore brought two distinct positive elements to the evaluation. The group provided service user expertise and also had the added benefit, described in Chapter 2, of helping to alleviate some of the problems associated with research on hard to reach groups.

According to McLaughlin there are a number of benefits to be gained from engaging service users as participants in the research process. The service users provide unique insights into the working and organisation of hard to reach groups and this knowledge

assists the researcher in understanding the actions of the group under study and in the design of the questionnaire. Ultimately this makes a positive contribution to the design and implementation of the evaluation as it results in enhancing “range and quality of data” (McLaughlin, 2009:34). The use throughout the evaluation research of peer researchers therefore brought a number of benefits to the evaluation. These included the recommendations made by the group and their further involvement in disseminating the results of the work through the SUIG contact networks. When obtaining feedback from the participating pharmacists two commented without prompting that they and their staff had welcomed the opportunity to meet with the peer researchers before the evaluation started and that they considered this to have been one of the most useful aspects of the training session. It is possible to speculate that this early introduction of pharmacy staff and peer researchers in a neutral environment, outside the busy pharmacy, helped to break down any perceived barriers or misconceptions and contributed to the success of the peer researchers role and integration into the daily routine of the pharmacy.

3.3 Ethical Aspects.

In the UK, policy recommends that where service users are “involved as co researchers or active members of project teams there is a need to consider ethical issues both on the part of the service users and to protect other participants in the research” (Smith, Ross, Donovan *et al*, 2008:97). The authors of this review of the evidence and practice relating to service user involvement in health care research claim that the literature “ reveals little of the negative consequences of involvement, which means it can be difficult to foresee ethical implications for researchers and

service users” (Smith *et al*, 2008:97). The need to protect both the peer researchers and the participants raised several significant ethical considerations for the conduct of the syringe marker evaluation.

There were a number of ethical dimensions associated with the use of members of the SUIG in the syringe marker evaluation that were outside the normal ethical considerations of data collection through use of a structured questionnaire. These were specific to the setting and the populations under investigation. The lead researcher operates with the benefit of clear guidance from their own professional governing body in relation to the participation of patients as research subjects. However, McLaughlin noted that merely following professional ethical codes “is no substitute for researchers exercising their own ethical integrity as morally active researchers” (2009:45). He further states that ethical codes can never fully anticipate every possible potential situation that a researcher may encounter (2009:45). For example, with the expansion of the role for members of the SUIG there is the need to ensure that the demands of the research did not destabilise their personal recovery or have any other potentially detrimental effects. As described in Chapter 2 in this evaluation the peer researchers were required to enter and spend time in the physical environment of the needle exchange resulting in exposure to both the physical environment and the injecting paraphernalia associated with their previous drug use. As previously discussed in Chapter 2 the setting for data collection in this evaluation is particularly relevant as research has shown that “in humans exposure to environmental contexts previously associated with drug intake often provokes relapse to drug use” (Crombag, Bossert, Koya *et al*, 2008:3233). An awareness of this background meant that it was possible to minimise the potential adverse effects of

these factors from the beginning by enabling potential problems to be identified at the earliest possible stage. Strategies employed included daily debriefing sessions for the peer researchers, working in pairs and not in isolation to ameliorate the effects of boredom, support from the permanent pharmacy staff and careful consideration when matching individual peer researchers to specific geographic locations. The latter consideration was deemed essential to minimise exposure to trigger factors that could potentially precipitate relapse or destabilisation. For this reason peer researchers were placed in pharmacies and locations that were unfamiliar to them. This had two main benefits, as not only were any contextual triggers minimised, but it also meant that the researchers were less likely to meet or interview individuals associated with their own previous personal drug use. A further benefit from placing members of the SUIG outside their local environment was that it helped to maintain aspects of patient confidentiality around both daily methadone supervision and the use of NEXs for those accessing the pharmacy services and for potential interviewees. This helped to reduce the impact of the demands of the research process on the routine operation of the community pharmacies involved. According to McLaughlin throughout the research period the ongoing interaction between service users and service user co-researchers can lead to “both anticipated and unanticipated ethical issues” (2009:57). The measures described above were put in place in advance to attempt to pre-empt any ethical issues from arising. The requirement on each of the participants to maintain confidentiality and the ethical aspects of the evaluation had been outlined and discussed at the initial training session that had included the pharmacy staff and the peer researchers. The pharmacy staff were able to act as an immediate source of advice if any issues did arise and acted as a support for the peer researchers. One of the main reasons for having joint, rather than separate, training sessions was to

introduce the peer researchers to the permanent staff and to establish relationships in advance of the fieldwork. However as noted, it is impossible to anticipate all eventualities and for this reason it was essential for the lead researcher to continually review the situation to monitor and be able to react to any emerging ethical issues.

One other major ethical dilemma for this evaluation involves the difficulties associated with what Elliot and colleagues outlined as “gaining from the skills and experiences of peer interviewers without exploiting their labour” (Elliott *et al*, 2002:172). Despite the fact that the involvement of the SUIG was on a voluntary basis there is no doubt that the use of peer researchers contributed positively to the quality of the final evaluation. According to Elliot *et al* there is a fine line between “involving and empowering people on one hand, and exploiting their labour and expertise on the other” (2002:175). These observations were made following a project that had used peer interviewers in a study examining the views and experiences of parents who used illegal drugs (Elliot *et al*, 2002:172). During this project the peer interviewers had expressed frustration at feeling “used” by both the community drug team and the local drug reference group. They had formed the view, whether justified or not, that the research was benefiting from their access to the contacts, networks and the experiences of the volunteers but that there was no reciprocal benefit in terms of “recognition, remuneration or a sense of ownership of the work” (Elliott *et al*, 2002:175). This was clearly a position that the researcher aimed to avoid in the syringe marker evaluation, as it would be unethical and also make it unlikely that there would be positive engagement by the SUIG members if a similar sense of exploitation was experienced by the peer researchers.

According to McLaughlin “reward and recognition covers both the reimbursement of expenses and payment for the skills, expertise and time that service user co-researchers contribute to a research project” (2009:55). The funds available to conduct this evaluation research are shown in Appendix 4. Although expenses were paid it was not possible to offer any further remuneration to the SUIG members. However the definition of “reward” should not be viewed solely in monetary terms. The SUIG had already been trained and supported by the user involvement group co-ordinator to prepare the members to participate as active service user researchers. At this stage the SUIG were actively seeking opportunities to put their training into practice and the opportunity to be involved in the data collection part of the syringe identifier evaluation fitted their needs. For this reason the group were keen to participate despite no payments, apart from travel expenses, being offered. This evaluation gave them a framework to develop their theoretical skills through direct experience of a real life research environment and the resulting interaction and collaboration with researchers, pharmacy staff and interviewees. This was reported to have been a useful training experience for the group members and perceived as a reward in itself (Currie, 2007: personal communication). It has been identified that other non monetary aspects of reward may be important where for some participants the rewards came from active participation (Tritter and McCallum, 2006:156). The researchers further claimed that “without clear evidence that involvement is linked to change, there is little chance that individual users or groups will remain engaged” (Tritter and McCallum, 2006:166). In the syringe marker evaluation it was established in the early stages that the results of the work would be used to implement changes in the NEX service. This led to two main benefits for the SUIG participation. These were firstly, effective participation in

the research process and secondly allowing the members to influence the decision making, and therefore the service delivery of the NEX scheme.

3.4 User Involvement Group Field Work Diary and Reflections

The original purpose of the field work diary was to record, on a daily basis, logistical information for the three pharmacies detailing the time spent in each site, the total number of completed questionnaires, number of refusals and any observations by the interviewers relevant to the research. The purpose of this was to monitor and direct the ongoing evaluation to ensure that the best use was made of the peer researchers time to try to maximise contact with those using the NEX who had been previously supplied with the syringe markers and to co-ordinate this into the practicalities of the day to day functioning of each community pharmacy site. Details are shown below in Table 3.1. Additional observations were also recorded by SUIG members.

Table 3.1.
Field Work Diary Data Collected During Second 4 Week (Data Collection) Period

	Pharmacy 1	Pharmacy 2	Pharmacy 3
Total Length of Time (Hours) in each Pharmacy.	40.5	27.5	29
(Daily Range)	(2 – 6.5)	(2 – 6.5)	(2 – 3.5)
Total Number of Completed Questionnaires	86	47	44
(Daily Range)	(2 - 13)	(0 – 9)	(1 – 5)
Total Number of Refusals	12	25	7
(Daily Range)	(0 – 6)	(0 – 7)	(0 – 2)

Although the initial aim was merely to use this as a practical recording tool the importance of the notes and observations recorded in the field word diaries increased over time. According to Gilbert “doing fieldwork has emotional costs, and one needs data on one’s own attitude to document one’s evolving relationship to others in the setting” (2003:153). This appears to describe accurately the type of situation that occurred with the peer researchers as the nature of the observations recorded reflected their emotional reactions to the research setting and their relationships and interactions with the pharmacy staff and participants. The effects of participation in the research for the peer researchers and the developing relationships with the permanent members of staff are illustrated in the quotes below. The quotes illustrate, firstly the peer researchers own reactions to the research setting that they were operating in:

“Really struggling hanging about the shop waiting for people to come in. Was offered a chair by the staff but didn’t want to sit down as I think I would have felt more awkward”

“Needle exchange very quiet today. Found it really difficult to being in a room with another peer researcher for two and a half hours”

Secondly the quotes below illustrate the peer researchers relationships and interactions with the regular staff. These indicated that positive working relationships were established and that the details and practicalities of the data collection and the peer researchers’ role were discussed.

“All staff at the chemist were very friendly”

“Staff gave us a key for the store room which made us feel very trusted”

“Pharmacist advised us that we were unlikely to get more clients attending at this time so we called it a day at 4.30 PM”

During the analysis stage it became obvious to the principle researcher that these field notes contained relevant qualitative data that could contribute to the final evaluation. At this stage the peer researchers had completed their involvement and moved to other projects and activities and were no longer available as a group to discuss the fieldwork entries in further detail. However the unanticipated amount and quality of the information contained in the fieldwork diaries meant that this was potentially a useful data source that warranted further analysis. In essence this can be viewed as a form of secondary analysis. Secondary analysis of data is routinely carried out on studies using quantitative data where it has been defined as being conducted by “researchers who will probably not have been involved in the collection of those data for purposes in all likelihood were not envisaged by those responsible for the data collection” (Bryman, 2004:201). There are additional difficulties in conducting secondary analysis on qualitative data and Hammersley has suggested that there may be problems associated with the “secondary analyst’s lack of an insider’s understanding of the social context within which the data were produced” (in Bryman, 2004:415). This analysis of the field work diaries is essentially a hybrid form of secondary analysis. Although the data constituted part of the evaluation research it was not produced or collected by the principle researcher but was produced independently by the peer researchers. However although it was not possible to discuss the observations, meanings and subsequent interpretations with the members

of the SUIG the researcher had the advantage of a full understanding of the background and the context in which the diaries had been completed.

An initial review of the field work diaries indicated that using “thematic analysis” would be the most appropriate method of analysing the recorded notes and observations. Thematic analysis has been defined as the “process of identifying themes or concepts that are in the data” (Strauss and Corbin, 1990:86). This is a useful tool to analyse data that is complete and over which the person conducting the secondary analysis has had no previous influence. Although the principle researcher had designed the evaluation and directed the work of the SUIG in administering the questionnaire they had no influence on the group’s recorded observations. It is these observations that were subjected to a thematic analysis. Thematic analysis is related to “grounded theory”. However this term should only be used “to refer to studies in which data collection and data analysis are conducted concurrent alongside theoretical sampling and other techniques distinctive of grounded theory, such as constant comparative method” (Strauss and Corbin, 1990:86). With grounded theory the data collection and analysis are inextricably connected. Although grounded theory identifies themes and concepts that are present in the data, it is open to the researcher to direct the field work and data collection in response to emerging themes. For example it is possible to “check interpretations with participants” (Ezzy, 2002:68). An analysis of the recorded observations contained in the field work diaries was not part of the original evaluation design. For that reason it was not possible to confirm or refute any emerging themes with the participants or to test new concepts as the research was being undertaken. Thematic analysis is therefore a useful tool to analyse data that is complete and where it is not possible to redirect the research process to

test any emerging theories. An initial review of the field work diaries had indicated that they contained additional information that gave the researcher access to an unanticipated source of relevant data on the inclusion of peer researchers and their role in this type of evaluation.

The analysis conducted on the field work diary contents has been inductive as with thematic analysis the “categories into which themes are sorted are not decided prior to coding data” (Strauss and Corbin, 1990:87). According to Robson, thematic analysis has the following structure. Initially descriptive codes are developed. This leads to axial coding when codes are integrated around the axes of central categories. This is followed by selective coding which can then identify the relationships between the emerging categories (Robson, 2002:495). The conclusions based on a thematic analysis of the field work diaries are discussed in the following section.

3.5 Field Work Diary Analysis.

Although the information on which this secondary analysis is based was limited to the written observations from the peer researchers, which were not a constituent part of the original design, it was possible to identify potentially significant and interesting areas for further investigation. Initial analysis of the field work diaries identified a number of themes, shown in detail in Appendix 10. The main themes to emerge were: reaction to research setting, relationships and interactions, identity, practical difficulties, observations and communication. On further analysis it emerged that identity was a key concept that began to link the initial descriptive themes. The key

findings associated with each theme and illustrative quotes from the field work diaries are described and discussed below.

Theme One: Reaction to the Research Setting.

Unsurprisingly, as the questionnaire was being administered by members of the SUIG who were relatively inexperienced in this process the aspect of their reactions to their placement in the research setting emerged as an initial theme.

“The set up was good and we got a room”

“Felt a lot more isolated in this pharmacy as we couldn’t see from the consultation room what was happening”

It can be seen from the illustrative quotes above that both positive and negative comments on the research setting and the peer researchers’ reactions to the setting were noted.

Theme Two: Relationships and Interactions.

This can be broken down into the peer researchers’ relationships and interactions with the regular pharmacy staff and with the participants that were approached to take part in the study. The success of this evaluation depended to a large extent on the peer researchers being able to engage those attending the NEX and to successfully facilitate completion of the questionnaire. This had to be done in an environment of a busy functioning community pharmacy. In order to do achieve this, peer researchers had to engage with staff and perform their research duties whilst causing minimum disruption to the daily routines. This inevitably required the employment of

negotiating skills and the establishment of effective working relationships. There was clear evidence of the establishment of these relationships and interactions with staff, illustrated by the quotes below that reflect the peer researchers' views of staff and illustrate examples of interactive conversations related to the conduct of the research.

“Staff very friendly and helpful”

“Informed by staff that sometimes people queue in the morning for the needle exchange to open”

“Staff commented that people only appeared to use the needle exchange when we are not about”

“Staff informed us that two people who had been given the stickers had asked for more stickers as they found them useful”

The peer researchers were effective in achieving successful completion of more than the original estimated number of questionnaires in the allocated time frame. From the quotes below it became clear that their interactions with participants extended beyond completing the questionnaire. Many of the quotes were illustrative of extensive further discussion, including disclosure of potentially sensitive health information to the peer researchers. This resulted in recording additional relevant material that ultimately contributed positively to the final evaluation.

“One interviewee said that they didn't use the stickers, as they are Hep C positive”

“The two people interviewed thought that the stickers were a good idea but we had some discussion as to whether or not they stuck”

“One interviewee said that he had been infected with Hep C after using his syringe in company and that he wished the syringes had been about years ago. He felt that the stickers should be available in multi coloured packs.”

Theme Three: Identity

This theme was multidimensional and contained a number of subcategories that centred on the researcher role that was being performed by the peer researchers. These subcategories included, trust, responsibility, role identity, view of self, unsolicited contributions to the research and perceptions.

“I felt a lot of trust was given to us as we got to sit in the consultation room that had a lot of stock lying about in it. This trust shown to us made me feel really good about myself”

“Staff were nice and came over to ask me how things were going and if I would like a cup of tea, felt like a member of the team”

“Staff gave us a key for the store room which made us feel really trusted”

In addition to the recorded observations and unsolicited comments, the production of a set of recommendations by the group can be considered within this theme as an example of how they perceived their identity and acted on this as researchers

throughout the evaluation. This view of themselves and the development of their extended role as researchers are examined further in the summary below.

Theme Four: Practical Difficulties.

With theme four there is a direct link to theme one, which deals with the physical aspects of the research setting where theme four is viewed in terms of the operational aspects of the peer researcher role and their reactions to the practical difficulties encountered during the daily conduct of the research.

“Chemist even quieter today. Really disheartening”

“We both felt a bit depressed. Nothing to report except no-one accessed the needle exchange in the time we were there.”

“Much the same as previous days. A bit frustrated as the pharmacist said three people had accessed the exchange before I arrived”.

Despite the difficulties that were recorded the entire group of six peer researchers completed their part in the evaluation and there were no absences during the data collection period.

Theme Five: Observations.

The peer researchers made a number of observations. These could be broken down into two sub sections. The first related directly to the research itself.

“Questionnaires completed were straightforward although sensed that people weren’t overly impressed with the stickers as they all said that they used on their own always”

“Overall the day went without any problems and most people were very positive about the stickers”

The second interesting strand that emerged from further study of the field work diaries was that the peer researchers also made observations and commented on areas beyond the immediate requirements of the evaluation questionnaire. These are illustrated by the quotes below and show that the observations related to other activities that were taking place in and around the pharmacy.

“Felt that some people were conscious that other people could over hear them in the shop”

“Noticed today that some people were going away with more than one pack”

“I feel methadone users are getting someone to come in for a pack then they are sharing it out as they don't want to ask for it because they collect their methadone there. I have observed a few people getting their meth and then waiting about or coming back later with someone else who uses the needle exchange. They then leave and hang about outside for a few minutes before going in separate directions”

Theme Six: Communication.

Communication is closely linked to Theme Two (Relationships and Interactions). There were numerous examples of ongoing communication between pharmacy staff and the peer researchers and between the peer researchers and the interviewees.

Examples of the types of communication between the peer researchers and the people they interviewed are shown below.

“The two people interviewed thought that the stickers were a good idea but we had some discussion as to whether or not they stuck”

“One drug user commented on why not just put the stickers in the pack instead of wasting money on the pilot study”

“One client spoke after the interview about the reasons why he doesn’t have to mark his syringe. He says he always uses alone and that the stickers wouldn’t be any use to him”

Effective communication is essential in the conduct of the research and in establishing effective working relationships. This was a prominent feature of this work as the evaluation was conducted in busy community pharmacies by a group who would not normally operate within this setting, making the need for effective communication of prime importance if the evaluation was to be completed successfully. There were numerous examples, shown below, of the communication between the regular staff and the peer researchers.

“Spoke to a member of staff who said we missed 35 service users on the afternoon of the 27th. Informed us that the needle exchange is a bit of a hit and miss”

“Pharmacist said that the previous day had been really busy at the needle exchange. She thought that maybe drug users had been paid the previous day”

All of the above themes are multidimensional as shown in Appendix 10. Further reviews of the diaries demonstrated the close relationships amongst the themes. The core concept that emerged linking the themes was one of identity. There is no clear universal concept of identity in modern sociology. However, the concept has been used “widely and loosely in reference to one’s sense of self and one’s feelings and ideas about oneself” (Scott and Marshall, 2009). For the analysis of the field work diaries the concept of identity relates to the role identity as researchers, particularly as participant observers in the research process, and the perceptions, reactions and interactions of the SUIG members that appeared to confirm their involvement from basic data collectors into full participants in the researcher and observer roles. It also relates to their own perception and reflections on the role they performed and how this affected their self identity within the setting and how this was affected by interactions with the pharmacy staff.

Although, as mentioned previously, it was not possible to confirm any theories that emerged from analysis of the field work diaries there are other pieces of evidence that support the conclusions. Informal feedback was sought from the pharmacists who participated in the evaluation. Despite the fact that no payments were made for their participation, all allowed the research to continue and accepted the involvement of the SUIG members on an equal basis as co-participants in the research. It is important to note that there were no reports from the pharmacists of any adverse impact that the peer researchers may potentially have had on the day to day operation of the pharmacy. If any problems had arisen it was possible for the pharmacists to immediately refuse continued access. This did not occur and the principle researcher received no negative reports on the peer researchers’ activities. This would appear to

support the view that the identity of the SUIG members was accepted and that they functioned effectively in the researcher role. It would also corroborate the positive comments that illustrated that the effective two way communication and establishment of good working relationships was a reality. It would not have been possible for the peer researchers to have completed the questionnaires if interactions and rapport with both staff and participants had not been successfully achieved. This indicates that the role performed by the peer researchers was identified and accepted as a research function.

The group also produced a set of recommendations that “outlines the views of the peer researchers on lessons, which can be learned, from the pilot study before the scheme should be rolled out to other community pharmacy based needle exchanges” (Field Work Diary). As these recommendations were not a requirement of the original peer research role, this is another illustration of the extension of the role identity that developed during the course of the evaluation to the stage where the group had the confidence in their own experience and role within the process to offer these recommendations. The recommendations from the field work diary are produced in full and listed below.

Recommendations

The Glasgow Involvement Group have agreed on the following recommendations to be taken in to consideration before the stickers should be supplied on a routine basis in Glasgow.

- *There is a need for staff to ensure that drug users are informed that stickers should be used to mark all paraphernalia and not just needles. This should be reinforced by information in the packs.*
- *Information on the scheme should be made available in prisons before people are liberated so they are aware of the changes and purpose of the stickers.*
- *Peer education should be used to ensure that people not directly accessing the needle exchange are clear to the purpose of the stickers.*
- *Peer education would also benefit people who want to spend as little time as possible in the pharmacy to ensure that they are aware of the purpose of the stickers.*
- *Information has to be included on safer injecting for people already Hep C positive*

These recommendations confirmed the results of the questionnaire and were consistent with many of the comments made by the respondents. It also reflected the group's own analysis based on their personal experiences, expert knowledge, observations during the data collection period and on the results of their own interactions with the survey participants.

3.6 Summary

In summary there are a number of practical and ethical issues associated with the involvement of service users in any form of research. It has been demonstrated that “involving service users in research must be done both with integrity and due diligence or it can, and does, cause as much harm as good to all involved”

(McLaughlin 2009:40). For this evaluation the potential benefits of incorporating service users in the research were considered alongside any potential adverse effects both for the evaluation and for the service users themselves.

Previous experiences of involving service user interviewers in the research process and the evaluation of services has shown that “user researchers bring a new and different perspective, which generates new ideas and constructs and enhances the quality of the whole research process” (Godfrey, 2004:229). In the syringe marker evaluation the incorporation of service users made a positive contribution and enhanced the work of the academic researcher by introducing additional new dimensions. The incorporation of SUIG members into the data collection role inevitably meant that the researcher was “distanced from the raw data they collected” coupled with the ethical implications due to concerns about “benefiting from their skills and experiences without exploiting their labour” (Elliot *et al*, 2002:173). Despite these concerns the decision to use members of the SUIG and their contribution appeared to have enhanced the final evaluation.

In a related research study when peer researchers were asked for their perspectives about their involvement in the research effort the “findings indicated that these community members felt their participation was a positive experience” (Jason *et al*, 2006:14). The SUIG members in the syringe marker evaluation reported similar positive experiences directly related to their participation as illustrated by the following quote from the fieldwork diary.

“Staff very friendly and helpful. I felt a lot of trust was given to us as we got to sit in the consultation room that had a lot of

stock lying about in it. This trust shown to us made me feel really good about myself”

In 1993 Griffiths and colleagues had utilised the expertise of drug users as “privileged access interviewers” in a qualitative study to access heroin users not in contact with treatment services (1993:1617). The results of this early work incorporating peers as part of the research team had demonstrated the need to establish “supportive and non exploitative relationships with the interviewer team” (Griffiths, Gossop, Powis *et al*, 1993:1617). Throughout the syringe marker evaluation there was an awareness, not only of the vulnerable nature of the participant group but also of the need to provide a supportive, non exploitative environment for the service users involved in the research. Only by providing this type of environment is it possible for peer researchers to function with maximum effectiveness.

As outlined in the literature review in Chapter 1, NEX is a harm reduction intervention delivered within a health care setting. The aim of this evaluation was to critically evaluate the feasibility of extending a new initiative, syringe markers, supplied through community pharmacies. It is impossible to divorce this type of initiative from its “ethical, legal and social contexts” (Pauly, Goldstone, McCall *et al*, 2007:19). Pauly and colleagues also highlighted that extensive evidence existed to support implementation of harm reduction strategies but cautioned that “scientific knowledge alone” was insufficient to ensure the introduction of harm reduction strategies across a range of health-care settings (Pauly *et al*, 2007:19). For this reason the views of the peer researchers on the use of syringe identifiers and their reflections on their participation in the evaluation had particular relevance and importance in the development of the service as part of their contribution was based on utilising their

personal experiences and expertise to augment the scientific dimensions of the research.

The field work diary was originally intended merely to be a practical daily record by the SUIG members of the time spent in each pharmacy, number of completed questionnaires and the number of refusals. As discussed above, this gradually evolved into a document that recorded their views on the researcher role, their feelings and perceptions and also of their wider observations made during the time spent in the pharmacy. Effectively the interviewer role had extended to incorporate one of observer where it is “essential to record your personal impressions and feelings” (Gilbert, 2003:153). The interviewers recorded subjective details of the interviews, their perceptions and impressions of the process and the setting and observations relating to syringe markers in the wider context of the NEX and the pharmacy setting.

In summary, for the syringe marker evaluation, the use of peer researchers to administer the structured questionnaire and their wider contribution helped to ensure that, in accordance with the recommendations made by Clark and colleagues, the “end product doesn’t merely reflect professional or academic considerations but is grounded in the reality of those who regularly navigate the health and social care system” (2005:34).

Chapter 4

Findings

4.1 Introduction

This chapter will discuss and analyse the responses to the questionnaire and attempt to uncover any patterns of association. The findings, including feedback from participating pharmacists, are explored. The questionnaire and the syringe marker Instruction Card are shown in Appendix 8 and 6. In total, 177 questionnaires were completed during the second, data collection phase of the evaluation. Details of the number of completed questionnaires from each site are shown in Table 4.1. Pharmacy 1 recorded the highest number of responses across the 3 sites with 48%, (n=86) of the total being completed in this pharmacy. Twenty seven percent, (n=47) attended Pharmacy 2 and 25% (n=44) of the responses were collected from Pharmacy 3.

Table 4.1.
Completed Questionnaires

	Completed Questionnaires
Pharmacy 1	86 (48%)
Pharmacy 2	47 (27%)
Pharmacy 3	44 (25%)
Total	177 (100%)

The gender distribution of respondents is shown in Table 4.2. The male respondents ranged from 79% to 83% (average, 80%) and the female proportion was 17% to 21% (average, 20%).

Table 4.2.
Gender Distribution

	Male Respondents	Female Respondents	Totals
Pharmacy 1	68 (79%)	18 (21%)	86 (100%)
Pharmacy 2	39 (83%)	8 (17%)	47 (100%)
Pharmacy 3	35 (80%)	9 (20%)	44 (100%)
Totals (3 sites)	142 (80%)	35 (20%)	177 (100%)

As discussed in Chapter 2, the central database gives details of the characteristics of those routinely attending all sites including the 3 pharmacies in this study where the percentage of male attendees for the three evaluation sites (rounded to the nearest whole number) was 76%, 80% and 78 % respectively. Examination of the characteristics of all sites in the health board area show that the gender breakdown of those attending is 78% male and 22% female. From this data there is no indication that there is any major deviation in the ratio of the sample numbers of males and females interviewed in the three sites compared with the pattern of attendances that are routinely recorded at the three sites and at all other sites in the health board area. Although not conclusive, these are strong indications that the strategies employed in the design of the evaluation resulted in the sample interviewed being representative, in terms of gender, of the population from which it was drawn.

Respondents were asked about their current housing status. This question was included to collect information on the relative stability of the home environment and to investigate if housing status affected syringe identification and use of the markers. The majority claimed to be in relatively stable accommodation with 60% (n=107) recorded as living in accommodation which was their “own tenancy” and a further 23% (n=40) were resident in the “care of another”. The responses to less stable options were as follows; “temporary furnished flat” 7% (n=12), “hostel” 5% (n=9),

“supported accommodation” 3% (n=6), “roofless” 1% (n=2) and one respondent had no fixed abode. It should be noted that it is not possible from these responses to identify if others living in shared households were drug users.

The main focus of the questionnaire was on information gathering, directly related to evaluation of the syringe marker supply. However it contains a number of variables that can be used to investigate potential associations. The results of this analysis may assist with planning service developments and refinements to the current intervention in the future.

Three potentially relevant independent variables (IV) were identified. These were, gender, length of time injecting and housing status. For the latter two a further subdivision using gender was undertaken where possible. From the questionnaire the relevant dependent variables (DV) selected were: current syringe identification (Q3a), mixing up syringe with some one else’s in the past year (Q4), use of the markers (Q2.2), usefulness of the markers as a method of syringe marking (Q3.1) and usefulness of the instruction card (Q4.2). Additionally it was anticipated that there may possibly be a relationship with the group of IDUs who reported that they currently identified their syringe with those who reported use of the markers. A series of null hypotheses were developed using combinations of these variables.

Chi squared tests were used to establish whether there was any significant relationship between the two variables. The chi squared test assumes that the expected value in each cell will be > 5 for 80% of the cells. If this condition was not met a Fisher’s

exact test was used as this can be utilised when > 20% of the cells have expected counts of less than 5 (Bruce, Pope and Stanistreet, 2008).

When those who had been supplied with the markers were asked if they had used them, 49 of the 132 IDUs who had been supplied did not use them. This represents 37% of the total 132 IDUs supplied with markers and is a significant minority. It is possible that the results obtained from utilising the use of markers as the DV with gender, length of time injecting and housing status as IVs will give an insight into any potential differences that may exist between those who were supplied with markers and used them and those who were supplied but did not use them. It is also important to compare the characteristics of this group (n=49) to attempt to uncover if there are any underlying differences that may be relevant when compared with the group (n=83) of IDUs who did report using the markers.

4.2 Refusal Rates.

During the data collection phase, a total of 221 IDUs attending the needle exchange were approached to complete the questionnaire. One hundred and seventy seven participated and the breakdown of completed questionnaires and refusals for each individual site are shown below in Table 4.3.

Table 4.3.
Refusal Rates by Pharmacy

	Completed Questionnaires	Refusals	Total number of individuals approached.
Pharmacy 1	86 (88%)	12 (12 %)	98 (100%)
Pharmacy 2	47 (65 %)	25 (35 %)	72 (100%)
Pharmacy 3	44 (86 %)	7 (14 %)	51 (100%)
Total (3 sites)	177 (80%)	44 (20%)	221(100%)

The high refusal rate for pharmacy 2 is worth noting and investigating further. In Pharmacy 2 refusals represented 35% of those approached when compared with 12% and 14% in the other two sites. As shown in Chapter 2 the population characteristics of those attending each pharmacy are similar across the 3 sites and the characteristics of the evaluation sample are similar to the population of IDUs across the health board who attend needle exchanges. Similarly, the six interviewers remained the same and rotated across the three pharmacy sites over the 4 week period and this is therefore unlikely to have been a factor contributing to the higher refusal rate in Pharmacy 2. The reasons for refusals were recorded in the fieldwork diaries. Examination of the field work diaries showed that the reasons given for refusal were consistent across all three sites. The reasons given by those approached concerned lack of time or having previously completed the questionnaire as illustrated by the quotes below.

“One drug user couldn’t take part as they had a taxi waiting”

“Three refusals as one had already completed the study; one was in for a starter pack. The third refusal was in a hurry”

“One person refused as they had to catch a bus”

“Two people had already completed the survey and two people refused as they said they were in a hurry”

On further investigation it was found that there were structural differences in the pharmacy premises and the NEX layout in Pharmacy 2 that may potentially have contributed to the higher refusal rate. In this pharmacy the SUIG members were based in a separate consultation room which was also used as the base to administer the

questionnaire. Because of the separation and distance from the NEX the SUIG members were dependent on the pharmacy staff to direct potential participants to them. Unlike the other two pharmacies this meant that the initial approach was from a member of the permanent staff and not from one of the peer researchers. This was illustrated by the following quotes from the fieldwork diary of pharmacy 2.

“Felt a lot more isolated in this pharmacy as we couldn’t see from the consultation room what was happening and were relying on staff to inform people using the needle exchanges of our presence”

“Joe spoke to the people coming in and directed them to us”

In the absence of any other identified explanatory factors it is possible to speculate that the reason for the higher refusal rate in pharmacy 2 is related to the fact that the initial approach was made by a member of the pharmacy staff and not by one of the peer interviewers. This situational problem had not been identified in the early stages as a potential issue but is an illustration of the problems associated with conducting any type of research or evaluation in a real life setting as discussed in Chapter 2. Any researcher in this type of scenario has to be flexible to adapt to the setting and to actively work to reduce any adverse effects their presence may cause whilst still maintaining the integrity of the research being undertaken. Despite the difficulties posed by the environment of Pharmacy 2, the peer interviewers were able to adapt and successfully completed 47 questionnaires, which constituted 27% of the total interviews conducted across the 3 pharmacies, in less favourable circumstances. The existence of the high refusal rate and the proposed explanation that it was due, at least

partly, to the initial approach being made by staff would seem to support the original decision to use peer researchers instead of permanent staff to increase the response rate by reducing any perceived interviewer bias. The respondents were all involved in illegal and potentially harmful behaviours and it was anticipated that the use of peer interviewers would be likely to increase their willingness to participate. It would also appear to confirm the findings from previous research where the experience of peer interviewers was used with drug using parents and which concluded that there needs to be a recognition that peer interviewers bring unique skills and also that acceptance and learning to work alongside individuals with this type of expertise is valuable despite the challenges this presents for traditional researchers (Elliott, Watson and Harries, 2002:177). It would appear that the skills of the peer researchers in this evaluation were effective, even in the pharmacy that posed the greatest practical challenge.

4.3 Questionnaire Responses

The Questionnaire was divided into four main sections and collected information under the following headings; personal information and injecting pattern, syringe markers, the use of the markers and the instruction card.

4.3.1 Personal Characteristics and Current Injecting Practices

In response to questions on length of time injecting and on the types of drugs injected it was found that the majority of individuals injected opiates (80%, n=140, Figure

4.1(a)) most often and that 36% of the total (n=64, Figure 4.1 (b)) had been IDUs for 11 years or more.

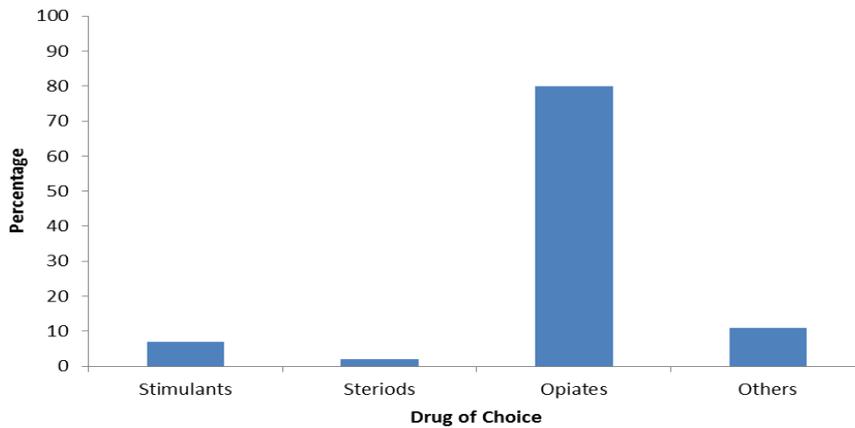


Figure 4.1 (a): What do you inject (most often)?

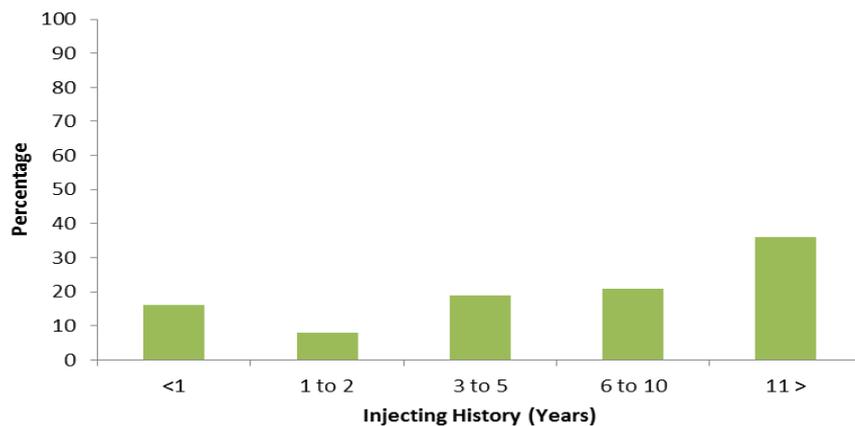


Figure 4.1 (b): How long have you been injecting?

These results would indicate that those interviewed were likely to be a representative sample of the injecting drug using population who routinely accessed needle exchange services. When asked to further elaborate, 11%, (n=19) of those who responded “other”, reported combinations of drugs injected which included opiates. The full list of “other” responses were “stimulant and opiates”, “steroids and opiates”, “stimulants, opiates and valium” and “valium and opiates”. When these additional 19 responses that involve opiate injecting are added to those who recorded single opiate injecting

this gives 89% of the total injecting opiates, (n=159). This is in line with the reported drugs of injection recorded on the central database, shown Table 2.1 (p64), where the normal pattern for the three pharmacy sites for opiate injecting ranged from 85% to 88% (average 86%). The central database records that for all health board sites, 85% of those attending report injecting opiates. The central data base records the whole population of IDUs who attend a NEX and not merely a sample of those attending. The figures for the population were taken from the 2003-2007 databases where only single drug use was recorded. Current database developments now record additional information including combinations of drug use, housing status and frequency of injecting in line with the recommendations of the Scottish National Injecting Equipment Providers (IEPs) Guidelines on Best Practice (Scottish Government, 2010).

Respondents were asked if they currently identified their syringe. The responses recorded that the majority of individuals (58%, n=102) did not currently identify their syringe. For those that did (42%, n=75), the most popular techniques of doing so were to “burn” it (39%, n=29), “scratch” it (24% n=18) or “mark” it (23%, n=17). It should be noted that this question was asked in the context of a NEX service where the safe injecting advice provided promotes the use of clean needles for each injecting episode and advises against the reuse or sharing of any injecting equipment. Despite this, a substantial number (42%, n=75) reported currently marking their syringes, giving an indication that they had recognised that they were likely to be exposed to practices and situations where there was an increased risk of BBVs and related infection transmission. The response options to this question were limited to three following discussion and advice from the peer researchers. These response options were “burn”,

“scratch” and “mark”. This appears to have been successful in capturing the majority of the responses, as only (14%, n=9) recorded “other” as an option. The 9 “other” responses are shown below in Table 4.4 and demonstrate the range of different inventive means reportedly employed to identify personal syringes. They also illustrate that despite being recorded as “other”, with the exception of “carry it about”, all of the responses could have been captured in the three options given in the questionnaire.

Table 4.4
“Other” methods of current syringe identification.

Burn	Scratch	Mark	None of the three options offered.
Both burn and scratch	Both burn and scratch	Bite top of plunger	Carry it about
	Scrape the numbers off the syringe	Bite	
		Chew end	
		Clip the top of it	
		Cracks the end of it	
	Mark the number		

The responses to the questions about syringe identification validated the premise of the evaluation that this is a subject of practical relevance and one that is open to further research and investigation as it confirms that attempting to identify syringes is an existing practice. In 2004, Taylor and colleagues published a ground breaking study in the UK involving in-depth observational study of injecting practices of IDUs in Scotland (2004). The setting for this research was the IDU’s own environment and the injecting practices were observed and video recorded (Taylor *et al*, 2004).

Through the course of this observational work the researchers had noted that 11 of the 48 observed injecting episodes demonstrated a variety of different methods being used to identify injecting equipment. These observed methods were described as “burning the plunger end of the syringe, scraping the units on the side of the syringe and pulling the plunger down” (2004:18). The fact that the responses to questions on current methods of identification in the present study are in accordance with the previous Scottish observational study would tend to indicate that the reported responses are an accurate reflection of actual practice.

The results of cross tabulation of current syringe identification with gender, length of time injecting and housing status are shown below in Tables 4.5 and 4.6

Table 4.5
Current Syringe Identification by Gender

Do you currently identify your syringe?	Male	Female	Total
YES	59 (42%)	16(46%)	75(42%)
NO	83(58%)	19(54%)	102(58%)
Total	142(100%)	35(100%)	177(100%)

N= 177, Chi squared = 0.199, 1 degree of freedom, p=0.66, not significant.

The difference between men and women in terms of whether or not they currently identified their syringe was not statistically significant. It cannot be established from these results whether men or women are more or less likely to be currently marking their syringes. This would tend to support the assertion that for this group of respondents, men and women were equally likely to make attempts to mark their syringes.

For the independent variable, length of time injecting, the original question offered five possible responses. These were: <1 year, 1-2 years, 3-5 years, 6-10 years and 11+ years. Inspection of the raw data showed that the numbers in some of the categories were small and these categories were therefore collapsed into 3, which were 0-5 years, 6-10 years and 11+ years.

Table 4.6
Current Syringe Identification by Length of Time Injecting

Do you currently identify your syringe?	How long have you been injecting?			Total
	0 - 5 years	6 - 10 years	11 years +	
Yes	37 (49%)	17 (46%)	21 (33%)	75 (42%)
No	39 (51%)	20 (54%)	43 (67%)	102 (58%)
Total	76	37	64	177

N=177, Chi Squared 3.829, 2 degrees of freedom, p=0.15, not significant.

The null hypothesis, stating that current syringe identification is not dependent on the length of time injecting, cannot be rejected. The results indicate that current syringe identification is not dependent on the length of time that an IDU has been injecting. However from the figures above it can be seen that for those injecting for a period of 0-5 years, 49% currently identified their syringe, for the 6-10 year group 46% identified their syringe and for the 11 years plus group, this figure fell to 33%. Although not shown to be statistically significant, this may potentially indicate evidence of an emerging trend. To investigate further length of time injecting was collapsed into two categories, 0-10 years and 11+ years. This gave a Chi Squared value of 3.752 (1df), p=0.053 which just failed to reach the level of statistical significance. However this value is approaching the critical value for Chi Squared (1df) of 3.84 and at the 90% significance level it is significant. Although this does not

provide definitive evidence that the longer an IDU has been injecting the less likely they are to make attempts to identify their syringes, it does indicate an area that is worth further exploration. These results illustrate the view of Garner who claims that bivariate analysis of this type tends to pose further questions (2005).

A further subdivision into male and female respondents was undertaken to investigate if gender and length of time injecting were associated with current syringe identification. This is shown in table 4.7

Table 4.7.
Current Syringe Identification by Length of Time Injecting and Gender

Do you currently identify your syringe?	How long have you been injecting?			Total	
	0 - 5 years	6 - 10 years	11 years +		
Male	Yes	31(48%)	12(40%)	16(34%)	59
	No	34(52%)	18(60%)	31(66%)	83
Total		65	30	47	142
Female	Yes	6(54%)	5(71%)	5(29%)	16
	No	5(46%)	2(29%)	12(71%)	19
Total		11	7	17	35

Male, N=142, Chi Squared 2.130, 2 degrees of freedom, p=0.34, not significant.
Female, N= 35, Chi Squared 4.031, 2 df, p=0.13, p ≥0.05 not significant, (p ≤0.10, significant), however, 2 cells (33.3%), have an expected count less than 5.

This appeared to indicate that there was a possibility that a negative association existed between women who marked their syringe and length of time injecting i.e. the longer they had been injecting the less likely they were to identify their syringes. Collapsing the data for men and women further found that the only significant

association to emerge was for women grouped into the 0-10 years and the 11+ year groups shown below in Table 4.8 where a significant association at the 90% level was demonstrated. To account for the number of cells with an expected count of less than 5 from Table 4.7 (female) a Fisher's exact test was carried out where the length of time injecting was contracted from the original 5 responses to two categories. Length of time injecting was dichotomised in the two ways described above (0-5 years and 6+ years) and (0-10 years and 11+ years).

Table 4.8
Current Syringe Identification by Length of Time Injecting (Female)

FEMALE Do you currently identify your syringe?	How long have you been injecting?		
	0 - 10 years	11+ years	Total
Yes	11 (61%)	5 (29%)	16 (46%)
No	7 (39%)	12 (71%)	19 (54%)
Total	18	17	35

N=35, Chi squared 3.540, 1 degree of freedom, p=0.06 not significant, ($p \leq 0.10$, significant).

Although it is possible to speculate that evidence is emerging to indicate that current syringe identification is negatively associated with the length of time injecting and that this is more evident for women than men it is difficult to draw any meaningful conclusions from these results. A significance level of $p \leq 0.10$ accepts that as many as 10 in 100 cases might demonstrate a relationship that does not exist in the population and increases the likelihood of Type 1 errors (Bryman, 2004: 238). Bearing this in mind the results shown in Tables 4.7 and 4.8 should be viewed with caution and considered as tentative early indications of a relationship. It is possible that stronger associations may have existed if, for example, more women had been recruited and

increased options, consisting of shorter time periods of length of time injecting, had been recorded to attempt to uncover subtle changes over time and between genders.

Reviewing the responses to the five options on housing status showed that the majority responded either as living in their own tenancy or staying care of an individual. A decision was made to reduce this from five to three categories for analysis. These were own tenancy, staying care of an individual and a third category of “other” that incorporated the replies to the remaining five categories. This amalgamated together the smaller number of individual responses into categories that can be considered to reflect less stable accommodation.

Table 4.9
Current Syringe Identification and Housing Status

Do you currently identify your syringe?	What is your current housing status?			Total
	Own tenancy	Staying care of an individual	Other(s)	
Yes	46 (43%)	17 (42.5%)	12 (40%)	75 (42.4%)
No	61 (57%)	23 (57.5%)	18 (60%)	102 (57.6%)
Total	107 (100%)	40 (100%)	30 (100%)	177 (100%)

N=177, Chi squared 0.086, 2 df, p=0.96, not significant.

From this analysis there is no indication that identification of syringes is influenced by, or associated with, housing status. However caution should be exercised in interpreting these results as the majority of IDUs (107 of the total 177 interviewed) reported living in their own tenancy. It is known that IDUs in unstable housing situations tend to participate in more risky injecting practices (Briggs, Rhodes, Marks

et al, 2009). Only 3 respondents of the 177 total reported that their housing status was roofless or of no fixed abode. It is therefore possible that there is an under-representation of IDUs in less stable housing situations and that this may have influenced the result.

Despite the finding that there is no association between current syringe identification and housing for the respondents as a whole it is possible that there may have been over or under representation of males or females in individual categories. For this reason a further subdivision by gender was undertaken to investigate if the relationship between housing status and syringe identification differed by gender. The results are shown below.

Table 4.10
Current Syringe Identification and Housing Status by Gender.

Do you currently identify your syringe?	What is your current housing status?			Total	
	Own tenancy	Staying care of an individual	Other(s)		
Male	Yes	36 (41.4%)	14 (45.2%)	9 (37.5%)	59 (41.5%)
	No	51 (58.6%)	17 (54.8%)	15 (62.5%)	83 (58.5%)
Total		87 (100%)	31 (100%)	24 (100%)	142 (100%)
Female	Yes	10 (50%)	3 (33.3%)	3 (50%)	16 (45.7%)
	No	10 (50%)	6 (66.7%)	3 (50%)	19 (54.3%)
Total		20 (100%)	9 (100%)	6 (100%)	34 (100%)

Male, N=142, Chi Squared 0.330, 2 degrees of freedom, p=0.85, not significant.

Female, N=35, Chi Squared 0.748, 2 degrees of freedom, p=0.69 not significant. (4 cells (66.7%) have expected count less than 5).

The results shown in Table 4.10 show that when examined individually by gender syringe identification was not shown to be dependent on housing status for males or females.

When asked whether they had mixed up their syringe with someone else's in the past year, 78% (n=138) of respondents reported they had never done this, 13% (n=23) reported having done so rarely, 6% (n=11) said that they had done so occasionally, 2% (n=4) said they had done so often and 1% (n=1) said very often. The responses to this question need to be interpreted with caution as the question does not record any information on mixing up of syringes that is unknown to the respondent. It should be noted that this does not refer to deliberate or planned sharing through other injecting practices which constitutes an additional hazard in the preparation and administration of illicit drugs. The figures also need to be viewed in the context that the questions deal with sensitive subjects such as illegal drug use where there will be a high possibility that this can result in under reporting (Gilbert, 2003). Despite this the responses indicated that, 22% (n=39) of the total sample were aware of, and prepared to admit to having personal experience of, the known risk related behaviour of mixing up their syringe with another's. It was reported in a study of those who had prepared drugs for injection in the previous month that 18% reported using someone else's needle and syringe (White *et al*, 2007). The observational study carried out in Glasgow in 2004 showed that even when individuals claimed not to share injecting equipment, the complexity and chaos of the circumstances surrounding the actual preparation highlighted potential ways of inadvertent sharing and participants in the study reported that they could have unintentionally used a syringe that was not their own in error (Taylor *et al*, 2004). This study showed that these problems could occur

when IDUs were living together as this resulted in needles and syringes being stored in a communal space within the residential setting, leading to potential confusion over the ownership and usage of individual needles and syringes leading to difficulties in distinguishing their own syringe (Taylor *et al*, 2004).

There is existing evidence to indicate that the social context of the drug preparation and injecting environment has an impact on and can affect the extent of inadvertent sharing. In a study conducted in Dublin, a city which has similar demographic characteristics to Glasgow, it was found that there was evidence to suggest that “accidental and unnoticed sharing” was a possible contributory factor that led to increased infection risks for IDUs (Smyth *et al*, 2005:166). Based on the evidence of previous research in Glasgow and Dublin it is therefore reasonable to assume that the 22% (n=39) who responded in the evaluation that they had experience of mixing up their syringe with someone else’s in the last year is likely to be an underestimate of the true numbers at risk of infection due to the combined risks of known and unknown sharing. If it is assumed that the respondents in the evaluation are representative of the wider population of drug injectors where this is estimated to be between 7,091 and 11,330 then the figure of 22% (n=39) can be extrapolated to suggest that in the region of 1560 to 2493 individuals are aware of mixing up their syringe with someone else in the last year (Hay *et al*, 2009:32). These extrapolated figures are speculative; however they do demonstrate that due to the size of the overall injecting population, even small percentages can represent significant numbers of IDUs who are likely to be affected by inadvertent sharing. If it is accepted that the factors outlined above demonstrate that there is an underestimation in the actual numbers sharing then it can be seen that the extrapolated figures potentially underestimate the true extent of the problem. It

should be noted that these figures relate solely to individual IDUs and not to the number of injecting episodes. The evaluation responses indicated that, despite the likely underestimation discussed above, 22% reported mixing up their syringe with others and 42% currently used a range of methods to identify their own syringes. It appears logical to assume that the 42% who report marking their syringe have identified, and are responding to, perceived risks related to their own injecting practices and environment. It is therefore possible to speculate that the true incidence of sharing when both known and unknown sharing is combined will be greater than the numbers recorded.

There are undoubted difficulties around quantification of the full extent of the problem. However the responses from the questionnaire do indicate that the intervention (syringe marker supply) is a relevant one for IDUs, as it is aimed at addressing what has been identified as an actual, and not merely a theoretical, aspect of illicit drug injecting practice.

To respond to the question on whether respondents were aware of having mixed up their syringe with someone else's in the past year, five response options were available. These were very often, often, occasionally, rarely and never. Investigation of the data showed that 161 of the 177 respondents (91%) answered never or rarely to this question. It was therefore not possible to establish any meaningful associations using mixing up of syringes as the DV and the IVs of length of time injecting and housing status. It would appear that this question is insufficiently sensitive to be used as the DV to uncover any patterns associated with previous mixing up of syringes. It should be noted that this question did not cover unknown mixing up of syringes and it

is possible to speculate that a number of those who responded never will include those who were unaware of any mixing up of their syringe with others.

4.3.2 Use of the Markers

One of the important unknown factors discussed in Chapter 2 was the design problem related to the timings of the supply of syringe markers and the length of the second 4 week period of data collection to ensure that the potential respondents had been exposed to the intervention and had had the opportunity to use the markers in practice. In the second section of the questionnaire 75% (n=132) of the 177 respondents interviewed indicated that they had been supplied with the syringe markers to trial, with 63% (n=83) of the 132 individuals having used the markers. The 83 individuals who were recorded as using the markers constituted 47% of the original 177 respondents. The relatively high percentage of individuals interviewed, 132 of the 177 (75%), who had been supplied with the markers was a positive confirmation of the success of the strategy employed to address the time and interviewer availability factors. If there had been no staffing or funding restrictions then it would have been possible to continue with the supply of markers and the data collection for an indefinite period until the coverage was such that 100% of those approached for interview had been supplied with the syringe markers.

A series of cross tabulations was undertaken with use of markers as the DV to investigate any potential associations with IVs from the questionnaire responses. The findings are shown below in Tables 4.11 to 4.18.

Table 4.11
Use of Markers and Gender

Did you use the markers?	Gender		Total
	Male	Female	
Yes	64 (62%)	19(68%)	83 (63%)
No	40 (38%)	9 (32%)	49(37%)
Total	104 (100%)	28 (100%)	132(100%)

N=132, Chi Squared 0.377, 1 degree of freedom, p=0.54, not significant.

From these findings there was no indication that the use of the markers supplied was associated with gender.

Table 4.12
Use of Markers and Length of Time Injecting

Did you use the markers?	How long have you been injecting			Total
	0-5years	6-10 years	11+years	
Yes	34 (57%)	19 (70%)	30 (67%)	83 (63%)
No	26 (43%)	8 (30%)	15 (33%)	49 (37%)
Total	60 (100%)	27 (100%)	45 (100%)	132 (100%)

N=132, Chi Squared 1.918, 2 degrees of freedom, p=0.38, not significant.

Similarly with length of time injecting as the IV it was not possible to reject the null hypothesis and no association was shown with use of the markers. This result, of no association between length of time injecting and use of markers, was replicated when the respondents were subdivided by gender.

Use of the markers was also shown not to be dependent on current housing status as there was no demonstrated association with these two variables as shown in table 4.13. Examination of the male and female respondents separately yielded the same pattern of results. Housing status was collapsed further into two categories of own tenancy and a grouping all other types of housing into a second category representing less stable forms of accommodation. Conducting a Fisher exact test on this 2x2 table still revealed no statistically significant association.

Table 4.13
Use of markers and current housing status

Did you use the markers?	What is your current housing status?			Total
	Own tenancy	Staying care of an individual	Other	
Yes	56 (68%)	16 (55%)	11 (52%)	83 (63%)
No	26 (32%)	13 (45%)	10 (48%)	49 (37%)
Total	82 (100%)	29 (100%)	21 (100%)	132 (100%)

N=132, Chi Squared 2.759, 2 degrees of freedom, p=0.25, not significant

Table 4.14 below appears to show an association between the use of the markers and whether respondents reported that they already marked their syringe. Examples of the reported range of strategies used to mark syringes were described previously and are shown in Table 4.4.

Table 4.14
Use of markers and current syringe identification

Did you use the markers?	Do you currently identify your syringe?		Total
	Yes	No	
Yes	43 (73%)	40 (55%)	83 (63%)
No	16 (27%)	33(45%)	49(37%)
Total	59 (100%)	73 (100%)	132 (100%)

N=132, Chi Squared 4.573, 1 degree of freedom, p=0.03, significant

These findings indicate that there is an association between previous identification of syringes and the use of the markers. Those who reported to already be identifying their syringes were more likely to report use of the markers supplied. Whilst it may initially appear disappointing that intervention is associated with those who are already attempting to identify their injecting equipment it should be noted that the syringe markers offer a more practical and safer alternative than the reported range of different strategies previously employed. Despite this finding it is important to note that 40 of the 83 respondents, who were supplied with the markers and used them, reported that they had not previously identified their syringes. This is a highly relevant finding which indicates that the intervention was potentially a feasible option to help promote safer injecting practices in a group who had not previously attempted to identify their syringes.

Tables 4.15 and 4.16 demonstrate that when the relationship is broken down and examined by gender the association initially appears to remain for men but not for women.

Table 4.15
Use of markers and current syringe identification (male)

Male Did you use the markers?	Do you currently identify your syringe?		Total
	Yes	No	
Yes	33(73%)	31(52%)	64 (62%)
No	12 (27%)	28(48%)	40(38%)
Total	45 (100%)	59(100%)	104(100%)

N=104, Chi Squared 4.662, 1 degree of freedom, p=0.03, significant.

Table 4.16
Use of markers and current syringe identification (female)

Female Did you use the markers?	Do you currently identify your syringe?		Total
	Yes	No	
Yes	10 (71%)	9 (64%)	19 (68%)
No	4 (29%)	5 (36%)	9 (32%)
Total	14 (100%)	14 (100%)	28 (100%)

N=28, Chi Squared 0.164, 1 degree of freedom, p=0.68, not significant.

A Fisher's exact test also showed that for women the relationship between current syringe identification and use of markers was not considered to be statistically significant. This finding should be viewed with caution as the number of women in this group is small. However Tables 4.17 and 4.18 show that when further examining the use of the markers and current syringe identification by gender, there appears to be no significant associations that would support any differences between the male and female groups. This indicates that the findings in Table 4.14, demonstrating that use

of the markers is associated with current syringe identification, are unlikely to be solely dependent on gender and may be relevant for both male and female IDUs.

Table 4.17
Use of markers and current syringe identification by gender

Did you use the markers?	Current Syringe Identification		Total
	Male	Female	
Yes	33 (73%)	10 (71%)	43 (73%)
No	12 (27%)	4 (29%)	16 (27%)
Total	45 (100%)	14 (100%)	59 (100%)

N=59, Chi Squared 0.02, 1 degree of freedom, p=0.88, not significant

Table 4.18
Use of markers and No current syringe identification by gender

Did you use the markers?	Do Not Currently Identify Syringe		Total
	Male	Female	
Yes	31 (52%)	9 (64%)	40 (55%)
No	28 (48%)	5 (36%)	33 (45%)
Total	59 (100%)	14 (100%)	73 (100%)

N=73, Chi Squared 0.63, 1 degree of freedom, p=0.47, not significant

Those who had used the markers were asked their views about the instruction card that was developed for use and distribution with the supply of syringe markers (Appendix 6). Of the 83 individuals who had used the markers, 87% (n=72) reported that they had received a card with the markers. When these 72 respondents were asked how useful they found the card in providing supplementary information on using the

markers, the responses were as follows: 82% (n=59) of individuals said they found the card either “very” or “quite useful”, 15% (n=11) had “no opinion” and 3% (n=2) found it “not very useful” When asked if the card provided them with all the information needed to use the markers 80% (n=58) said “yes” and 7% (n=5) said that the card did not provide them with all the information needed to use the markers. No information was recorded on how the current card could be improved other than two individuals who reported that “more information could have been provided”. Table 4.19 demonstrates that there appears to be an association between gender and the perceived usefulness of the instruction card as a guide to using the markers.

Table 4.19.
Usefulness of the Instruction card as a guide to the markers and gender.

Using the scale, indicate how useful you felt the instruction card was as a guide to using the markers	Gender		Total
	Male	Female	
Quite useful / Very useful	48 (89%)	11 (61%)	59 (82%)
No opinion	6 (11%)	5 (28%)	11 (15%)
Not very useful / Not at all useful	0 (0%)	2 (11%)	2 (3%)
Total	54 (100%)	18 (100%)	72(100%)

N=72, Chi Squared 9.726, 2 df, p=0.008, significant, (3 cells (50%) had expected values less than 5).

This appeared to indicate that there was a statistically significant difference between men and women whereby men were more likely to find the instruction card useful than women. However due to the number of cells with expected values less than 5 it is not possible to accept this as a reliable result. Therefore the table was collapsed into a 2x2 contingency table and a Fisher Exact test performed and shown in Table 4.20.

Table 4.20

Usefulness of the Instruction card as a guide to the markers and gender (2x2).

Indicate how useful you felt the card was as a guide to using the markers	Gender		Total
	Male	Female	
Useful	48 (89%)	11 (61%)	59 (82%)
Not Useful	6 (11%)	7(39%)	13 (18%)
Total	54 (100%)	18 (100%)	72 (100%)

N=72, Chi Squared 7.04, 1df, p=0.01, significant.

The “no opinion” responses were included in the “not useful” category. It is open to debate as to whether those who had no opinion on the usefulness of the instruction card should be allocated to the “useful” or “not useful” responses. The reason for allocation to the “not useful” category is that these responses did not make any positive statement on the usefulness of the instruction card. In order to check whether this re-allocation affected the apparent statistical relationship, the results were cross checked with the “no opinion” responses (6 male, 5 female) included in both categories and also with the responses excluded. For all of these permutations, the relationship indicating that men found the instruction card more useful as a guide to using the markers than women remained statistically significant. Possible reasons for the apparent discrepancy between the male and female responses are discussed below in section 4.5.

No association was demonstrated between the reported usefulness of the instruction card as a guide to using the markers with either length of time injecting or housing

status. This lack of association was replicated when the latter two categories were subdivided by gender.

When asked if they would use the markers again the response was overwhelmingly positive, where 99% (n=82) of the 83 individuals who had used the markers responded “yes” with only 1% (n=1) reporting that they would not use the markers again. This should be viewed in the context that within the group of 83 who used the markers, 40 (48%) of the 83 IDUs reported that they had not previously identified their syringes. Uncovering of this group is important when considering the potential usefulness of the marker supply as it provides an early indication that the markers were used by a group of IDUs, who had not previously identified their syringes. It appears that the intervention was acceptable to IDUs and was potentially able to promote safer injecting practices by providing an option that offered the possibility of helping to reduce inadvertent sharing.

4.3.3 Attitudes Towards the Markers

When asked how useful they felt the markers were as a method of marking their syringe, 94% of the 83, (n=78) were recorded as saying they were “very” or “quite useful”, with only 5% (n=4) reporting that they were “not very useful” and 1% (n=1) having “no opinion”. If the markers were to be made available on a routine basis from the pharmacy needle exchange, 90% (n=75) of individuals said they would be “more likely to mark their syringe”, 8% (n=7) said they would make “no difference” and 1% (n=1) said they would be “less likely to mark their syringe”.

When asked whether the markers could be improved in any way, 82% (n=68) of individuals said “no”. Of the 18% (n=15) who responded “yes” to this question, 13 individuals gave constructive comments on practical ways the markers could be improved. The answers were grouped into the following categories and are listed below:

38% (n=5) suggested that a variety of colours could be used.

31% (n=4) said the markers could have been bigger so they could have been written on.

23% (n=3) said that they came off easily and were not very sticky.

8% (n=1) said they could have been smaller.

Although the numbers are small, there are indications in these extended responses confirming that the markers were actually being used in practice as the comments appear to relate directly to practical problems that had been experienced, such as the degree of stickiness and the difficulties this caused.

A series of cross tabulations with the responses to perceived usefulness of the markers as a method of identifying the syringe as the DV with the three IVs of gender, length of time injecting and housing status were performed. The results are shown in tables 4.21, 4.22 and 4.23.

Table 4.21
Usefulness of the Markers and Gender.

Using the scale, indicate how useful you felt the markers were as a method of marking your syringe	Gender		Total
	Male	Female	
Very Useful	45 (73.3%)	9 (47.4%)	54 (65.1%)
Quite Useful	16 (25%)	8 (42.1%)	24 (28.9%)
No Opinion	1 (1.6%)	0 (0%)	1(1.2%)
Not at All Useful	2 (3.1%)	2 (10.5%)	4 (4.8%)
Total	64 (100%)	19 (100%)	83 (100%)

N=83, Chi Squared 4.630, 3 df, p=0.20, not significant. (4 cells (50%) have an expected count less than 5).

Table 4.22
Usefulness of the markers and length of time injecting.

Using the scale, indicate how useful you felt the markers were as a method of marking your syringe	How long have you been injecting?			Total
	0 - 5 years	6 - 10 years	11 years +	
Very Useful	23 (67.6%)	15 (78.9%)	16 (53.3%)	54 (65.1%)
Quite Useful	9 (26.5%)	4 (21.1%)	11 (36.7%)	24 (28.9%)
No Opinion	0 (0%)	0 (0%)	1 (3.3%)	1 (1.2%)
Not at all Useful	2 (5.9%)	0 (0%)	2 (6.7%)	4 (4.8%)
Total	34 (100%)	19 (100%)	30 (100%)	83 (100%)

N= 83, Chi Squared 5.307, 6 df, p=0.50, not significant. (6 cells (50%) have expected values less than 5).

Table 4.23
Usefulness of the markers and housing status.

Using the scale, indicate how useful you felt the markers were as a method of marking your syringe	What is your current housing status?			Total
	Own Tenancy	Staying care of an individual	Other	
Very Useful	33 (58.9%)	12 (75%)	9 (81.8%)	54 (65.1%)
Quite Useful	20 (35.7%)	3 (18.8%)	1 (9.1%)	24 (28.9%)
No Opinion	0 (0%)	0 (0%)	1 (9.1%)	1 (1.2%)
Not at all Useful	3 (5.4%)	1 (6.3%)	0 (0%)	4 (4.8%)
Total	56 (100%)	16 (100%)	11 (100%)	83 (100%)

N= 83, Chi Squared 7.191, 4 df, p=0.13, not significant. (6 cells (50%) have expected values less than 5).

In all three cases no differences in the perceived usefulness of the markers were found across the three IVs of gender, length of time injecting and housing status. As 94% of the 83, (n=78) who responded to the question on the usefulness of the markers recorded that the markers were “very” or “quite useful”, this means that for any cross tabulation the numbers who can populate the remaining cells are very small and this therefore limits the possibility of uncovering any statistically significant relationships with usefulness of the marker as the DV. In view of this, the responses to the question on usefulness of the markers were collapsed into two categories. The single “no opinion” response was excluded and the remaining responses allocated to a “useful” or “not useful” category. However this subsequent categorisation did not lead to any significant findings.

4.4 Feedback from Participating Community Pharmacists.

As detailed in Chapter 2 (2.3), the evaluation was conducted in three community pharmacies with permanent pharmacist managers. The three pharmacists were contacted at the end of the study by the principle investigator (two by telephone and one by pharmacy visit) to ascertain their feedback on the whole process from the initial training session to completion. These were informal feedback sessions where their views and comments on the following topics were sought; the impact of the peer researchers on the pharmacy, payment structure, staff training and clarification on the discrepancy between the 83 who had been supplied with markers and the reduced number of 72 who reported that they had received the instruction card along with the marker supply.

As reported in Chapter 3, during the data collection period, there were no reports of any problems or disruption to the routine functioning of the pharmacy caused by the presence and work of the peer researchers when administering the questionnaire. When questioned directly, the 3 pharmacists all reiterated that the peer researchers had at all times behaved professionally and their work had no adverse impact on the pharmacy staff, patients or members of the public. One pharmacist commented that this was “far better than having to do it yourself!” The 3 pharmacies had all participated in the evaluation voluntarily. Locum fees were paid for attendance at the joint training sessions. As part of the health board scheme, pharmacists are paid a fee per individual NEX transaction which is negotiated annually. No additional fee was offered for the supply of markers alongside supplies of packs of injecting equipment. All noted that if the marker supply was to be extended, in the current format, where a separate supply and explanation to patients was required that this should attract an

additional fee. However all agreed that if incorporated into existing packs, claims for additional fees would not be justified. When asked if the joint training session had been useful and covered the relevant material for staff, there was unanimous agreement and no-one identified any gaps in the training that had appeared as the implementation progressed. All reported that they had been well supported throughout the evaluation.

Of the 83 clients who received supplies of the markers, 13% (n=11) reported that they did not receive an instruction leaflet with the markers. This conflicted with the replies of the participating pharmacists who claimed that the markers and instruction leaflet were always supplied together along with verbal instructions during the supply phase. As the markers were packaged and supplied together with the instruction cards this is an indication that for the 13%, the card had no impact as information about or contained on the card was not retained. There is evidence to demonstrate that when health care professionals provide medical information 40-80% can be forgotten by patients (Kessels, 2003:219). This work showed that patients' recall of medical information is affected by a number of factors including age, anxiety and distress, the perceived importance of the information being relayed and whether it is presented in a written, spoken or non-verbal form (Kessels, 2003:221). He concluded that any spoken information should be reinforced by written or visual materials. Whilst these results are not completely transferable from the traditional health care professional and patient interaction, information provided in a NEX setting is likely to be affected to some extent by these factors plus other site and situation specific factors including, desire to maintain anonymity and confidentiality due to the illegal nature of drug use

and potentially being in a state of withdrawal. When viewed in this context it is not unexpected that 13% (n=11) claimed not to have received the instruction card.

In summary, from the pharmacists' perspective, the supply of syringe markers was an acceptable and straightforward intervention to implement and the presence of the peer researchers in the pharmacy for extended periods was managed successfully with no adverse impacts.

4.5 Discussion of Findings.

In summary, the design of the evaluation enabled a total of 177 questionnaires to be completed during the data collection period. All three pharmacies completed the supply and data collection phases with no reported problems. A majority of the 177 respondents, 75% (n=132), had been supplied with the syringe markers during the initial phase and 63% (n=83) of the 132 reported using the markers. When asked how useful the markers were as a method of marking their syringe an overwhelming majority of the 83 who had used the markers, 94% (n=78), responded that they were very or quite useful and 99% (n=82) reported that they would use the markers again if they were to be made freely available. This indicated that the marker supply did constitute a feasible method of supply that was acceptable to both the staff involved in the supply and to the IDUs. As there was no direct observational data of injecting practices collected during this evaluation it is therefore only possible to report that the results indicate that this provides a potential means of preventing the inadvertent accidental sharing of syringes within a group setting.

For the original group of 177 respondents interviewed, 80% (n=142) were men and 20% women (n=35). This resulted from opportunistic sampling which was based on the interplay of timings of the peer researchers' attendance in the pharmacy and those attending the exchange who agreed to be interviewed. Chi squared tests showed that there was no significant difference between this gender distribution and the health board database figures of 78% male, and 22% female, for the population who attend NEXs.

Cross-tabulations demonstrated that current methods of syringe marking or identification were not shown to be associated with gender, length of time someone had been injecting or current housing status. It should be noted that although there may be a lack of evidence to demonstrate an association this does not automatically infer that evidence exists to support the null hypothesis of no association (Bruce, Pope and Stanistreet, 2008). It indicates that the available evidence is insufficient to reject the null hypothesis. There was an indication that some evidence was beginning to emerge that women who had been injecting for longer periods of time were less likely to mark their syringes and, by implication, were more likely to be involved in unsafe injecting practices. Alternative, although less plausible, explanations could also be proposed. For example, it could be suggested that women were less likely to mark their syringes as they injected alone or always used new equipment and therefore had no need to prevent inadvertent sharing. Although this relationship was not immediately obvious it serves to highlight an area that is worthy of further study to attempt to uncover the extent and nature of any potential relationship. The apparent differences between men and women IDUs that emerged from the evaluation and the wider implications are discussed below in more detail.

Use of the markers was shown not to be associated with gender, length of time injecting or housing status. It is worth noting that the converse is also true, where non-use of the markers was also not associated with gender, length of time injecting or housing status. This is relevant as it provides confirmation that there were no apparent differences, in these recorded characteristics, between the group who used the markers (n=83) and the group (n=49) who were supplied with markers but did not use them. This can be interpreted that the use of the markers was not associated with any specific demographic group or characteristic. This therefore makes it difficult to target the intervention as there was no indication of the characteristics of the individuals who would utilise this intervention and equally it gave no indication of the characteristics of the IDUs for whom this intervention had no relevance. The one positive association that was demonstrated was between those who reported that they currently identified their syringes and those who had used the markers supplied to them. Although this may initially appear that the intervention was only of relevance to IDUs who were already making attempts to minimise risks, it should be noted that the marker supply offers an easier and safer option than the existing strategies used of burning, scratching or marking that were described in section 4.3.1. Despite the apparent statistical association between use of the markers and those already identifying their syringes, Table 4.14 also highlights that 48% (n=40) of the total of 83 who used the markers had not previously identified their syringes. This indicates that the intervention appeared to be successful in reaching an important group who previously reported not making any attempts to identify their syringes. However caution should be exercised in interpreting the results as the responses are based on reported rather than observed behaviours. As discussed in Chapter 3 the use of peer researchers helps to militate against some of the factors that lead to biased responses.

Therefore it is reasonable to assume that the responses from those who used the markers, but had not previously identified their syringes, indicates a reaction to perceived risks related to their own injecting practices and situations.

Despite the inability to identify any specific characteristics associated with marker use, other than pre existing syringe identification, 94% of the 83 who used the markers (n=78) responded that the markers were very or quite useful and 99% (n=82) responded that they would use the markers again. Although these overwhelmingly positive responses on the reported usefulness of the markers and indications that their availability would make IDUs more likely to mark their syringe, there needs to be an element of caution in interpreting and extrapolating these results as these responses are reported and not observed. It is therefore difficult to make any definitive claims about the use of the markers in real life settings.

The responses in this evaluation to a question on whether syringes had been mixed up with another's in the past year yielded little useful information. Seventy eight percent, (n=138) of the total 177 claim that this has never happened. It is possible that this form of questioning may not be the best method to elicit accurate responses on risky and unsafe injecting practices and that alternative methods should be explored. Recent work comparing responses from IDUs to questions on HCV risk behaviours using visual and written cues demonstrated that using written questions only, led to an underestimation of unsafe injection sharing practices (Beynon, Taylor, Allen *et al*, 2010). It is possible that use of different media and incorporation of pictorial representations of risk related practices within the questionnaire may give a more accurate estimation of the extent of risky injecting practices.

The most significant factor to emerge from analysis of the findings was the individual differences that became apparent between male and female respondents. These should not be considered in isolation but serve to prompt further reflection on the possible reasons why there should be differences in the responses of male and female IDUs. The findings gave some preliminary indication that the longer women had been injecting the less likely they were to mark their syringes and men found the instruction card more useful than women. Tables 4.15 to 4.18 indicated that further investigation of female IDUs would be useful to allow definitive conclusions to be reached on the use of markers and association with current syringe identification. As the characteristics of the sample interviewed were similar to the usual pattern of attendees at each NEX and of the population as a whole across all sites, it is unlikely that these differences were due to an artefact of the group interviewed. This appears to provide some preliminary evidence that warrants further investigation as it indicates that there may be underlying differences in the injecting practices of male and female IDUs leading to speculation that female IDUs may engage in higher risk related injecting behaviours. There is existing evidence to suggest that women IDUs experience more physical problems with the injecting process than men including difficulty accessing veins and the resultant greater number of injecting sites and associated increased risks of blood spillage, contamination, and of infection and BBV transmission (Darke, Ross and Kaye, 2001). A previous exploration of the injecting practices of women IDUs reported on the differences and the underlying social complexity that affected women's decision making in relation to their injecting behaviours (Sheard and Tompkins, 2008). This work noted that women IDUs are more likely to have a sexual partner who is also using drugs and that within this type of relationship; women were more likely to inject or to be injected using equipment

that they did not directly source themselves but had obtained from their partner (Sheard and Tompkins, 2008). This is further confounded by the interplay of trust and sharing of injecting equipment within a sexual relationship as outlined by McKeganey and Barnard in the early 1990's and discussed in Chapter 1. Sheard and Tompkins highlighted that women may have different priorities that can adversely affect attempts to minimise injecting risks (2008). These were reported to include avoiding physical exposure of the visible signs of injecting and violence that is often inherent in dependent relationships. As part of this qualitative study the authors reported that the women described a range of different techniques that they used to identify their own used needles to prepare for situations where new supplies were not available. One of the recommendations from this work was that any health promotion and injecting advice to women in a relationship with a drug using partner should be specifically tailored to "reflect the dynamics" of these relationships (Sheard and Tompkins, 2008:1545).

According to Clarke achieving success with any type of interview is dependent on the skills of the interviewer and how effective they are as an "active listener" and their ability to quickly establish a rapport with those being interviewed (2005:75). Despite the relative inexperience of the SUIG members it would appear that they were able to successfully manage the interview process with minimal direct supervision in all three sites. This was demonstrated by the initial estimate of 150 being exceeded and 177 questionnaires being successfully completed during the second data collection period. In follow up discussions with the pharmacy staff there was no identified adverse problems caused for staff or disruptions to the delivery of routine pharmacy services by the research or the presence of the peer researchers in the pharmacies. This

provided further evidence that the group had managed the process effectively. The absence of any problems is an important factor as not only did the peer researchers have to implement the survey, they had to do this within a busy community pharmacy where the situations they may have to deal with are unpredictable and often out of the direct control of staff. As discussed in Chapter 2 the pharmacies had been previously identified as sites that dealt with large numbers of people attending their NEX and were chosen to maximise potential contact with respondents. This therefore meant that due to the busy and public nature of the pharmacies chosen, there existed the likelihood that the practical aspects of administering the questionnaire could be adversely affected by any number of unexpected problems that were impossible to anticipate and plan for in advance.

Feedback from the participating pharmacists indicated that the supply of markers could be successfully implemented in this setting. The intervention and the content of the associated training session held prior to the pilot were acceptable to the pharmacy staff. It is relevant to note that no site or staff related problems emerged during the duration of the pilot. The recorded observations and recommendations contained in the field work diaries completed by the peer researchers provided the researcher with additional relevant data for inclusion in the evaluation. The recommendations, arrived at independently by the peer researchers, appear to support the results of the questionnaire in confirming that the supply and use of syringe markers provides IDUs with a useable practical means of reducing the accidental sharing of syringes. Discussion of the wider implications of these findings and areas of work proposed for further exploration that have emerged from the evaluation are explored in detail in Chapter 5.

Chapter 5

Conclusions

“Evaluation is important for determining the extent to which a policy has met or is meeting its objectives and that those intended to benefit have done so” (Booth, 2009:257).

5.1 Summary

This study involved the development, implementation and evaluation of syringe markers as a pilot study within three community pharmacy NEX sites in Glasgow. The aims have been to evaluate the supply of markers which are designed to identify syringes and to determine if this offers a practical solution as a potential means of reducing accidental and unintentional sharing of injecting equipment and thereby contributing to minimising some of the health harms associated with injecting drug use. The study also aimed to identify whether the supply of syringe markers from community pharmacy needle exchanges was acceptable to IDUs and staff.

The ACMD report into the primary prevention of HCV among IDUs reported on a number of innovative practices, including the provision of additional injecting paraphernalia and coloured syringes, designed to prevent this transmission however it was reported that despite the level of innovation there was a lack of supporting evidence of effectiveness. The report concluded that continued support should be provided for new initiatives but also stated that “more attention needs to be given to evaluation” (ACMD, 2009:29). This emerging evidence, discussed in Chapter 1, on the possible routes of transmission of HCV, including through accidental or

inadvertent sharing of injecting equipment, formed the basis for the design of the syringe markers supply pilot. The implementation of this new intervention within an existing service has been coupled with an evaluation of its acceptability for staff and service users. The design of the evaluation incorporated the active participation of peer researchers both in the preparatory work and in the administration of the questionnaire.

Although this evaluation contributes to the emerging knowledge base on syringe identification, caution needs to be exercised in drawing final conclusions. It is possible to conclude from the results that the intervention can be successfully implemented and, due to the fact that the groups of IDUs attending the three pharmacy NEX sites chosen exhibited similar characteristics to those in all other sites in the area, that it would be possible to successfully extend the supply to other sites. However, although the implementation and the product can be considered successful and acceptable in practice to IDUs, this does not provide any definitive indication of its effectiveness in reducing the transmission of BBVs and other related infections. Proposals on how effectiveness could potentially be measured are discussed further below.

The emerging differences between the male and female groups merit further investigation. This should not be confined only to future syringe marker supply but should be extended to the totality of the NEX service as it is possible to speculate that the current structure of generic NEX services may not be fully meeting the needs of female IDUs. This is important as previous work, across an extended time period, has shown that women injectors have greater risks of exposure to BBVs and other health

risks and women, particularly drug using mothers, often experience increased stigmatisation and rejection from society (Taylor 1993, Hankins 2008, Olszewski, Giraudon, Hedrich *et al*, 2009). This contributes to the desire to reduce the visibility of drug use often resulting in participation in increasingly unsafe and higher risk injecting practices (Sheard and Tompkins, 2008).

The findings of the cross tabulations in Chapter 4 indicated no associations between the use of markers and attitudes towards them and other variables such as gender, length of time injecting and housing status. The identification of any relationships amongst groups with specific characteristics and different injecting practices may yield information to assist in the design and development of any intervention aimed at reducing injecting related risks. However, ideally, the utility of any syringe markers should have a universal appeal that is not strongly influenced by or associated with any limited defined groups. Therefore any lack of association is not necessarily a negative factor. The most significant association noted was between those who currently identify their syringes and use of the markers. The results shown in Table 4.14 demonstrated that 73% of IDUs who previously reported identifying their syringes claimed to have used the markers. However use of the markers was not solely confined to this group as 55% of those who reported that they did not previously attempt to identify their syringes also reported use of the syringe markers supplied. These results provide some indication that the usefulness of the markers extended beyond the group already marking their syringes and included a proportion of those who are potentially engaged in more risky injecting practices and therefore more at risk.

The incorporation of peer researchers was a successful part of the evaluation. The field work diary that they collectively produced made a positive contribution to the final evaluation and opened up avenues for further work and collaboration. The relatively low number of refusals when compared to the rates in other Glasgow based NEX evaluations, and the number of responses exceeding the original estimate, is a testament to their commitment and successful participation. Based on this it is important that ways are found to further expand the unique contribution and insights that peer researchers can bring to assist, not only with the syringe marker supply, but also with other innovative work and the wider development of NEX services. This is an area where the views of the service users are paramount as even when NEX services and equipment are designed based on current academic theory and evidence, for any positive health benefits to be achieved both the service and the equipment supplied has to be acceptable to and used by IDUs. As was seen from the literature review and the evaluation this is affected by a complex and changing interplay of various internal and external factors.

5.2 Potential Options to Monitor Effectiveness of Syringe Marker Supply.

If the distribution of markers is to be expanded on a wider scale and incorporated into all of the NEXs in the area then it is possible to propose a number of proxy measures that could be used to identify if wider distribution has positive effects leading to reduced sharing behaviours and producing a subsequent reduction in the transmission of HCV. For example, the Health Protection Scotland (HPS) agency produces the Hepatitis C Diagnosis Database. This database provides anonymised epidemiological information from Scotland since 1991 on individuals who have had positive HCV

and/or Polymerase Chain Reaction (PCR) results (HPS, 2011). One of the main aims of this database is to provide a monitoring tool to identify trends in diagnosed HCV infection in the population in Scotland. Recent advances in avidity testing have been introduced (S Hutchison, 2010: personal communication). The avidity test enables an estimate of the length of time an individual has been infected with HCV to be made. For the purposes of using the Hepatitis C Diagnosis Database information as a proxy indicator of success of the extended distribution of syringe markers, the introduction of new avidity testing means that it is possible to distinguish newly acquired infections from those of much longer existence. To be deemed as successful, any programme, including the supply of syringe markers, aimed at reducing sharing and thereby reducing the transmission of HCV should be able to demonstrate a correlation with a reduction in newly acquired infections even if the total number of diagnoses increases with increased levels of testing. If the expanded supply programme was to be effective, the number of newly acquired HCV infections should decrease with a concurrent increase in the levels of markers supplied.

Further examples of existing data that can be used to corroborate the effectiveness of a programme aimed at reducing sharing of injecting equipment include the information contained in the Scottish Drug Misuse Database (SDMD) and from the National Needle Exchange Surveillance Initiative (NESI). The SDMD is published annually and is the major source of statistical information on the misuse of drugs in Scotland. The dataset is based on the information provided by new clients attending medical and specialist drug services. It contains information on a wide range of behavioural and demographic characteristics of the clients and this includes details of

injection practices and sharing behaviours. The NESI study also provides information on injecting equipment sharing behaviours. However as the NESI study was conducted amongst those attending NEXs it is likely to have included relevant information from IDUs who are not in contact with treatment services, unlike the SDMD population which is drawn exclusively from new attendees at treatment services. If an extended syringe marker programme was to be deemed as effective then there would be an expectation that co-inciding with this, reduced equipment sharing behaviour trends would begin to be reported through these two separate monitoring mechanisms described above.

As discussed in Chapter 1, injecting drug use is influenced by the interplay of combinations of practical, community, personal and physical health factors. Due to this multifactorial aspect, in practice it is difficult to devise a means of isolating any single causative effect associated with a specific intervention like the introduction of syringe markers. Although it appears intuitive that achieving a reduction in sharing of injecting equipment will lead to reduced BBV transmission this correlation does not necessarily imply a causal effect. This is due to the need to recognise the complexity and interplay of health, social, legal and other factors and means that attributing a beneficial response to one specific intervention is impossible in the absence of a randomised controlled trial (RCT). It is not possible to conduct a RCT with this type of intervention as all of the potential relevant variables cannot be controlled in a real life setting. This was recognised in Scotland's Hepatitis C Action Plan. In discussing the prevention recommendations it was noted that if any reductions in virus transmission were to be found, attributing this conclusively to any single intervention would not be possible (Scottish Government, 2008). Despite this, the syringe marker

evaluation has shown that, even within an ongoing service setting, it is still possible to devise studies that help to provide useful data to contribute to the emerging evidence base.

A combination of the information available from the three data sources mentioned above (the Hepatitis C Diagnosis Dataset, SDMD and the NESI study) offers a viable means of monitoring the effectiveness of the wider introduction of syringe markers. It is possible to speculate that if reduced sharing could be demonstrated (for groups both in and out of treatment) and if a reduction in new cases of HCV infection could also be identified that these reductions would then potentially be positively correlated with an extended supply of syringe markers. The same principles can be applied to other areas including, for example, investigation of trends in Accident and Emergency admissions of IDUs with infected injecting wounds and any patterns of association with supplies of clean injecting equipment and specific products designed to reduce sharing and also reuse of equipment.

5.3 Discussion of Findings and Proposed Areas for Further Work.

Despite the apparent success of the pilot in offering a simple and easy to use means of identifying an individual IDU's syringe, this gives no guarantee that it will actually be used in practice. A further range of observational and other studies would have to be undertaken to confirm the results from the evaluation, where 94% of those who had used the markers reported to have found them "very" or "quite useful". It would be possible to design an observational study to test the accuracy of these results and to identify if the reported practices were replicated in real life settings. Despite these

cautions and the lack of published materials on effectiveness and feasibility of use, the distribution and use of the markers by the IDU community has been noted and acted upon by a commercial company who have produced their own version of syringe and paraphernalia markers for wider distribution (Appendix 11). This would indicate that there is already an existing demand for this type of product that has been identified and acted upon.

Research in the USA into the risk related behaviours associated with the transmission of BBVs and related infections amongst the injecting drug using population used self completion daily diaries to investigate the correlation of behaviour and HIV risk (Stopka *et al*, 2004:73). The researchers claimed that this method had a number of advantages and that it was a useful corroborative method for a range of other qualitative and ethnographic designs. It was also a feasible method to employ with a hard to reach drug using group. They concluded that the diaries allowed a contextualised record to be built up that provided a deeper understanding, not only of injecting and risk behaviours but also of their “interrelatedness” (Stopka *et al*, 2004:74). This work allowed the researchers to track risk related behaviours, related emotional states and high risk use associated with injecting by tracking what they termed the “life cycle” of an individual syringe (Stopka *et al*, 2004:78). The results from these diaries gave valuable information over a number of areas, including changing patterns of drug use related to unexpected risk related events, BBV risks and how this related to the life cycle of the syringe and the IDU’s emotional state. It is clear that the use of diaries is a potential method that could be used and adapted to expand the evidence base on the relevance of syringe markers in practice.

The findings have identified tentative differences in the male and female use of the markers. This is an area that requires work to further investigate the complex inter-relationships and co-existing factors that affect women's injecting practices, sharing behaviour and their sources of injecting equipment. Previous evidence has demonstrated the different experiences of men and women IDUs and calls have frequently been made for services to be tailored to meet the needs of women (Becker and Duffy 2002, Ettore 2004). In Glasgow and across Scotland NEX services remain, almost exclusively, generic with minimal consideration being given to strategies to address this gap. This is despite previous identification of the relatively low uptake of injecting equipment by women from pharmacy NEXs and previous recommendations that women only exchanges should be established (Roberts, Gilchrist, Cameron *et al*, 2002, Cameron, Gilchrist and Roberts, 2004). The findings of this evaluation indicate that this is an area that should be addressed particularly as there is evidence to show that female injectors are more likely to share injecting equipment than men (Eaves, 2004). Consideration should be given to developing a women only service along the lines of the enhanced and specific NEX service provided on a once weekly basis for users of performance and image enhancing drugs (PIEDs). It is interesting to note that offering a bespoke service for this group has been successful in attracting a large number of individuals who are injecting PIEDs and who were not previously known to, or attending generic NEX services (John Campbell, 2012, personal communication). Although the challenges and the barriers facing women accessing NEX are different it is possible that a tailored women only service would help to address some of the barriers and gaps that are inevitable with a generic service. In research that utilised a social mapping tool with women involved in street sex work in Vancouver it was discovered through mapping the geographic relationships, that

access to health and harm reduction services, including NEXs, for these women was adversely affected by violence and policing activity (Shannon, Rusch, Shoveller *et al*, 2008). It is difficult to make any cross cultural comparisons but this serves to illustrate the range of unknown and unexpected factors that could affect access, not only to syringe markers, but to the service as a whole. Recent examination of the electronic data collection system in Glasgow has highlighted distinct reductions in NEX transactions that appear to co-incide with the timings of local enhanced police stop and search activities in the immediate vicinity of NEXs (John Campbell, 2011: personal communication). Previous work has demonstrated that women IDUs are more likely to be involved in sex work than men (Hankins, 2008:95). Therefore it is possible to speculate that this type of policing activity may have more relevance for women resulting in greater impact in preventing women IDUs accessing harm reduction services. This is an area that should be considered in any further work aimed at developing and promoting syringe markers to women IDUs as access to the NEX and time spent there to engage with healthcare professionals on safer injecting and harm reduction issues could be affected by external factors.

The findings of the evaluation indicate that further work in this area should explore the needs of men and women as two separate populations. Farris and Fenaughty described women who are using drugs as a population which is “dually disadvantaged” (2002:348). They examined the association of social isolation and domestic violence among female drug users and claimed that this affects the women’s ability to access health and support services. They recommended that treatment providers should design services to take account of these factors. It is reasonable to propose that NEX services should also be aware of, and respond to, the specific needs

of IDU women. From the findings of the evaluation and the previous evidence on the physical and social factors affecting women IDUs it is essential that future work on the syringe marker supply should consider the specific needs of women IDUs. This applies equally to the future design of all harm reduction information and interventions which should be responsive to the specific needs and incorporate a strategy to target women IDUs

The SUIG consisted of 4 men and 2 women who acted as peer researchers. There is no information on whether this affected the number or the responses. Based on the findings it is worthwhile pursuing the involvement of peer researchers to interview respondents of the same sex in future work.

In a review of qualitative research into injecting drug use and risk related behaviours associated with the transmission of HIV, Rhodes and colleagues concluded that if any intervention was to be successful in promoting a reduction in needle and syringe sharing then there was an imperative to relate how attempts at reducing risk are affected by the social situation and other contexts that impact on injecting practices (Rhodes *et al*, 2001:58). It is reasonable to assume that relevance of the social context of injecting is equally applicable to HCV transmission and to the totality of the health risks associated with sharing and re-use of used injecting equipment. This reinforces the need for further observational studies to build on the findings of the syringe marker evaluation and to investigate the use of markers within the relevant social context, interactions and conditions of injecting drug use. Early qualitative studies into risk behaviour by Rhodes had shown that for public health interventions to be successful in achieving a reduction in risk related behaviours that it was necessary to

employ “social action theories” to understand the how perceptions of risk are influenced by a complex interaction of a range of social factors (Rhodes, 1997:208). This qualitative study was supported by later quantitative work in Dublin that demonstrated how accidental and unnoticed sharing of injecting equipment was only one factor responsible for increasing the risks of infection transmission but that having a positive HCV status was statistically associated with the social context of injecting (Smyth *et al*, 2004).

An understanding of the social context of injecting and the effects that this has on harm reduction initiatives is a relevant factor that has to be considered when discussing the implications of the findings of the syringe marker evaluation. It demonstrated that the evaluation has only addressed specific aspects of injecting practices and that there is an interplay of other factors out with the scope of this evaluation that need to be considered when discussing the findings. Providing simple and easy to use tools to enable IDUs to identify their own equipment and to prevent inadvertent sharing or mixing of equipment in a group setting may only be partly successful in promoting safer injecting behaviour amongst the IDUs community due to the interplay of various social factors outlined above. An additional factor was identified by Millar who showed that there was limited evidence to support the effectiveness of “safe using messages” in relation to overdose prevention and BBV transmission (2009:18). He undertook a combined quantitative and qualitative study in Australia to investigate IDUs experiences of overdose and prevention, and BBV experience and risk behaviours. Although there are limitations to the study that affect its generalisability, he concluded that harm reduction and health promotion messages were regularly disregarded or ignored. For the group interviewed, experiences of the

death of members of the group were common and, despite this and the adverse consequences to their own health, they continued to engage in hazardous and risky behaviour to an extent where the authors concluded that death was viewed with “indifference or resignation” (Miller, 2009:18). Despite the recognised difficulties in promoting behaviour change in this group there is still a need to provide the tools, equipment and advice to maximise the opportunities available to reduce the health harms associated with injecting drug use. The ultimate aim is to enable individuals to enter treatment services and to engage in a recovery process having sustained minimal permanent physical health problems as a result of their injecting drug use. It would appear from the results of the evaluation, that the provision of syringe markers has a part to play in potentially contributing to reducing these health harms.

The Health Belief model is of relevance when discussing the different factors and influences that can affect an individual’s actions and behaviours. This is directly linked to the evidence from the Miller study with IDUs discussed above. This model has been defined as “a model of the relationship between attitudinal and cognitive variables and the likelihood of an individual engaging in some desirable health-promoting behaviour” (Dyson and Brown, 2006:161). These authors concluded in a critical review of the health belief model that it was difficult to predict health related behaviour with any level of certainty as this type of behaviour can be viewed not only in health but also in social terms due to the concurrent existence of numerous social factors in people’s lives that become linked with any health behaviours (Dyson and Brown, 2006). There is a direct link here to the use of syringe markers as these markers are inevitably introduced into a social setting that is further complicated by numerous health, legal and social factors that constitute the often chaotic nature of the

routine daily life of an IDU. It is clear that further work involving direct observational studies in the real life setting would be required to enable a full picture of the benefits and difficulties associated with the use of syringe markers in practice to be determined. It is possible to speculate that this type of research would provide confirmatory evidence to support the initial findings of the syringe marker evaluation.

Despite the cautions outlined above about the lack of direct observational evidence in the evaluation, it is clear that the syringe markers were viewed positively by those interviewed and supported by the research setting observations and independent recommendations of the peer researchers. The evaluation demonstrated that the markers reportedly offered an easy to use, simple solution to the problem of inadvertent and accidental sharing in a group situation that has been identified by previous research. Although the work described in this evaluation was carried out in 2006 / 07, minimal progress has been made in extending the use of any means of syringe identification. In 2010, the Scottish Government guidelines on best practice for all types of injecting equipment providers, including community pharmacies, made a number of recommendations. Recommendation 8 stated that all suppliers should “Provide methods for syringe identification” (Scottish Government, 2010:19). This recommendation goes on to elaborate that “a method of equipment identification should be made available to clients who inject in the company of other injectors in order that they can identify their own equipment and avoid accidental sharing” (2010:19). It is clear from the results of the syringe marker evaluation that these markers can offer a potentially viable means of identifying needles, syringes and other items of paraphernalia.

It is possible to draw cautious conclusions from the evaluation. It appears from the results that the practice under study of syringe marker supply does offer a useable method of marking syringes which potentially can help to prevent inadvertent sharing of equipment. There is a need, however, to fully recognise the role of the individual in taking responsibility for protecting their own health and the health of others in their community. Whilst acknowledging the results of Miller's research in Australia which demonstrated the association of indifference to individual health and the problems inherent in promoting positive health behaviours in this group there is some emerging evidence to show that IDUs do make some attempts to protect both themselves and others from the transmission of BBVs. Previous research has shown that HCV can be transmitted between IDUs through sharing of other pieces of injecting paraphernalia apart from needles and syringes (Thorpe, Quellet, Hershaw *et al*, 2002). This was confirmed by an in-depth observational study in Glasgow into IDU's injecting practices in their own environment (Taylor *et al*, 2004). This study recorded a high level of awareness of the risks that were associated with needle and syringe sharing but highlighted many of the social and practical difficulties that made safe injecting practices difficult to achieve. The same study also concluded that "indirect sharing" of all injecting paraphernalia was a common occurrence despite some observational evidence to show that attempts were sometimes made to mark individual syringes (2004:36). The responses from the syringe marker evaluation questionnaire support these findings where 42% of the respondents claimed to identify their syringe using a range of methods including burning and scratching. One of the findings with policy implications from the observational study was the recommendation that when IDUs were injecting in group situations a solution should be found so that IDUs could effectively identify and distinguish their own injecting equipment (Taylor *et al*, 2004).

The syringe marker intervention described in this evaluation would appear to offer a practical solution to the problem highlighted in the observational study by providing IDUs with the opportunity to mark and to easily identify all of their own paraphernalia and therefore to prevent inadvertent sharing. It would also appear to support the observational evidence that within the group under study, some basic attempts are made at safer and less risky injecting practices despite the adverse and unhygienic circumstances where this occurs.

This evaluation was of a pilot study conducted in 3 community pharmacy sites. The rationale for the choice of the sites was discussed in Chapter 2. The characteristics of those who attended and the exchange transactions at the pilot sites were shown to be consistent with the wider NEXs and attendees (Table 2.1). Similarly those who responded to the questionnaire had broadly similar characteristics to the IDUs who used these 3 NEXs and to the board wide population of attendees. It is therefore likely that the conclusions drawn from the evaluation can be applied to other pharmacy NEXs. On this basis it would be legitimate to extend the supply of syringe markers to other sites across the health board. The implications and the role that the central database could play in the ongoing monitoring and evaluation of an extended syringe marker supply and its potential to contribute to future research are discussed below.

If the intervention was extended and made available from all community pharmacy NEXs it would be possible to use the data contained in the central database for extended statistical manipulation to monitor and investigate the relationship of syringe marker supplies with data on a number of other collected variables. This would enable further exploration of the male and female differences that appeared to emerge from

the evaluation. This central database contains extensive information on transactions and individual characteristics and offers a range of opportunities for further detailed statistical exploration. This is an area of potential future work that would contribute to the evidence on syringe identification and can provide quantitative information that would complement the proposed qualitative observational work to measure the impact of this or any other intervention. The database records relevant information on all individual NEX transactions that occur in the health board area. The variables include gender, age, ethnicity, type of drug use, frequency of injecting, quantity of returns, location and type and amount of equipment issued. It is possible to add syringe markers to the type and amount of equipment issued. The database is therefore not a sampling frame of injecting equipment supplied from the NEXs but reflects the full population who attend NEXs. To date this is an extensive database that has been underutilised in terms of any statistical analysis. Along with qualitative research into their use in practice, this combination can potentially enable interventions and safer injecting messages to be more specifically targeted at particular groups or areas. There is an obvious link with the information contained in the national databases on sharing of equipment and on the incidence of new HCV infections, discussed above, that can be included in future research into the effectiveness of syringe markers. For example, this combination could be used to examine any potential links between the geographical location of new cases of HCV infection and the location and characteristics of the population supplied with syringe markers, injecting frequency and the quantities supplied.

The incorporation of peer researchers in the evaluation was considered to be successful and this is a role that should be actively developed and extended in future

work. The background and reasons for using peer researchers in this role were discussed in detail in Chapter 3. Initially there was some uncertainty and hesitancy from the principle researcher about the capacity of the peer researchers to undertake this work within the setting and if they would be able to complete the task successfully. However any fears proved groundless and despite some of the practical difficulties associated with the work, outlined in the field work diary, their participation in the pilot was successful. Any development of the syringe markers and other related research or evaluation in NEX settings should incorporate, develop and extend the role of peer researchers.

5.4 Evaluation Limitations.

As noted in Chapter 4, of the 177 respondents, 132 had been supplied with markers during the supply phase of the pilot and 83 reported that they had used them. The questionnaire focussed on this group of 83. The questionnaire was originally designed in collaboration with the members of the SUIG who would be administering this in the pharmacy NEXs. The initial priorities included targeting those who had used the markers in the limited time frame available, minimising the length and complexity of the questionnaire partly based on the inexperience of the SUIG members and to minimise any potential disruption within the pharmacy. The piloting of the questionnaire was undertaken with members of the group. On reflection, it would have been more productive to have piloted the questionnaire by the peer researchers in one of the pilot sites at the end of the supply phase. This would have indicated at an earlier stage that the peer researchers could cope with the practicalities of recruitment and questionnaire administration in this busy setting without adversely affecting the

routine activities. This may have given the opportunity to extend the questionnaire and to use visual cues in questions and on the instruction card as described in the recommendations from the field work diary discussed in Chapter 3.

Further work needs to be undertaken with the 37%, (n=49) of the 132 who were supplied with the syringe markers to trial but did not use them, as this may potentially indicate alternative interventions that may be more relevant for them and their injecting practices. However this does not invalidate the positive responses from those who did use the markers. Due to the large numbers of IDUs and the diverse range of injecting behaviours it is unlikely that one option for syringe identification would ever be sufficient as the sole means of identification. The majority of the 132 respondents who had been supplied with the markers did report that they used them (n=83, 63%) and 99% of the 83 (n=82) of those who used them indicated that they would use them again if they continued to be supplied. This would appear to support syringe marker supply as a useful and practical option that should be extended and made more widely available. This is particularly relevant where, due to the high estimated numbers of IDUs and sharing practices, any intervention that has the potential to be used by 63% of the population gives an opportunity to have a positive impact in promoting safer injecting practices for large numbers of IDUs covering multiple injecting episodes. Although information is not available from the 37% who were supplied with, but did not use the markers, this should not detract from the fact that this appears to be an intervention with potential positive benefits at minimal additional costs to the service.

In this evaluation study there was no scope for direct observation of injecting episodes that would have confirmed or refuted the evidence from the questionnaire. Using this

form of method triangulation would assist in establishing more definitive conclusions on the use of syringe markers in real life injecting episodes. The evaluation results could have been corroborated if it had been possible to provide independent evidence of actual use. For example, confirmatory evidence may have been present if there had been residual evidence of syringe marker use on injecting equipment that was returned for safe disposal. To comply with good practice procedures and work place health and safety regulations, the returned individual disposal bins are sealed and the contents are not normally visible. This is an area that should be explored for ongoing monitoring and for any extension of this study.

5.5 Role of the Practitioner-Researcher in the Syringe Marker Evaluation

Dyson and Brown have shown that there are a number of issues for a health care researcher who has a dual role as a practitioner leading to the requirements of the research causing the practitioner to be placed from the beginning in what they describe as a “dilemmatic position” (2006:130). They highlight the expectations that are placed on healthcare workers to participate and to build evidence based research into routine professional practice and the associated problems that this causes. They highlight the fact that critical reflection is essential for the health care practitioner to help inform the structure of all phases of any research (Dyson and Brown, 2006). In this evaluation of the syringe markers there was a dual role for the researcher in managing the service and in designing the intervention and conducting the evaluation. The ethical dilemmas and the potential conflict between undertaking an academic research evaluation of a service that the researcher was responsible for managing were discussed in Chapter 2. The role of the researcher in this evaluation was one of

“Practitioner-Researcher”. This has been defined as some-one who “holds down a job in some particular area and is, at the same time, involved in carrying out systematic enquiry which is of relevance to the job” (Robson, 2002:534). Robson discussed the advantages and disadvantages associated with this type of dual role all of which were relevant to the syringe marker evaluation. Disadvantages were shown to include “time, lack of expertise, lack of confidence and “insider” problems” (Robson, 2002:535). The research role for any practitioner is always the secondary role and this constitutes the main barrier to conducting any form of research. The advantages have been described as ““Insider” opportunities, “Practitioner” opportunities and “Practitioner-researcher” synergy” (Robson, 2002:535). This evaluation demonstrates the practical application of the advantages and disadvantages listed by Robson. In this evaluation the role advantages of the practitioner-researcher were in gaining access to the research sites, obtaining funding and in the inherent professional insights that assisted the design and conduct of the study as evaluation research. The disadvantages mentioned were countered by combining academic study and support with the professional practitioner role where the aim of the additional academic study was to develop the “ability to relate academic knowledge to professional interests” (University of Stirling, 2005:17).

5.6 Concluding Observations.

The primary purpose of any evaluation is to assess the impact of an intervention or social programme. According to Clark, evaluation is a type of applied research which should contribute relevant information to enable those people in decision making positions to take these future decisions with the benefit of the evidence from the

evaluation (Clark, 2009). Using peer researchers in the role described in this evaluation was successful and should be promoted and extended. For the syringe marker evaluation the initial aims were partly achieved. The results indicate that for IDUs this is an acceptable means of identifying individual injecting equipment and that in practice it was feasible to make this supply through the community pharmacy NEX network. Whether this then leads to a decrease in sharing of equipment and a subsequent decrease in HCV transmission is an area that needs further work before any definitive conclusions could be drawn. Discussion of the findings of the evaluation has indicated a number of areas of further work, including the use of proxy measures that could be used to investigate the impact of the markers on levels of sharing and of newly acquired HCV infections and the need to investigate further the group who did not use the markers with a view to design of alternative methods and strategies to help prevent inadvertent sharing.

There are a number of difficult methodological challenges that exist when attempting to evaluate an intervention in an existing service setting. The NEX setting sets natural boundaries and limits the control and manipulation of the intervention and the participants that can be exercised by the researcher. The incorporation of peer researchers in the design was a factor that contributed positively to the overall evaluation and with hindsight the role of the peer researchers could have been extended and possibly incorporated at an earlier stage in the design. If the proposed areas of further work previously outlined were undertaken this would make it possible to enhance the validity of the initial results and the credibility of the conclusions that could be drawn.

For the widespread expansion of syringe markers or any other innovative interventions in NEXs it is essential that changes to policy and practices should be made on the basis of evidence. It is not always a straightforward process to embed evidence into practice as, for example, there may be competing priorities for limited funds. However the collection of evidence is a vital tool and it has been shown that it is essential that strategies are put in place to enable evidence to be integrated into any new practice developments or interventions (Nutley, Walter and Davies, 2003).

The wider political, social and legal policies that are required to tackle drug use prevention, treatment and recovery are outside the scope of this study as it is restricted to the investigation of one specific health related harm reduction intervention. However there is a continuing pressing need to minimise the potential permanent health harms that injecting drug use can cause for individuals and for the wider community. There is an important role for practitioners and health care professionals to act within the scope of their professional responsibilities and boundaries to minimise the harms to individuals. This evaluation has demonstrated that there is likely to be a useful role for the wider distribution of syringe markers in reducing some of the health harms associated with injecting drug use by providing a potential means of reducing the accidental sharing of injecting equipment. Ideally the role of the health care professional in the context of syringe marker supply is summed up by the following quotation from Testa.

“For many people with drug addictions, it is the development of a relationship with someone in the health care field who cares foremost about keeping them as safe as possible—no matter what type of behaviour they are engaging in – that ultimately leads to recovery” (2009:10).

References.

Aceijas C and Rhodes T. 2007. Global Estimates of Prevalence of HCV Infection Among Injecting Drug Users. *The International Journal of Drug Policy*. 18, 352-358.

Advisory Council on the Misuse of Drugs (ACMD). 1988. *AIDS and Drug Misuse: Part One*. London. Department of Health and Social Security.

Advisory Council on the Misuse of Drugs (ACMD). 1993. *AIDS and Drug Misuse Update*. London. Department of Health and Social Security.

Advisory Council on the Misuse of Drugs (ACMD). 2009. *The Primary Prevention of Hepatitis C Among Injecting Drug Users*. London. Home Office.

Alexander B. 2000. The Globalization of Addiction. *Addiction Research*. 8, 6, 501-526.

Alonso Y. 2004. The Biopsychosocial Model in Medical Research: The Evolution of the Health Concept over the Last Two Decades. *Patient Education and Counselling*. 53, 239-244.

Arnstein S. 1969. A Ladder of Citizen Participation. *Journal of the American Institute of Planners*. 35, 216-224.

Ashton M. 2003. Hepatitis C and Needle Exchange. *Drug and Alcohol Findings* 8, 4-7

Battjes R J and Pickens R W (eds). 1988. *Needle Sharing Among Intravenous Drug Abusers: National and International Perspectives*. National Institute on Drug Abuse (NIDA) Research Monograph 80. United States. Department of Health and Human Services.

Becker J and Duffy C. 2002. *Women Drug Users and Drugs Service Provision: Service-level Responses to Engagement and Retention*. DPAS Briefing Paper 17, London. Home Office..

Beresford P. 2002. User Involvement in Research and Evaluation: Liberation or Regulation ?. *Social Policy and Society*. 1, 95-105.

Berridge V. 1999. *Opium and the People. Opiate Use and Drug Control Policy in Nineteenth and Early Twentieth Century England*. London. Free Association Books.

Beynon C, Taylor A, Allen E and Bellis M, 2010. Visual Versus Written Cues: A Comparison of Drug Injectors' Responses. Have Surveys Using the Written Word Underestimated Risk Behaviours for Hepatitis C ? *Substance Use and Misuse*. 45, 1491-1508.

Blackburn S. 2008. The Oxford Dictionary of Philosophy. *Oxford Reference Online*. Available at:
<http://www.oxfordreference.com/views/ENTRY.html?subview=Main&entry=t98.e2466> (Accessed 31st January 2012).

Blaikie N. 2003. *Analyzing Quantitative Data*. London. Sage Publications.

Boote J, Telford R and Cooper C. 2002. Consumer Involvement in Health Research: A Review and Research Agenda. *Health Policy*. 61, 2, 213-236.

Boote J, Barber R and Cooper C. 2006. Principles and Indicators of Successful Consumer Involvement in NHS Research: Results of a Delphi Study and Sub-group Analysis. *Health Policy*. 75, 3, 280-297.

Booth A. 2009. Research or Evaluation? Does it Matter? *Health Information and Libraries Journal*. 26, 3, 255-258.

Briggs D, Rhodes T, Marks D, Kimber J, Holloway G and Jones S. 2009. Injecting Drug Use and Unstable Housing: Scope for Structural Interventions in Harm Reduction. *Drugs: Education, Prevention and Policy*. 16, 436-450.

Brownlie J, Anderson S and Ormston R. 2006. *Children as Researchers*, Edinburgh. Scottish Executive Education Department. Available at:
<http://www.scotland.gov.uk/Publications/2006/06/SprChar/Q/Page/3>. (Accessed 19th July 2010)

Bruce N, Pope D and Stanistreet D. 2008. *Quantitative Methods for Health Research. A Practical Interactive Guide to Epidemiology and Statistics*. England. J Wiley and sons Ltd.

Bryman A. 2004. *Social Research Methods, 2nd Edition*. Oxford. Oxford University Press.

Buchanan D, Shaw S, Ford A and Singer M. 2003. Empirical Science Meets Moral Panic : An Analysis of the Politics of Needle Exchange. *Journal of Public Health Policy*. 24, 427-444.

Bucknell P and Ghodse H. 1989. *Misuse of Drugs and Drug Trafficking Offences Act*. Supplement Number 3. Waterlow Publishers.

Bulmer M. 1986. *Social Science and Social Policy*. London. Allen and Unwin.

Butcher L. 2005. No home, No job. *Care and Health Magazine*. 16, 30-31.

Cameron, J, Gilchrist G and Roberts K. 2004. Needle Exchange Services: A Profile of Service Users in Community Pharmacies and other Settings. *International Journal of Pharmacy Practice*. 12, 211-215.

Campbell J, 2011. *Personal Communication*. Development and Improvement Manager, Injecting Equipment Provision, NHS Greater Glasgow and Clyde.

Cayton, H and Hanley B. 2001. *Improving Research Through Consumer Involvement*. In: Baker M and Kirk S (eds) *Research & Development for the NHS*. Oxford. Radcliffe Medical Press.

Clark A. 2005. *Evaluation Research: An Introduction to Principles, Methods and Practice*. London. Sage Publications.

Cohen S. 1980. *Folk Devils and Moral Panics: The Creation of the Mods and Rockers*. Oxford. Martin Robertson.

Commonwealth of Australia. 2002. *Return on Investment in Needle and Syringe Programs in Australia. Summary Report*. Publication Number 3123. Australia. Commonwealth Department of Health and Ageing.

Cooper D and Schindler P (eds). 2003. *Business Research Methods*. 8th edition. International Edition. McGraw Hill.

Coupland H, Maher L, Enriquez J, Le J, Pacheco V, Pham A, Carroll C, Cheguelman G, Freeman D, Robinson D and Smith K. 2005. Clients or Colleagues? Reflections of the Process of Participatory Action Research with Young Injecting Drug Users. *International Journal of Drug Policy*. 16, 3, 191-198.

Creswell J. 2003. *Research Design: Qualitative, Quantitative and Mixed Method Approaches*. London. Sage.

Crofts N, Aitken C K and Kalder J M. 1999. The Force of Numbers: Why Hepatitis C is Spreading Among Australian Injecting Drug Users while HIV is Not. *The Medical Journal of Australia*. 170, 5, 220-221.

Crombag HS, Bossert JM, Koya E and Shaham Y. 2008. Context-induced Relapse to Drug Seeking: A Review. *Philosophical Transactions Royal Society London Biological Sciences (Philos Trans R Soc Lond B Biol Sci)* 363, 1507, 3233-3243.

Currie J. 2007. *Personal Communication*. Service User Group Co-ordinator. Scottish Drugs Forum (SDF).

Darke S, Ross J and Kaye S. 2001. Physical Injecting Sites Among Injecting Drug Users in Sydney, Australia. *Drug and Alcohol Dependence*, 62, 77-82.

Department of Health. 1996. *The Task Force to Review Services for Drug Misusers. Report of an Independent Review of Drug Treatment Services in England*. London. Department of Health. HMSO.

Department of Health. 2001. *Governance Arrangements for NHS Research Ethics Committees*. London. Department of Health. HMSO. Available at:

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/document_s/digitalasset/dh_4058609.pdf

(Accessed 13th March 2010)

Department of Health and Social Security. 1983. *NHS Management Inquiry (The Griffiths Report)*. London. Department of Health and Social Security. HMSO
Derricott J, Preston A and Hunt N. 1999. *The Safer Injecting Briefing. An Easy to use Comprehensive Reference Guide to Promoting Safer Injecting*. Liverpool. HIT.

Downie R S and Calman K (Eds).1994. *Healthy Respect*. Oxford: Oxford Medical Publications.

Drug Misuse Statistics Scotland. 2009. Annual Report. Common Services Agency. Edinburgh. Information Services Division (ISD) Publications. Available at: www.drugmisuse.isdscotland.org
(Accessed February 7th 2010)

Drug Trafficking Offences Act 1986. Available at:
http://www.opsi.gov.uk/acts/acts1986/pdf/ukpga_19860032_en.pdf
(Accessed 11th October 2009)

Dyson S and Brown B. 2006. *Social Theory and Applied Health Research*. England. Open University Press.

Eaves C. 2004. Heroin Use Among Female Adolescents: The Role of Partner Influence in Path Initiation and Route of Administration. *American Journal of Drug and Alcohol Abuse*. 30, 1, 21-38.

Edwards R and Graber G (eds). 1988. *Bio-Ethics*. United States of America. Harcourt Brace Jovanovich, Inc.

Elliott E, Watson AJ and Harries U. 2002. Harnessing Expertise: Involving Peer Interviewers in Qualitative Research with Hard to Reach Populations. *Health Expectations*. 5, 172-178.

Engel GL. 1977. The Need for a New Medical Model: A Challenge for Biomedicine. *Science*. 196, 129-136.

Ettore E. 2004. Revisioning Women and Drug Use: Gender Sensitivity, Embodiment and Reducing Harm. *International Journal of Drug Policy*. 15, 327-335.

Everitt A and Hardiker P. 1996. *Evaluating for Good Practice*. London, MacMillan.

Exchange Supplies: Tools for Harm Reduction. Available at :
http://www.exchangesupplies.org/shopdisp_A903.php (Accessed 21st June, 2010).

Farid B. 1988. AIDS and Drug Addiction Needle Exchange Schemes: A Step in the Dark. *Journal of the Royal Society of Medicine*. 81, 375-376.

Garden J, Roberts K, Taylor A and Robinson D. 2003. *Evaluation of the Provision of Single Use Citric Acid Sachets to Injecting Drug Users*, Effective Interventions Unit. Edinburgh, Scottish Executive.

Garner R, 2005. *The Joy of Stats. A Short Guide to Introductory Statistics in the Social Sciences*. Canada, Broadview Press.

Ghodse H, Treganza G and Li M. 1987. Effect of Fear of AIDS on Sharing of Injecting Equipment Among Drug Abusers. *British Medical Journal*. 295, 698-699.

Gourlay Y, 2008. *Personal Communication*. Lead Anti Microbial Pharmacist, NHS Greater Glasgow and Clyde.

Gilbert N. 2003. *Researching Social Life*. London. Sage Publications.

Glasby J and Beresford P. 2006. Who Knows Best ? Evidence-based Practice and the Service User Contribution. *Critical Social Policy*. 26, 1, 268-284.

Godfrey M. 2004. More than "Involvement". How Commissioning User Interviewers in the Research Process Begins to Change the Balance of Power. *Practice*. 16, 3, 223-231.

Goldberg D, Burns S, Taylor A, Cameron D, Hargreaves D and Hutchison S. 2001. Trends in HCV Prevalence Among Injecting Drug Users in Glasgow and Edinburgh During the Era of Needle/Syringe Exchange. *Scandinavian Journal of Infectious Disease*. 33, 457-461.

Gossop M, Griffiths P, Powis B and Williamson S. 1997. Continuing Drug Risk Behaviour: Shared Use of Injecting Paraphernalia among London Heroin Injectors. *Aids Care*. 9, 6, 651-660.

Greater Glasgow Health Board. 1996. *Community Care in Glasgow: A Joint Planning Strategy for HIV and AIDs in the Greater Glasgow Health Board Area 1996-1999*. Glasgow. Greater Glasgow Health Board.

Green J. 2006. *Personal Communication*. Senior Health and Safety Manager. Chair of National Waste Management Steering Group for the NHS. NHS Greater Glasgow and Clyde.

Greene JC, Benjamin L and Goodyear L. 2001. The Merits of Mixing Methods in Evaluation. *Evaluation*. 7, 1, 25-44.

Griesbach D, Abdulrahim D, Gordon D and Dowell K. 2006. *Needle Exchange Provision in Scotland. A Report of the National Needle Exchange Survey*. Edinburgh. Scottish Executive. <http://www.scotland.gov.uk/Publications/2006/06/16110001/0> (Accessed 13th Sept 2009)

Griffiths P, Gossop M, Powis B and Strang J. 1993. Reaching Hidden Populations of Drug Users by Privileged Access Interviewers: Methodological and Practical Issues. *Addiction*. 88, 1617-1626.

Gruer L. 2001. *A Review of Needle Exchange in Greater Glasgow*. Glasgow. Prepared by a Short Life Working Group for the City of Glasgow Addictions Planning and Implementation Group on behalf of the Greater Glasgow Drug Action Team.

Grund J-P C, Friedman S R, Stern L S, Jose B, Neaigus A, Curtis R and Des Jarlais D C. 1996. Syringe-mediated Drug Sharing among Injecting Drug Users: Patterns, Social Context and Implications for Transmissions of Blood-Borne Pathogens. *Social Science and Medicine*, 42, 691-703.

Grund J-P, Kaplan C, Adriaans N F P and Blanken P. 1991. Drug Sharing and HIV Transmission Risks: The Practice of “Front-loading” in the Dutch Injecting Drug User Population. *Journal of Psychoactive Drugs*, 23, 1-10.

Hall S, Critcher C, Jefferson T, Clarke J, and Roberts B. 1978. *Policing the Crisis: Mugging, The State and Law and Order*. London, MacMillan.

Handy C. 1993. *Understanding Organisations*. London. Penguin.

Hankins C. 2008. Sex, Drugs, and Gender? High Time for Lived Experience to Inform Action. *International Journal of Drug Policy*, 19, 2, 95-96.

Hanley B, Bradburn J, Barnes M, Evans C, Goodare H, Kelson M, Oliver S, Thomas S and Wallcraft J. 2004. *Involving the Public in Health and Social Care Research: Briefing Notes for Researchers*. Eastleigh. Involve. Available at: www.invo.org.uk (Accessed 25th April 2010)

Hay G, Gannon M, Casey J and McKeganey N. 2009. *Estimating the National and Local Prevalence of Problem Drug Use in Scotland*. Edinburgh. ISD Scotland.

Haynes P. 2003. *Managing Complexity in the Public Services*. Maidenhead. Open University Press.

Health Protection Agency, Health Protection Scotland, National Public Health Service for Wales, CDSC Northern Ireland, CRDHB. 2009. *Shooting Up: Infections Among Injecting Drug Users in the United Kingdom 2008*. London: Health Protection Agency.

Health Protection Scotland website. *Blood Borne Viruses and Sexually Transmitted Diseases*. Available at: <http://www.hps.scot.nhs.uk/bbvsti/hepatitisc.aspx> (Accessed 27th April 2010)

Health Protection Scotland website. *Hepatitis C Diagnosis Database*. Available at: <http://www.hps.scot.nhs.uk/bbvsti/ssdetail.aspx?id=33> (Accessed 23rd Feb 2011)

Hedrich D, Pirona A and Wiessing L, 2008. From Margin to Mainstream: The Evolution of Harm Reduction Responses to Problem Drug Use in Europe. *Drugs: Education, Prevention and Policy*. 15, 6, 503-517.

Hope V, Kimber J, Vickerman P, Hickman M and Ncube F. 2008. Frequency, Factors and Costs Associated with Injecting Site Infections: Findings From a National Multi-Site Survey of Injecting Drug Users in England. *BMC Infectious Diseases*. 8, 120, 1-8.

Hunter G, Stimson G, Jones S, Judd A and Hickman M. 1998. *Survey of Prevalence of Sharing by Injecting Drug Users not in Contact with Services*. An Independent Study Carried out on Behalf of the Department of Health, The Centre for Research on Drugs and Health Behaviour, Imperial College, London.

Hunter G, Stimson G, Judd A, Jones S and Hickman M. 2000. Measuring Injecting Risk Behaviour in the Second Decade of Harm Reduction: A Survey of Injecting Drug Users in England. *Addiction*. 95, 9, 1351-1361.

Hutchison S, Bird S, Taylor A, and Goldberg D. 2006.. Modelling the Spread of Hepatitis C Virus Infection Among Injecting Drug Users in Glasgow: Implications for Prevention. *International Journal of Drug Policy*. 17, 211-221.

Hutchison S, Roy K, Wadd S, Bird S, Taylor A, Anderson E, Shaw L, Codere G and Goldberg D. 2006. Hepatitis C Virus Infection in Scotland: Epidemiological Review and Public Health Challenges. *Scottish Medical Journal*. 51, 2, 8-15.

Inciardi J and Harrison L. 2000. *Harm Reduction: National and International Perspectives*. London. Sage Publications.

International Harm Reduction Association (IHRA). 2009. *What is Harm Reduction ? A Position Statement from the International Harm Reduction Association*. London. Available at: <http://www.ihra.net/Whatisharmreduction> (Accessed 21st Nov 2010).

INVOLVE. Available at: <http://www.invo.org.uk/>

INVOLVE (2003) Available at: http://www.invo.org.uk/About_Us.asp (Accessed 20th Dec 2010).

INVOLVE (2004). *Involving Marginalised and Vulnerable People in Research: A Consultation Document*. Available at: <http://www.invo.org.uk/> (Accessed 20th Dec 2010)

Jason L A, Ferrari J R, Davis M I and Olson B D (eds). 2006. *Creating Communities for Addiction Recovery. The Oxford House Model*. London. Haworth Press.

Johnson T. Dec 2008 / Jan 2009. Public Health Leaders Hope for Renewed Health Agenda Under New Administration:Health Outlook. *The Nation's Health, American Public Health Association*. 38, 1-29.

Jones L, Pickering L, Sumnall H, McVeigh J and Bellis M. 2008. *A Review of the Effectiveness and Cost-effectiveness of Needle and Syringe Programmes for Injecting Drug Users*. Centre for Public Health. Liverpool John Moores University. October 2008.

Kemshall H and Littlechild R (eds). 2000. *User Involvement and Participation in Social Care. Research Informing Practice*. London. Kingsley.

Kessels R, 2003. Patients' Memory for Medical Information. *Journal of the Royal Society of Medicine*. 96, 219-222.

Koester S. 1996. The Process of Drug Injection: Applying Ethnography to the Study of HIV Risk among IDUs, in Rhodes T and Hartnoll (eds). *AIDS, Drugs and Prevention*. London. Routledge.

Koester S, Booth R and Wiebel W. 1990. The Risk of HIV Transmission from Sharing Water, Drug Mixing Containers and Cotton Filters among Intravenous Drug Users. *International Journal on Drug Policy*, 1, 28-30.

Last J M (Ed), 2007. Joint United Nations Programme on HIV/AIDS. A Dictionary of Public Health. Oxford University Press. *Oxford Reference Online*.. Available at <http://www.oxfordreference.com/views/ENTRY.html?subview=Main&entry=t235.e2434> (Accessed 16th Jan 2011).

Lowes L and Hulatt (eds). 2005. *Involving Service Users in Health and Social Care Research*. Oxfordshire. Routledge.

Loxley W. 2000. Doing the Possible: Harm Reduction, Injecting Drug use and Blood Borne Viral Infections in Australia. *International Journal of Drug Policy*. 11, 407-416.

Lurie P and Drucker E. 1997. An Opportunity Lost: HIV Infections Associated with the Lack of a Needle-Exchange Programme in the United States. *The Lancet*. 349, 604-608.

McKeganey N and Barnard M, 1992. *AIDS, Drugs and Sexual Risk. Lives in the Balance*. Buckingham. Open University Press.

McLaughlin H. 2009. *Service User Research in Health and Social Care*. London. Sage Publications.

Miller D C and Salkind N J (eds). 2002. *Handbook of Research Design and Social Measurement*. 6th Edition. London. Sage Publications.

Miller P. 2009. Safe Using Messages May Not be Enough to Promote Behaviour Change Amongst Injecting Drug Users who are Ambivalent or Indifferent Towards Death. *Harm Reduction Journal*. 6.18. Available at: <http://www.harmreductionjournal.com/content/6/1/18> (Accessed 8th May 2011).

Minogue V and Girdlestone J. 2010. Building Capacity for Service User and Carer Involvement in Research. The Implications and Impact of Best Research for Best Health. *International Journal of Health Care Quality Assurance*. 23, 4, 422-435.

Misak C (ed). 1999. *Pragmatism*. Canada. University of Canada Press.

Misuse of Drugs (Amendment) (No2) Regulations 2003. Statutory Instrument 1653. Available at : http://www.opsi.gov.uk/si/si2003/uksi_20031653_en.pdf (Accessed 29th Nov 2009).

Morrison A, Duff L, Taylor A, Sherval J, Ahmed S and Haw S. 2002. *Hepatitis C: Risks and Prevention Strategies in Injecting Drug Users. Research Review*. Effective Interventions Unit. Edinburgh. Scottish Executive.

Morrow E, Ross F, Grocott P and Bennett J. 2010. A Model and Measure for Quality Service User Involvement in Health Research. *International Journal of Consumer Studies*. 34,532-539.

Moser CA and Kalton G. 1989. *Survey Methods in Social Investigation*. England. Gower Publishing.

National Health Service Reform (Scotland) Act. 2004. HMSO. Available at: http://www.opsi.gov/legislation/scotland/acts2004/pdf/asp_20040007_en.pdf (Accessed 28th Feb 2010)

National Institute for Health and Clinical Excellence (NICE). 2002. Principles for Best Practice in Clinical Audit. Abingdon. Radcliffe Medical Press. Available at: <http://www.nice.org.uk/media/796/23/BestPracticeClinicalAudit.pdf> (Accessed 26th March 2010)

National Institute for Health and Clinical Excellence (NICE). 2009. Needle and Syringe Programmes: Providing People who Inject Drugs with Injecting Equipment. *Public Health Guidance 18*. Available at: <http://www.nice.org.uk/Guidance/PH18>

National Patient Safety Agency. 2006. *Differentiating Audit, Service Evaluation and Research*. London. Department of Health. Available at: <http://www.nres.npsa.nhs.uk/applications/guidance/research-guidance/?entryid62=66988> (Accessed 26th March 2010)

National Treatment Agency for Substance Misuse. 2007. *The NTA's 2005 Survey of Needle Exchanges in England*. London. National Treatment Agency for Substance Misuse.

Needle Exchange Surveillance Initiative (NESI). 2010. *Prevalence of HCV and Injecting Risk Behaviours among Injecting Drug Users attending Needle Exchanges in Scotland, 2008/2009*. University of the West of Scotland, Health Protection Scotland and West of Scotland Virology Centre. University of the West of Scotland. Available at: <http://www.hepcscotland.co.uk/media/50084/nesi-report-08-09.pdf> (Accessed 24th August 2011)

Nutley S, Walter I and Davies HTO. 2003. From Knowing to Doing. A Framework for Understanding the Evidence-Into-Practice Agenda. *Evaluation*. 9, 2, 125-148.

Olszewski D, Giraudon I, Hedrich D and Montanari L. 2009. Thematic Paper- *Women's Voices. Experiences and Perceptions of Women Who Face Drug-related Problems in Europe*. European Monitoring Centre for Drugs and Drug Addiction (EMCDDA). Luxembourg.

Oxford Medical Dictionary. Oxford University Press. 2007. *Oxford Reference Online*. Available at:
<http://www.oxfordreference.com/views/ENTRY.html?subview=Main&entry=t60.e236> (Accessed 20 April 2010)

Patient Focus and Public Involvement, 2001. Guidance. Edinburgh. Scottish Executive. Available at:
<http://www.scotland.gov.uk/Resource/Doc/158744/0043087.pdf> (Accessed 11th Dec 2010)

Patton M Q. 1981. *Creative Evaluation*. London .Sage Publications.

Pauly B, Goldstone I, McCall J, Gold F and Payne S. 2007. The Ethical, Legal and Social Context of Harm Reduction. *Canadian Nurse*, 103, 8, 19-23.

Piot P and Cherney S. 2007. "AIDS: The Great Killers". The Oxford Companion to Medicine. Stephen Lock, John M. Last, and George Dunea (eds). Oxford University Press . *Oxford Reference Online*. Available at:
<http://www.oxfordreference.com/views/ENTRY.html?subview=Main&entry=t185.e14> (Accessed 20th April 2010)

Rhodes T. 1997. Risk Theory in Epidemic Times: Sex, Drugs and the Social Organisation of "Risk Behaviour". *Sociology of Health and Illness*. 19, 2, 208-227.

Rhodes T, Greenwood G and Robertson K. (eds). 2001. *Injecting Drug Use, Risk Behaviour and Qualitative Research in the Time of AIDS*. European Monitoring Centre for Drugs and Drug Addiction (EMCDDA).

Ritter A J, Fry C L and Swan A. 2003. The Ethics of Reimbursing Injecting Drug Users for Public Health Research Interviews: What Price are we Prepared to Pay? *International Journal of Drug Policy*. 14, 1, 1-3.

Roberts K. 2009. The UKs Paraphernalia Laws and Impact on Cocaine and Crack Injectors. *Pharmacy Misuse Advisory Group, PharMAGazine*. 10, 1, 2-3.

Roberts K. 2004. *Personal Communication*. Member of Advisory Council on the Misuse of Drugs (ACMD). Needle Exchange Coordinator NHS Greater Glasgow 2003- 2005.

Roberts K. 2007. *Personal Communication*. Member of Advisory Council on the Misuse of Drugs (ACMD). Needle Exchange Coordinator NHS Greater Glasgow 2003- 2005.

Roberts K, Gilchrist G, Cameron J and Ahmed S. 2002. *Evaluation of the Greater Glasgow Pharmacy Needle Exchange Scheme, 1997-2002*. Effective Interventions Unit. Edinburgh. Scottish Executive.

Roberts K and Hunter C. 2004. A Comprehensive System of Pharmaceutical Care for Drug Misusers. *Harm Reduction Journal*. 1, 6.

Robertson J R, Bucknall A B V, Welsby P D, Roberts J S K, Inglis J M, Peutherer J F and Brettle R P. 1986. Epidemic of AIDS-related Virus (HTLV-111/LAV) Infection among Intravenous Drug Abusers. *British Medical Journal*. 292, 527-529.

Robson C. 2002. *Real World Research*. Oxford. Blackwell.

Rossi P H and Wright J D, 2002. Evaluation Research: An Assessment in Miller D C and Salkind N J (eds),. *Handbook of Research Design and Social Measurement*. 6th Edition. London. Sage Publications.

Royal Pharmaceutical Society of Great Britain (RPSGB). 1982. Council Statement: Sale of Syringes. *Pharmaceutical Journal*. 228, 692.

Royal Pharmaceutical Society of Great Britain (RPSGB). 1986. Council Statement: Sale of Hypodermic Syringes and Needles. *Pharmaceutical Journal*. 236, 205.

Royal Pharmaceutical Society of Great Britain (RPSGB). 2005. Medicines Ethics and Practice. Guidelines for Pharmacists. London. Pharmaceutical Press.

Royal Pharmaceutical Society of Great Britain (RPSGB), 2010. *Code of Ethics for Pharmacists and Pharmacy Technicians*. London. Pharmaceutical Press.

Scott J, 2008. *Safety, Risks and Outcomes from the use of Injecting Paraphernalia*. Edinburgh. Scottish Government Social Research.

Scott J and Marshall G. 2009. Identity. Oxford. Oxford University Press. *Oxford Reference Online*. Available at: <http://www.oxfordreference.com/views/ENTRY.html?subview=Main&entry=t88.e1061> (Accessed 14th August 2010)

Scottish Drug Misuse Database (SDMD). Available at: <http://www.drugmisuse.isdscotland.org/sdmd/sdmd.htm>

Scottish Executive. 2002. *Needle and Syringe Exchange Schemes*. NHS Health Department Letter (HDL) (2002) 90. Available at: http://www.sehd.scot.nhs.uk/mels/hdl2002_90.pdf (Accessed 2nd Nov 2009)

Scottish Executive. 2006. *Hepatitis C Action Plan for Scotland Phase 1: September 2006-August 2008*. Edinburgh. Scottish Executive.

Scottish Government. 2008. *Hepatitis C Action Plan for Scotland Phase II: May 2008-March 2011*. Edinburgh. Scottish Government.

Scottish Government. 2010. Guidelines for Services Providing Injecting Equipment: Best Practice Recommendations for Commissioners and Injecting Equipment Provision (IEP) Services in Scotland. *Edinburgh. Health Department*. Available at: <http://www.scotland.gov.uk/Publications/2010/03/29165055/2> (Accessed 25th September 2010)

Scottish Home and Health Department. 1986. HIV Infection in Scotland. Report of the Scottish Committee on HIV Infection and Intravenous Drug Misuse. Edinburgh. SHHD

Scottish Home and Health Department. 1988. AIDS and Drug Misuse: Sale of Injecting Equipment by Retail Pharmacies. NHS Circular No 1988(GEN) 19. Edinburgh. SHHD.

Shannon K, Rusch M, Shoveller J, Alexson D, Gibson K and Tyndall M. 2008. Mapping Violence and Policing as an Environmental-structural Barrier to Health Service and Syringe Availability Among Substance-using Women in Street-level Sex Work. *International Journal of Drug Policy*. 19, 2, 140-147.

Sheard L and Tompkins C. 2008. Contradictions and Misperceptions: An Exploration of Injecting Practice, Cleanliness, Risk, and Partnership in the Lives of Women Drug Users. *Qualitative Health Research*, 18, 1536-1547.

Shepard C, Finelli L and Alter M. 2005. Global Epidemiology of Hepatitis C Virus Infection. *The Lancet Infectious Diseases*. 5, 9, 558-567.

Sheridan J, Strang J, Barber N and Glanz A. 1996. Role of the Community Pharmacies in relation to HIV Prevention and Drug Misuse: Findings from the 1995 National Survey in England and Wales. *British Medical Journal* . 313, 272-274.

Shorrocks T. 2003. The History and Operation of Pharmacy Needle Exchanges in Sheridan J and Strang J (eds). *Drug Misuse and Community Pharmacy*. London. Taylor and Francis.

Smith E, Ross F, Donovan S, Manthorpe J, Brearley S, Sitzia J and Beresford P. 2008. Service User Involvement in Nursing, Midwifery and Health Visitor Research: A Review of Evidence and Practice. *International Journal of Nursing Studies*. 45, 2, 298-315.

Smyth B P, Barry J and Keenan E. 2005. Irish Injecting Drug Users and Hepatitis C: The Importance of the Social Context of Injecting. *International Journal of Epidemiology*. 34, 1, 166-172.

Speed S. 1998. The Sharing of Injecting Paraphernalia Among 96 Regular Attenders at Needle-Exchange Schemes in the North West of England; Implications for Local Public Health Policy. *International Journal of Drug Policy*. 9,351-358.

Stimson G. 1995. AIDs and Injecting Drug Use in the United Kingdom, 1987-1993: The Policy Response and the Prevention of the Epidemic. *Social Science Medicine*, 41, 5, 699-716.

Stimson G. 1988. Injecting Equipment Exchange Schemes in England and Scotland in Battjes R and Pickens R (eds). *Needle Sharing Among Intravenous Drug Abusers: National and International Perspectives*. National Institute on Drug Abuse (NIDA) Research Monograph 80. United States. Department of Health and Human Services.

- Stimson G, Allritt L, Dolan K and Donoghoe M. 1988. Syringe Schemes for Drug Users in England and Scotland. *British Medical Journal*, 296, 1717-1719.
- Stone D. 2001. *Policy Paradox; The Art of Political Decision Making*. New York. WW Norton and Co.
- Stopka T, Springer K W, Khoshnood K, Shaw S and Singer M. 2004. Writing about Risk: Use of Daily Diaries in Understanding Drug-User Risk Behaviours. *AIDS and Behaviour*. 8, 1, 73-85.
- Strang J and Gossop M (eds). 2005. *Heroin Addiction and the British System. Treatment and Policy Responses. Volume 2*. London, Routledge.
- Strauss and Corbin. 1990. *Basics of Qualitative Research*. London. Sage.
- Szmukler G. 2009. Service Users in Research and a “Well Ordered Science”. *Journal of Mental Health*. 18, 2, 87-90.
- Taylor A. 1993. *Women Drug Users. An Ethnography of a Female Injecting Community*. Oxford. Clarendon Press.
- Taylor A, Fleming A, Rutherford J and Goldberg D. 2004. *Examining the Injecting Practices of Injecting Drug Users in Scotland*. Effective Interventions Unit. Edinburgh. Scottish Executive.
- Testa M. 2009. Effective Addictions Strategy is Often Overlooked. *Psychiatric News, American Psychiatric Association*. 44, 18, 10.
- Thompson K. 1998. *Moral Panics*. London, Routledge.
- Thorpe I, Quillet L, Hershaw R, Bailsy S, Williams I, Williamson J, Monterroso O and Garfein R. 2002. Risk of Hepatitis C Virus Infection Among Young Adult Injecting Drug Users who Share Injecting Equipment. *American Journal of Epidemiology*. 155, 645-653.
- Tritter J Q and McCallum A. 2006. The Snakes and Ladders of User Involvement: Moving Beyond Arnstein. *Health Policy*. 76, 156-168.
- University of Stirling, 2005. *Doctor of Applied Social Research. Programme Guide 2005-2006*. Department of Applied Social Science.
- Van Haastrecht H. 1997. HIV Infection and Drug Use in the Netherlands: The Course of the Epidemic. *Journal of Drug Issues*. 27, 57-72.
- Vlahov D, Des Jarlais D, Goosby E, Hollinger P, Lurie P, Shriver M and Strathdee S. 2001. Needle Exchange Programs for the Prevention of Human Immunodeficiency Virus Infection: Epidemiology and Policy. *American Journal of Epidemiology*. 154, 12, Supplement S70-S77.
- Webb J. 2007. Pragmatism (Plural) Part 1: Classical Pragmatism and Some Implications for Empirical Inquiry. *Journal of Economic Issues*. XLI, 4, 1063-1086.

White B, Day C and Maher L. 2007. Self Reported Risk Behaviour Among Injecting Drug Users: Self Versus Assisted Questionnaire Completion. *AIDS Care*. 19, 3, 441-447

Whitely S, Ellis R and Broomfield S. 1996. *Health and Social Care Management- A Guide to Self-Development*. London. Arnold.

Wilkinson A, Redman T, Snape E and Marchington M. 1998. *Managing with Total Quality Management: Theory and Practice*. London. MacMillan.

Winter M de and Noom M. 2003. Someone Who Treats You as an Ordinary Human Being...Homeless Youth Examine the Quality of Professional Care. *British Journal of Social Work*. 33, 325-337.

Wodak A and Cooney A. 2005. World Health Organisation Evidence for Action for HIV Prevention, Treatment and Care among Injecting Drug Users. Effectiveness of Sterile Needle and Syringe Programmes. *International Journal of Drug Policy*. 16S, 1, 31-44.

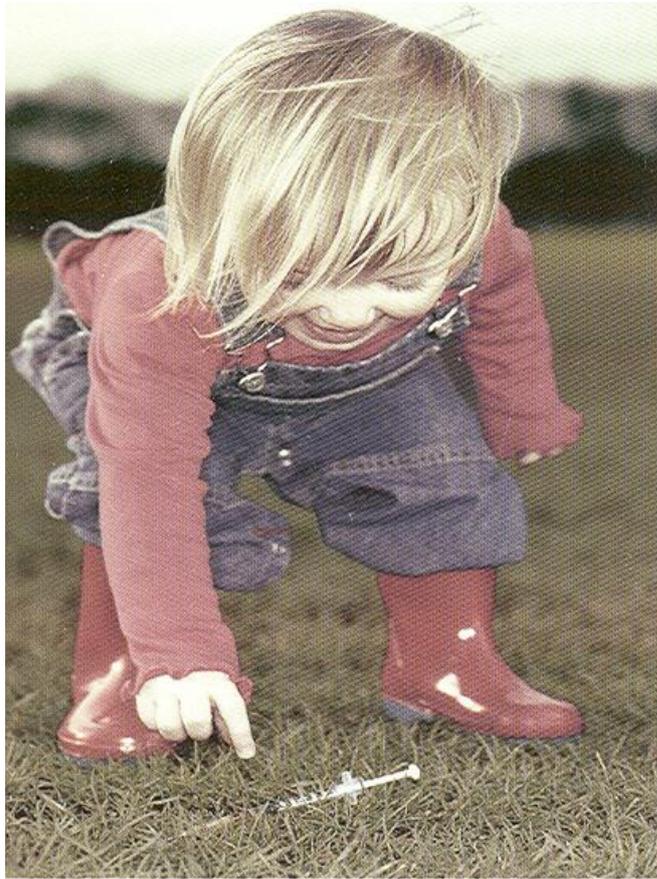
Wright D, Foster C, Amir Z, Elliot J and Wilson R. 2010. Critical Appraisal Guidelines for Assessing the Quality and Impact of User Involvement in Research. *Health Expectations*. 13, 4, 359-368.

Wright N, Millson C and Tompkins C. 2005. *What is the Evidence for the Effectiveness of Interventions to Reduce Hepatitis C Infection and the Associated Morbidity?* Copenhagen, WHO Regional Office for Europe (Health Evidence Network Report). Available at: <http://www.euro.who.int/document/E86159.pdf> (Accessed 8th June 2010).

Young J. 1971. *The Drugtakers: The Social Meaning of Drug Use*. London . Paladin.

Yates R. 2002. A Brief History of British Drug Policy, 1950-2001. *Drugs Education, Prevention and Policy*. 9, 2, 113-124.

Appendix One : Media examples illustrating “moral panic” type reporting.



Community opposition to ‘fixed site’ needle exchange November 1999

Mystery fire hits clinic at centre of needle exchange row

A RUN-DOWN Kirkcaldy clinic being considered for a needle exchange scheme has been damaged in a mystery fire.

Firefighters were called out to Alison Street clinic during the early hours of Saturday when it was discovered that the premises had been broken into.

Although the fire was out by the time they arrived, a room used for chiropody was damaged and other rooms affected by smoke.

Fife police said the blaze was being treated as

suspicious.

A spokesman for Fife Primary Healthcare Trust said initial estimates put the cost of repair at over £12,000, and the clinic is expected to be closed for at least a fortnight.

A Trust spokesman said: “Various pieces of equipment were stolen and one of the rooms at the rear of the building was badly damaged by fire. Other rooms were smoke damaged. Patient records were not affected. This will cause major disruption to local chiropody, speech therapy and baby clinics.”

He explained that alternative temporary

Report by TANYA SCOON

arrangements had been made for baby clinics at the Linktown Community Action Centre in Ramsay Road, and for chiropody at Whyteman’s Brae.

Alternative arrangements for speech therapy services were being planned, possibly for Kirkcaldy Health Centre.

“Criminal damage costs the NHS and other public authorities large sums of money each year. This means that resources have to be diverted from direct patient care that could, and should, be used for treatment, advice and

other NHS services,” said the spokesman.

Fife police added: “We would ask anyone who was in the area at the time who may have seen something to contact Kirkcaldy police station on 416700.”

The clinic attracted controversy recently when Fife Primary Healthcare Trust revealed it was considering using it as a needle exchange facility for the Linktown area of Kirkcaldy.

And it pledged money for additional security measures for the premises.

At a subsequent public meeting, local resi-

dents made it clear that they did not want needle exchange in the community.

Following a meeting of the Linktown Community Action Centre’s management committee on Monday, the following statement was issued: “The committee is seeking a statement from the health trust that it has no plan to form a needle exchange in the Linktown area.

“It is also looking for a statement from Fife Council that it will not allow a needle exchange facility in any Council building anywhere in the Linktown area now or in future.”

Users warned syringe service may be axed

Drug addicts dump 400,000 needles in city

By **John McCann**
Health Reporter

DRUG addicts are dumping more than 400,000 used needles in Glasgow every year.

Needle exchanges in the city gave out more than 1.1million clean needles to injecting drug users to discourage them from sharing them - but fewer than 600,000 were handed back.

The discarded needles have been found outside schools, on people's doorsteps and even in pub toilets, posing a threat to children, householders and bar workers.

Addicts are being warned the needle exchange could be scrapped if they refuse to clean up their act.

The scheme has proved effective in reducing the spread of HIV and Hepatitis C, with a dramatic reduction in needle-sharing by addicts.

But there are concerns too many users drop their needles in the street or in ordinary bins, where they could injure cleansing staff.

The figures emerged in NHS Greater Glasgow's annual report on Aids prevention, presented to the health board this week.

Dr Syed Ahmed, of NHS Greater Glasgow's public health department, said: "The distribution of needles is one reason why HIV and



Aids have not spread as quickly in Glasgow as in other UK cities.

"But many needles are discarded irresponsibly and we are working on ways to reduce this."

He reassured parents, saying: "It is very worrying for people, particularly the parents of children who prick themselves on a needle - but these viruses live for a very short time outside the body.

"There has never been a case of anyone contracting HIV or hepatitis from a discarded needle."

Dr Ahmed warned anyone finding a needle to contact the city council to have it removed.

Carol Hunter, lead pharmacist at the city's needle exchange which operates from 25 chemists, said: "We make it very clear to people they have to return used needles. Our average return rate is 62%."

● Anyone finding a used needle should call the city council on 0141 287 6501, then press button 2.

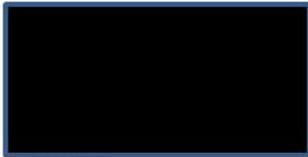
John McCann
eveningtimes.co.uk

Appendix Four: Costs

ITEM	COSTS
Markers (coloured stickers)	£200
Pharmacist Locum fees (Training day)	£600
Lunch (Training day)	£100
Expenses for Service User Group Members (£5 daily)	£430
Stationary / Printing	£50
TOTAL	£1380

Appendix Five: Participation Letter

Direct Line 0141 276 6625
Our Ref JK/AW
Your Ref:
Date 6 September 2006
Email [REDACTED]



Dear Colleague

Thank you for volunteering to participate in the Syringe Marker Pilot. We will be holding a short training session for the pharmacists taking part on **Wednesday 27th September**. This will allow you to understand the need for the pilot and also let you meet the members of the SDF User Involvement Group who will be evaluating the pilot within the pharmacies. It will be an informal session from 9.30-1.00 where you will be provided with lunch and your locum expenses will be reimbursed. It will be held in the **Claremont Centre**, which is Glasgow Addiction Service HQ and will allow you to have a look around and ask any questions about the service.

Could you please confirm with myself or Duncan that you are able to attend on 276 6625.

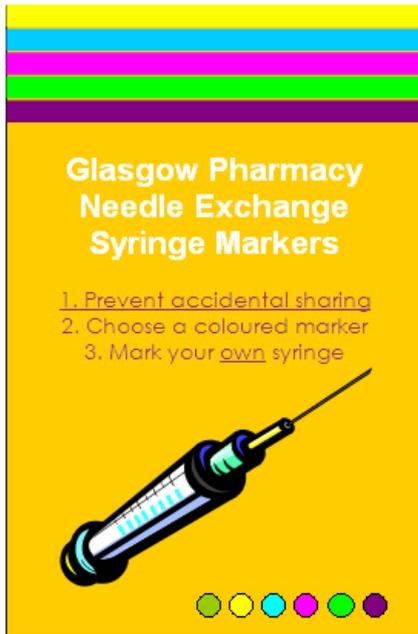
Thank you for your support.

Yours sincerely



Pharmacist
Glasgow Addiction Services

Appendix Six: Markers and Instruction Card



**Glasgow Pharmacy
Needle Exchange
Syringe Markers**

1. Prevent accidental sharing
2. Choose a coloured marker
3. Mark your own syringe



Syringe markers

To protect yourself from contracting a blood-borne virus you should always inject with a clean needle & syringe.



To help you identify your own equipment when other people are injecting at the same time, syringe markers are provided. Please use them **every time** to prevent accidental sharing.



Use markers on barrel, plunger or both

Appendix Seven: Training Presentation

ADDICTION GLASGOW
RECOVERY CARE AND SUPPORT WITHIN THE NHS



Glasgow Pharmacy Needle Exchange Syringe Marker Pilot

Carole Hunter
Lead pharmacist
Carole.hunter@glasgow.gov.uk

ADDICTION GLASGOW
RECOVERY CARE AND SUPPORT WITHIN THE NHS



Background

- The need for a way of identifying syringes was flagged up by the Effective Interventions Unit study by Prof Avril Taylor
- It was also an action point in the Hep C Action Plan for Scotland that was produced by the Scottish Executive.

ADDICTION GLASGOW
RECOVERY CARE AND SUPPORT WITHIN THE NHS



Not Endorsing Re-using!

- The most important part of the project is that we are not encouraging the clients to re-use their syringes
- This project is about stopping **accidental** sharing of needles and syringes in a group situation
- Clients must be encouraged to use a new syringe for every injection

ADDICTION GLASGOW
RECOVERY CARE AND SUPPORT WITHIN THE NHS



The Project so far....

- Exchange supplies produced a plastic identifier which we decided to pilot and compare with the more cost effective sticker option
- The SDF User Involvement Group were involved in the initial meetings and had expressed that they felt the stickers were more versatile and easier to use
- The UIG also stated that many clients were already marking their syringes in less conventional ways ie: scratching and burning

ADDICTION GLASGOW
RECOVERY CARE AND SUPPORT WITHIN THE NHS



Risk Assessment!!!

- As we would be giving these out to clients we had to have them risk assessed and unfortunately the plastic identifiers did not pass as they were found to be a potential choking hazard
- We then had another plastic marker designed which was also felt to be unsafe
- So we are left with the stickers that the UIG suggested in the first place!

ADDICTION GLASGOW
RECOVERY CARE AND SUPPORT WITHIN THE NHS



The Pilot

- Each pharmacy will supply a sheet of stickers to every needle exchange client who attends the pharmacy over the period of 4 weeks
- They will also supply a card which explains what the stickers are for
- The staff should explain to all clients verbally what they are for if it is the first time that they have been given them

GLASGOW
ADDICTION
SERVICES
NHS
Quality Standard
and Code

- Staff should mention that they can be used in a variety of ways
- - placing on the plunger
- - placing on the barrel
- - using more than one sticker on the barrel if two people have the same colour
- - if two people have the same colour then the initials of the users can also be written on the stickers

GLASGOW
ADDICTION
SERVICES
NHS
Quality Standard
and Code

- The stickers have an advantage over the plastic markers due to the fact that they can be used on both 1ml and 2ml syringes.

GLASGOW
ADDICTION
SERVICES
Evaluation
NHS
Quality Standard
and Code

- The evaluation will start on the 5th week and will involve 2 members of the UIG spending time in each pharmacy
- The evaluation will run for 4 weeks
- They will question NEX users about their use of the markers
- Clients are not obliged to take part and we have ethical approval to speak to anyone who is willing to participate.

Syringe Marker Pilot Community Pharmacy Needle Exchanges June 2006

Patient Information

This study has been compiled in order to investigate the effectiveness of markers for the identification of syringes. This information will be used to inform planning and future service developments throughout Glasgow Addiction Services.

This study is voluntary and completely anonymous. It should take no longer than 5-10 minutes. If you do not wish to take part or want to stop at any time please indicate to the interviewer. All data will be used in accordance with the Data Protection Act 1998.

If you have any queries in relation to this survey please contact Carole Hunter, Lead Pharmacist on 0141-276-6612 or Lauren McElroy, Senior Officer Monitoring, Performance & Evaluation 0141-276-6626.

(*Note: Pharmacy Name Recorded
Forms Colour Coded
Gender recorded on front page)



TREATMENT, CARE AND SUPPORT WHERE IT'S NEEDED



Service User Questionnaire

Section One: Personal Information & Injecting Pattern

1. How long have you been injecting?

<1 year ₁ 1-2 yrs ₂ 3-5 yrs ₃ 6-10 yrs ₄ 11 yrs + ₅

2. Which of the following do you inject [most often]?

Stimulant ₁ Steroid ₂ Opiate ₃
E.g. cocaine, coke, crack, E.g. roids, juice E.g. heroin, smack, brown
amphetamines, speed

Other ₄ Please specify _____

3a. Do you currently identify your syringe? Yes ₁ No ₂

3b. If 'yes', how do you identify it?

Burn ₁ Scratch ₂ Mark ₃

Other ₄ Please specify _____

4. In the past year, have you mixed up your syringe with someone else's...

Very Often ₁ Often ₂ Occasionally ₃ Rarely ₄

Never ₅

5. What is your current housing status?

Own tenancy ₁ Staying care of an individual ₂ Hostel ₃

Temporary Furnished Flat ₄ Supported Accommodation ₅

Roofless ₆ Other ₇ Please specify _____

Section Two: Syringe Markers

1. Have you been given markers to trial? Yes ₁ No ₂

IF 'YES' TO THIS, PLEASE PROCEED, IF 'NO' THEN END OF STUDY

2. Did you use the markers? Yes ₁ No ₂

IF 'YES' TO THIS, PLEASE PROCEED, IF 'NO' THEN END OF STUDY

Section Three: The Markers

1. Using the scale below please indicate how useful you felt the markers were as a method of marking your syringe:

₁ ₂ ₃ ₄ ₅
Very Useful Quite Useful No opinion Not very Useful Not at all Useful

2. If the markers were available to you, would you be:

More likely to mark your syringe ₁
Less likely to mark your syringe ₂
No different ₃

3. Would you use the markers again? Yes ₁ No ₂
4. Could they be improved in any way? Yes ₁ No ₂

If 'yes' please explain how:

Section Four: The Card

1. Did you receive a card with your markers?
[Glasgow Pharmacy Needle Exchange Syringe Markers]
Yes ₁ No ₂

2. If you answered 'yes' to the above please answer the following questions, otherwise this is the end of the study.

Using the scale of below please indicate how useful you felt the card was as a guide to using the markers:

₁ ₂ ₃ ₄ ₅
Very Useful Quite Useful No opinion Not very Useful Not at all useful

3. Did the card provide you with all the information needed to use the markers? Yes ₁ No ₂

What in your opinion would improve the current information card:

END OF STUDY

Appendix Nine: Patient Information

Patient Information

This study has been compiled in order to investigate the effectiveness of markers for the identification of syringes. This information will be used to inform planning and future service developments throughout Glasgow Addiction Services.

This study is voluntary and completely anonymous. It should take no longer than 5-10 minutes. If you do not wish to take part or want to stop at any time please indicate to the interviewer. All data will be used in accordance with the Data Protection Act 1998.

If you have any queries in relation to this survey please contact Carole Hunter, Lead Pharmacist on 0141-276-6612 or Laureen McElroy, Senior Officer Monitoring, Performance & Evaluation 0141-276-6626.

Appendix Ten: Field Work Diary Themes

Key Codes from Thematic Analysis of Field Work Diaries.

1. Reactions to Research Setting

- i) Structural
- ii) Boredom
- iii) Frustration
- iv) Interactions with staff
- v) Communication with staff

2. Relationships and Interactions

- i) Communication with staff.
- ii) Interaction/ communication with participants
- iii) Trust
- iv) Interactions with other peer researchers

3. Identity

- i) Trust
- ii) Responsibility
- iii) Unsolicited contributions to research
- iv) Role identity
- v) View of self
- vi) Perceptions

4. Practical Difficulties

- i) Isolation
- ii) Physical barriers
- iii) Boredom

5. Observations

- i) Recording additional participant comments
- ii) Observing and recording interactions related to research
- iii) Observing and recording interactions external to research
- iv) Participant observation role

6. Communication

- i) Pharmacy Staff
- ii) Research Participants
- iii) Field Work diary reflections
- iv) Recommendations produced
- v) Researcher

Appendix Eleven: Commercially Produced Syringe and Paraphernalia Markers.

