66We're people too?? Views of drug users on health services Report by Fiona O'Reilly, Emily Reaper and Tom Redmond June 2005 **The Mountjoy Street Union for Improved Services** The Participation and **Practice of Rights Project Family Practice Communication & Education**



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Preface

This report is the result of the collaborative effort of the Participation and Practice of Rights Project (PPR), UISCE (The Union for Improved Services Communication and Education) and the Mountjoy Street Family Practice (MJFP).

The Participation and Practice of Rights Project (PPR)

The focus groups described in this report were initiated by the Participation and Practice of Rights project (PPR). This grew out of an all Ireland initiative and links North City Dublin with North Belfast. In Dublin it is managed by a Steering Committee, which is composed of representatives of the two community networks North West Inner City Network (NWICN), Inner City Orgainsations Network (ICON), the Dublin Inner City Partnership, Combat Poverty and the Irish Council of Civil Liberties (ICCL).

The central objective of the Participation and Rights project is to encourage the communities in disadvantaged areas to use a rights based approach to redress many of the social and economic deficiencies, which affect them.

The project aims to develop a Rights Based Approach within community development work. It seeks to help people identify the barriers, constraints, inequalities and the abuses that they face. Once these are identified it attempts to make them aware of the rights that they possess and to demonstrate how to achieve those rights. At the end of the day it is people themselves and the community projects that they have created which will be the motor of redress.

The Participation and Rights Project decided after wide consultations with community organisations and particularly with those offering drug services to focus on the rights of those who have been seen in the past in the most negative light by society, 'drug users' and therefore opted to listen to the voice of people receiving methadone for an opiate addiction.

This work is not just a piece of research it is

- i) a testimony of a group of drug users' experiences of the services to which they are entitled
- ii) an exercise in the right to participate through the expression of voice and
- iii) a call for action for redress

UISCE

The Union for Improved Services Communication and Education (UISCE) is a group made up of users, ex-users and professionals who believe that the voice of the drug user is integral in the development of drug policy and in realising an effective treatment response.

UISCE was formed as a result of a North Inner-City Drugs Task Force (NICDTF) initiative. The NICDTF is one of 14 local Drugs Task Forces in Ireland overseen by the National Drugs Strategy

Because of their unique proximity to the voice of drug users UISCE were approached by PPR to convene and facilitate group discussions among drug users. Emily Reaper assisted by Christy Flood facilitated the group discussions.

Mountjoy Street Family Practice

This is a progressive GP run family practice, which aims to provide quality primary care services which are appropriate, affordable, accessible, and acceptable to all members of the local community. The practice has a special interest in opposing discrimination in all its forms.

The practice has a large group of patients receiving methadone maintenance services and has an interest in listening to the views and voice of particularly marginalised groups such as homeless people and drug users.

The practice was awarded a research grant by the Royal College of Surgeons in Ireland with which it employed Fiona O'Reilly to assist with practice research projects. Collaboration in this action research project is one such project. The Mountjoy Street Family Practice provided financial and technical support.

Introduction

Inner city Dublin over the past three decades has been ravaged by the problems associated with widespread illegal drug use. Lives have been lost, families torn apart and communities left reeling in the wake of the opiate epidemic. At the same time, communities have responded to the problem. They have campaigned and demanded to be involved in the State response. Communities have been involved, services have been developed, and legislation has been passed. In fact it could be argued that the organisation of services for drug users has had a higher degree of consultation with, and involvement with, community groups than other services. However as drug users are often a disenfranchised group viewed very negatively within the larger community, full representation of their particular views and concerns in this involvement is not guaranteed. This said, it is recognised that there are specific initiatives to make channels for the voice of drug users, notably the establishment of UISCE itself.

Nevertheless while it is acknowledged that the expansion and improvements to drug services over the last decade have been immense, there still is room for the voice of drug users to be heard within the health system. Furthermore, drug users as service users and patients are entitled to mainstream health services. However anecdotal information led the partners in this project to question whether drug users' experience of and access to health entitlements was equal to those of the general population. In seeking to give voice to drug users we asked them about their experiences of the health services.

Drugs and the Social Context

The drug problem in Ireland was largely concentrated in Dublin prior to and during the 1980s when heroin took root in areas of socio-economic deprivation in the capital. Prior to this there was very little intravenous drug use at all. However 1979 saw the beginning of the opiate epidemic involving the large scale use of heroin in Dublin.

In the mid eighties the supply of heroin dried up and users turned to other drugs such as Morphine sulphate tablets (MSTs), these were often crushed and injected giving rise to abscesses, thrombosis and occasionally the amputation of a limb. The growing concerns world wide about HIV and the acknowledgement that this and hepatitis could be contracted through the sharing of needles led to harm reduction programmes. In the early nineties thousands of young people began to use heroin and some local authority flat complexes were seen as open markets for all kinds of drugs. People were injecting openly and discarding injecting equipment in school yards and children's playgrounds. Drug related crime was at an all time high and from the communities' perspective dealers were openly flaunting their wealth while the police appeared to be doing nothing. Many young people were dying as a result of drug overdoses, drug related suicide and aids related illnesses.¹

Neighbourhood committees were formed and drug dealers, often addicts themselves were sometimes forcibly evicted from their homes. The 1997 housing act legitimised evictions by allowing Dublin corporation evict tenants accused of 'antisocial' behaviour.



Thousands of people marched on the Dail demanding a comprehensive response from government and community leaders insisted that the community be involved in any policy making. The Inner City Organisations Network (ICON) took the initiative of inviting groups to come together in Liberty Hall to launch a campaign on behalf of affected communities. This was the beginning of the Citywide Drugs Crisis Campaign, which has continued to have a dual focus of supporting communities at local level in responding to the drugs crisis, while at the same time increasing their involvement in and impact on developing policy at local, regional and national level. The growing political awareness of the seriousness of the drugs problem led to the creation of community-based Local Drugs Task Forces. These agencies act as a cooperative effort between statutory and non-statutory agencies and local communities in tackling drugs.¹

 $^{^{\,\,1}\,}$ Methadone: What's the Story?, UISCE Union for Improved Services Communication and Education

Methadone Treatment Services

The policies and structures that had been set in place in the early days of illicit drug use in Ireland were seriously deficient. They followed the system in Britain and were conservative and centralised with a central treatment agency established at Jervis street under the clinical direction of a consultant psychiatrist. In 1988 following the closure of Jervis Street clinic the National Treatment and Rehabilitation Board (NTRB), widely know as Trinity Court, moved to Pearse Street. Over the next decade services and policy changed from a service that was centralised and specialised with an ideology tending towards abstinence models to the institutionalisation of regulated methadone prescribing by general practitioners. The introduction of the methadone protocol was seen as a pragmatic success albeit one that was necessarily covert in process².

GPs had no role in the initial services and the psychiatric services saw no role for them, stating that they were 'not in favour of the treatment by GPs of drug addicts'³. Not surprisingly GPs were wary of involvement with drug users. However a small group felt that they could not ignore the problem and supported the view that methadone maintenance at primary care level was legitimate and 'evidence based practice'⁴. Over time this view became accepted and the Irish College of General Practitioners (ICGP) in 1990 produced a policy statement on the management of problem drug users in general practice. A formal protocol for methadone prescribing by GPs was published in 1993⁵. In 1997 the ICGP was involved in producing guidelines for its members and updating the methadone protocol and this was given statutory authority in 1998 through amended legislation⁶. Together with the Eastern Health Board it urged its members to treat drug users in their localities⁷.

Similarly the pharmacists' professional bodies, the Pharmaceutical Society of Ireland and the Irish Pharmaceutical Union were initially concerned that the provision of services would not disrupt conventional services. However over time this position changed and in 1996 the Pharmaceutical Society of Ireland acknowledged the valuable role played by methadone treatment in the management of opiate addiction.

The Methadone Protocol

The methadone protocol makes provisions for treatment services based in primary care with GPs providing treatment to drug users within their localities. This service is supported by a secondary level service for unstable drug users in treatment clinics. The idea is, that once stabilised, clients would be transferred to GPs where continuity of care could be guaranteed. The GP would be supported with training and support by GP coordinators and the client by key workers and community addiction counselling if necessary. Pharmacists would dispense the methadone on receipt of the client's treatment card and special prescription from the GP.

Terms are set out for the involvement of GPs and Pharmacists which govern the numbers they can treat, training requirements and legalities about notification and registration, dispensing and prescription and contracts. An upper limit of 50 clients at any one pharmacy is advised. GPs on contract level 1 can treat 15 clients and more experienced GPs with a contract level 2 can treat up to 36 clients.

There is an important ideology contradiction in review group reports of 1993 and 1998 which establish policy in this area. The 1998 protocol sees methadone maintenance as a 'valid form of treatment for opiate dependence' but the 1993 guidance (annexed in the same document) cautioned that 'methadone should not be seen as an easy solution to a complex problem... and should be regarded as an adjunct to treatment and not treatment per se."

² Drugs: education, prevention and policy, Vol9, No.4, 2002

Stationery Office (1984) The Psychiatric Services: planning for the future Dublin Stationary Office

⁴ Irish College of General Practioners (1990). Policy Statement on Ilicit Drug Use and the Problems of Drug Addiction. Dublin ICGP

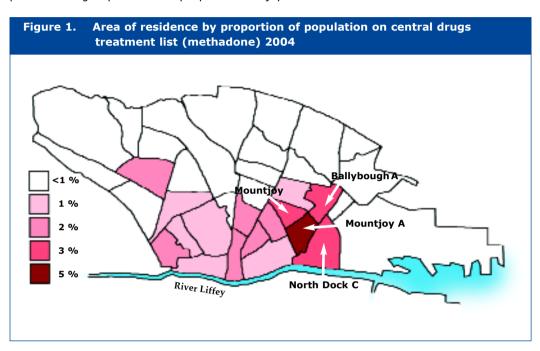
⁵ Report of the Expert Group on the Establishment of a Protocol for the Prescribing of Methadone. 1993 Dept. of Health.

Department of Health. Misuse of drugs (supervision of prescription and supply of methadone) regulations, 1998. Dublin: Stationery Office, 1998. (Statutory Instrument No 225.)

⁷ Report of the Methadone Treatment Services Review Group (undated) Dept of Health and Children.

The Extent of Methadone Usage

The North Inner City Partnership (NICP) in Primary Care, covers an area which includes the 35 electoral divisions (EDs) represented below. A total of 1244 people living in this area receive methadone maintenance according to the Central Treatment List (CTL). Based on the 2002 census this represents 1.16% of the total population in these 35 EDs. Just over two percent (2.2%) of the people living in the North East Inner City (NEIC) receive methadone maintenance while 1.6% of people living in the North West Inner City (NWIC) are registered for methadone maintenance. However as can be seen form the map of EDs below and the table in annex 1 specific localities, in particular those closer to the centre of the city have a much higher prevalence e.g. 1 person in 20 people in Mountjoy A.



Extent of Participating GPs

In the Eastern Regional Health Authority (ERHA) area, the numbers of patients on the Central Treatment List doubled from just over 3000 in 1998 to over 6000 in 2004. Thirty percent were treated in General Practice in the ERHA in 1998; this rose to 37% six years later. The participation of GPs in primary care in the scheme is vital as it means there is progression of stable users from secondary care to primary care where all their health needs can be addressed. This transfer then frees places for cases with more serious addiction problems. Presumably reduced numbers in secondary care services would also allow for the more intensive care of these clients.

According to the Central Treatment List figures, only 16% of people on methadone and resident in the 35 EDs in the North inner city area are receiving methadone from GP Practices (i.e. not Health Board Clinics). Though the number of GPs participating in the Methadone treatment protocol has doubled since 1998 this is still only a minority (28%) of GPs in the North Inner City Partnership area. Though GP professional bodies and health boards have recommended treatment of drug users in the community and GPs receive additional payment for their treatment, numbers would suggest a certain reluctance by GPs to treat this patient group. According to these figures it looks like GPs in the north inner may be more reluctant to treat drug users than GPs in the ERHA as a whole.

Table 1. Participating GPs in the NICP and ERHA areas					
	31.12.98	31.12.00	31.12.04		
No of clients in ERHA Clinics	2136	2849	3785		
No attending GPs in ERHA	923	1574	2316		
No attending GPs in NICP area	92	165	204		
No of Participating GP's in ERHA	97	136	179		
No of Participating GP's in NICP area	7	13	14		



Health Rights and Entitlements

International:

Good health is an essential element in the empowerment of poor people to escape from poverty. Enjoyment of the right to health is instrumental in securing other rights such as education and work. The right to health is protected by several international human rights instruments, including, the United Nations International Covenant on Economic, Social and Cultural Rights (ICESCR) and the European Social Charter (ESC) See Annex 2.

The right to dignity and treatment without discrimination, equitable access to health care and professional standards, is protected under the Convention on Human Rights and Biomedicine⁸.

National:

In Ireland as in other parliamentary democracies ultimate responsibility for policy and particularly policy which is enshrined in legislation, is deemed to lie with parliament.

The Policies that govern people's entitlements and those which govern how entitlement will be delivered are set out in Department of Health and Social Welfare documents.

The Health strategy sets out a vision of a

"A health system that supports and empowers you, your family and community to achieve your full health potential. A health system that is there when you need it, that is fair, and that you can trust. A health system that encourages you to have your say, listens to you, and ensures that your views are taken into account."

Specific entitlements such as medical cards give people access to a range of services:

Medical Card holders

If you have a medical card, you are entitled to:

- GP services,
- prescribed drugs and medicines,
- public hospital services,
- dental services,
- optical services
- aural services,
- · maternity and infant care services,
- a range of community care and personal social services

all free of charge.

source: www.oasis.gov.ie/health

Methadone Treatment Services:

In 1997 the updated Report of the Methadone Treatment Services Review Group (Annex 3) stated a number of recommendations which effectively established policy in this area. Among these are recommendations which are of particular relevance in the context of the views expressed by drug users in group discussions in the next section of this report.

Focus Groups

This assessment of views primarily involved focus group discussions with 25 drug users about their experiences of health care services.

The purpose was twofold:

- **a)** To gather information for the Participation and Rights Project on drug users' perceptions on how they were treated by duty bearers with respect to their health entitlements.
- **b)** To assess drug users views of health services in order that they may be taken into account by the services.

This assessment is important for a number of reasons:

- i) Drug users are rarely seen as a consumer group whose expectations and experiences need to be taken into account when designing and operating treatment protocols.
- ii) Drug users are an extremely vulnerable group with very poor health.
- **iii)** Recent research has pointed to the need to assess participants' views of services⁹ The central role of UISCE in this work provides access to insights otherwise off limits to researchers and service providers.

Methods

Participants where selected by UISCE by

- i) Asking for volunteers outside City Clinic Drug Treatment Centre on Amien Street,
- ii) Meeting drug users in the street and
- iii) Going into flats to look for volunteers.

Twenty five drug users agreed to take part in discussions and three groups were held on three consecutive days in July 2004. The venue for the group discussions was the SAOL building on Amiens Street. This is a venue known to most of the group participants and was convenient as it is situated across the street from Amiens Street City Clinic, the drug treatment centre where most of the group participants receive their methadone. SAOL is a drug rehabilitation project for women and has a crèche, which was available for the participant's children.

The question route was co-designed by UISCE staff and the researcher. Groups were facilitated by UISCE members with experience of having also been service users. UISCE have a proven track record in conducting and partaking in research. The organisation occupies a unique position as it enjoys the trust and confidence of the drug using community.

Participation was voluntary and participants gave permission for the findings to be published. Anonymity was assured and only first names were used to protect the participant's identity. Names have been changed in this report.

A total of approximately six hours of discussions were taped, transcribed and analysed using a thematic approach.

Four months later, after the tapes were transcribed and analysed participants were asked to come together again to verify the initial findings and to prioritise problems with services. Thirteen of the original 25 focus group participants reconvened for the 'feedback' session.



⁹ NCAD report on Dual Diagnosis.

always been homeless, since I was ten or eleven?

Group Participants

Thirteen of the 25 participants were or had, at some time in the past, been homeless. Homelessness was understood to mean, living in hostels or B&Bs or on the streets.

"I was an 'anti social behaviour' (eviction) that's why I was in a hostel so long... they had me barred from the housing list for 10 years and anyone who took me in was evicted as well. That's how I was in and out of B&Bs. That's all still on my record, I'm only a subtenant. My husband's the tenant. They said I will never be a tenant; I will always only be a sub tenant. So if anything ever happened to my husband ... I would have nowhere to go."

While for most, drug use preceded homelessness, there were two men who started drug use having already become homeless. Both of these men had been homeless since childhood. One of these men now 22 years old had started drugs very young and was addicted to heroin by the age of 15 years. At the time he tried to get on a methadone treatment programme at one of the clinics but says he was too young.

"I had to go back on the streets. They wouldn't let me on. Maybe if they had I wouldn't be sittin' here now"

Length of time on drugs ranged from 1.5 years to 18 years with an average of 11 years.

Some of the participants gave information about their living environment.

"The house I got is falling to pieces. When the kids are having a shower the water pours down into the sitting room. There is a big crack in the ceiling. The plugs are all smashed, the light fittings all have to be fixed. The switch for the cooker is broke. Every time we touch it we get a shock. Out in the back I have the main sewage and that is blocked half the time and it pours out all over the back. Anyway it's not for the want of complaining, I complain all the time and I get nowhere."

"I'm a single fella, no kids. I've always been homeless. Since I was 10 or 11. Then when I turned 18, I put my name on the housing list. I'm 22 now. I have nowhere at all".

"I have two young fellas; 16, 14 and a girl 6 and I'm still not housed. I'm living in a little one bedroom, in a landlord's house. I'm waiting on a house. The toilet and all is broke. Sometimes I have to send the kids to me ma's to go to the toilet because mine's not working. There's nowhere to wash clothes".



supposed
to be
confidential
and it's not
at all >>



Experience of Health Services

Health Service Use

There was a heavy use of secondary health care services i.e. hospitals, drug treatment clinics and detoxification centres. Only 14 of the 25 participants had a GP and many did not actually have medical cards. Participants clearly had many health problems and some spoke of having HIV and hepatitis. Others had taken overdoses, some accidentally and some had attempted suicide.

Drug Treatment Centres

Most of the participants were attending City Clinic for their drug problem however there were also experiences of Pearse Street, the Thompson centre and Cooley Road represented.

Participants talked about their experiences of treatment at the centres and about how their treatment by the service made them feel.

Attitude of Staff

There were varying opinions about staff member attitudes towards them however most felt that staff did not 'care' about them.

Marie describes a service void of 'care' for the person as a whole:

"They just treat you like you're on 'Phy' and that's it. They don't treat you with respect, you're just a number".

"The other day I went in and a lovely young fella, only a child... out of it on tablets, he didn't know where he was.... They didn't even know what way to approach him. They left him lying on the floor. I said "can you not give him an injection or get an ambulance?"

Marie did acknowledge however that there was one member of staff who did care and without her she'd be lost:

"I find (names nurse) has a little bit of time for you, but the rest..."

"If I was worried or anything I'd go to (names nurse). The doctor just sits back "ah no you're alright", (nurse) would take blood off me and she'd send it away ...to reassure me. Cause I've an awful lot of things going on, so... she's alright".

Confidentiality

Participants felt confidentiality was not assured in the clinics and that people who should not know their business did. People could hear what was going on in the counsellor's room.

"I find the GAs (General Assistants) know everything of your business in there, and it's supposed to be confidential, and it's not at all. They're laughin' at you. I'm on take aways now, but when I wasn't on takeaways they'd say "When are you going to?" (Go on take aways)

"The GA's know everything about you. I said something to the doctor over there and a GA came back to me 2 days later and said it back to me".

"I think there's not enough privacy, if you go up to a counsellor. For instance, I was sitting outside waiting for my counsellor and there was someone in with her and I could hear everything they were saying, 'cause where you're sitting you can hear everything. That's why I won't go up to see my counsellor, 'cause I don't want people listening outside. They're out the door with their confidentiality anyway".

"The doors are paper over there, and you're sitting right on top of the door."



Paula had been discharged from hospital after taking an overdose but would not go for counselling because,

"Everyone can hear your business in that place, so I just can't.. I don't go anywhere even though I want to. You know what I mean, but that turns you off".

Some participants noted that in one of the drugs treatment centres the counsellor was separate.

"In the Thompson centre they have counselling sessions but the good thing is it's up the top of the building and no one can sit outside the door".

Damian expressed surprise that the clinic passed information onto his GP.

"They're in contact with your GP, they put your GP wide... what you are. You think the GP doesn't know what you are. The GP knows every single thing. Cause, I asked my GP for something to help me sleep and he said "not with what you're on"."

Others felt information about them should not be shared with other staff members within the clinic.

"My files were left open on the kitchen table upstairs where people have read them. The fella (non-medical staff) read my files and has come back to me an has told me about my urines, and how they've been clean... he got in too much into my personal life. He was able to tell me that my files were left open and he knew that I was clean now".

Access to Counsellors

Use of counselling services in the drugs treatment clinics seems to be affected by views on privacy as seen above; however there was also the view expressed by a number of participants that in some centres there were not enough counsellors.

"I don't want any tablets or anything I just want a bit of advice or someone to go to. He (the doctor) says to me about counselling. There's a waiting list for counsellors, which I never heard of in City Clinic."

Some also relayed positive experiences of counselling.

"It's one to one and it's handy. It's a half hour a week but you can have an hour if you want. But it is good. When we were getting referred to a clinic we did go to Pearse Street, after 4 months we still had no word back so we got referred to Thompson. Since then I've done a lot of counselling sessions, whereas ye wouldn't see a counsellor in Pearse street, I heard. You'd be lucky to see a counsellor walk by ye never mind see ye for counselling!"

One woman who was recently discharged from a psychiatric ward in an acute Hospital was asked if she had gone for counselling in the drugs treatment centre. She said,

"No, I won't go to counselling there. I took a breakdown last week-end and me ma had to send for (names friend present also). I did try and do something again. But I think if I had a havin' counselling and was able to talk about things and address things, I think I wouldn't have done it."

(Friend interrupts)

"She needed help and there was no help there for her"

"There's no one there at the week-end that can talk to you. You have to wait for an appointment. Jasus... You're nearly trying to do it at that stage, and then you just let go ...and then ye do. It's all mad." stressed out to bits and I need someone to talk to...?? Others were asked would they go to the counsellor in the clinic,

"Yes I'd see a counsellor if it was in better condition than it is over there."

"I need counselling I'm stressed out to bits and I need someone to talk to. But I'm not going to go over there and let everyone know me business. It's bad enough without everyone knowin' my business."

Some expressed dissatisfaction at the lack of involvement in their own care.

"They had a meeting about me, I wasn't at that meeting. I should have been there. They were talking about my life, no one else's, my problems".

Complaints procedure

The City Clinic drug treatment centre had been piloting a complaints procedure which was advertised through posters in the clinic and letters¹⁰ to service users. However, some participants were not aware of such a procedure. Others had used the procedure and there was some evidence of satisfactory outcome.

"I went to the complaints board again, and there was a group meeting called and he apologised. He said he didn't remember it but he apologised, that was that."

Other health issues not catered for

A number of participants complained that their other health issues were not always catered for in the drugs treatment centre, however it did appear that this was not across the board and that some doctors would treat illness which was not drug related.

"I was only in the place two weeks and I went up to get a headache tablet off the doctor. My own doctor wasn't on, so the other fella said,

"I can't give you one 'cause I'm not your doctor." So I said

"are you the doctor on call?" and he said he was. I said,

"if you're the doctor on call and I call you out to the house you'd have to see me right? So you're the doctor on call in the clinic and I need to see you. I know I'm not your patient but all I'm looking for is a headache tablet." He said,

"no I can't give you one." So with that I ended up snapping. I should have just walked out but I ended up snapping."

It was clear that participants had complex lives with many problems. Jean's experience is an example of this.

"I'm going through depression since I had my son and he's six months now and I'm not getting anything for it. No treatment. Sometimes I'm pulling me hair out, fighting with people...fightin' with me ma and...I don't know."

"I was in a suicidal state of mind...There's a lot going on for me in my life and not only for me but my partner. And (names partner), he's trying his best to get into treatment and he can't. He's facing jail, and he doesn't want to go in there on methadone, not on any 'phy' at all. He wants to be clean."

Draft Report on City Clinic Pilot of Service User Complaints Procedure. July 2004

Hospitals

There was a heavy use of acute hospitals among participants: Beaumont, St. James' and the Mater being the most frequently mentioned. Participants attended hospitals as inpatients and outpatients. Some of the reasons for admission were serious illness e.g. pneumonia, overdose, servere abscess and for detoxification. Some of the women had attended the Rotunda when they were having their children. Participants felt they were discriminated against in hospital.

One man was admitted quickly from casualty and instead of seeing this in a positive light did not like being treated differently because he was an 'addict':

"I was in a bad car crash a couple of months ago and I was lucky to live. But when I went into the hospital, at first they were grand, but I think the minute they hear you're a drug addict their attitude just changes altogether. Because there was a person, for instance, lying on a trolley for two days before, but the minute I came in to the accident and emergency, they just push me up into a ward. I think they were hoping that I would walk out of the hospital. At first they were concerned and they were coming to me every few minutes but the minute they heard drug addict they just more or less vanished and just forgot about me. As for my 'Phy' they were just leaving it till the last minute hoping that I'd walk out of the hospital."

"I think it's when they hear you're a drug addict they say why should we be taking up beds when ours is "self inflicted"."

"They say terrible things to you, and treat you like dirt."

Annette did not like how she was given her methadone when she was an inpatient.

"The nurse shouts from the top of the ward about me methadone, so everyone knew."

Though participants felt their treatment was poor by acute hospitals that often discharged them or failed to admit when they were in a serious condition there were some accounts of good services. The experience of St James's hospital was more positive than others. Particularly the 'GUIDE clinic' and 'hepatitis ward' where it was felt there was a different attitude to clients.

"I think James's is very good. The good thing about it is that you get counselling before you actually go in and counselling after it. At least in James's they will spend some time with you, to help you understand, and prepare you for the worst. They make sure you've got someone there. I think James's is brilliant compared to any other hospital I've been in."



"I go to the hepatitis clinic at the back, it's the only part I've ever been in and for a hospital they go out of their way. When you walk in you've to sit there until you're called, there's security doors blocking anyone else from coming down and listening. They help you out, they more or less prepare you for the worst. But I only ever went to see what stage the hepatitis was at, and how I was doing."

When asked if he felt he was treated 'fairly', this participant responded:

"Yes very fair I'd have to say that, I'd be wrong to say anything else, even the nurses that work in that part. Even though I came from prison at the time and even though they seen handcuffs it didn't change them. I was just like the ordinary person that walked in off the street."

On the other hand participants in all three groups were unimpressed with The Mater hospital. Most of the complaints were related to the way their treatment differed form those around.

"They treat drug addicts a lot different there. I don't think they like drug addicts and I don't think they like taking ye in."

"They're real cheeky you know. They say "you wouldn't be here if you wasn't using drugs" and say ours is "self inflicted"."

Much of the difference was with attitudes of staff as well as lack of sensitivity e.g. they felt the sign in the front of the hospital for 'Infectious disease' let everyone know the reason they were attending. They felt dirty and diseased when staff wore gowns and gloves and tried to move them along as fast as possible.

"Do you know what's very bad about the Mater hospital, the sign 'Infectious disease' clinic. That sign shouldn't be there. People are goin" to be saying "Jasus, he has Aids, he has the Virus he has HIV or he has hepatitis. It's a sign that's lit up. Like the sign that's over the door that says exit. You're labelled. There and then, you know what I mean; you're labelled.

Others were particularly sensitive to being labelled by identifying stickers on their charts.

"They have that luminous sticker so the doctors know and nurses know immediately that you're drug related, once they see that sticker on your file which is wrong I think. I have often snuck in and taken the sticker off."

"I can tell you what it says on the red sticker 'caution hazardous risk'."

"This sticker is put on to your file so that the minute the doctor picks up your file he knows you're a drug user."

How abscesses were treated specifically came up. Some participants felt that proper care was not taken in incising or lancing abscesses. They felt that the 'X' shaped scar which many were left with was an indication to other health professionals that they were drug users. In one group they agreed it was better to treat abscesses yourself than to let themselves be "butchered".

"When they cleaned up my abscess she just got the blade and when they done that I said will you just put a little hole. She wouldn't, she just cut across it. Like an x, that's to say – you are on drugs"

"Personally I don't know anyone that has gone in there to have an abscess done that hasn't come out with a scar...a huge scar."

"I had one here and they sliced it 3 or 4 times before they actually punctured the abscess, trying to relieve the pressure, but they scarred me pretty bad there I thought, you can see it there."



like the ordinary person that walked in off the street ??



Claire clearly wanted to be treated like all the 'other' women attending the Rotunda to have their babies

"I'm labelled with a red sticker because of my hepatitis. The women that are pregnant go to room seven and we've a doctor especially for us from City clinic because, we're transferred up. Other women come in from all over the country and they go around in a whole circle, all in a circle (indicating the queuing system that 'other women' use)... Me with my red dot up here (on the chart), and up here on the door it says, 'infections', now where would you get that."

When asked how this makes her feel

"It makes me feel like I have leprosy. I'm the same as them! But you go in and you see your doctor ... These doctors they don't understand, they don't give you the time of day. I feel low; I feel they've no time for me. Like I'm not in about me, I know how I am; I'm in about the child, the health of my child."

"That thing there in the rotunda hospital is a disgrace - sectioning people off for methadone and other diseases."

Psychiatric services

There were a few experiences of Vincent's hospital Fairview where the general impression was that patients where left to wander around and not given the psychiatric support needed.

"My mother brought me because I was very bad, at the last of me tether... at the end of the road. It was the only place that would take me (the psychiatric hospital)."

When asked about referral or follow up treatment, this participant said

"I was supposed to go down to the health centre to see a psychiatrist, but I didn't cause I didn't want to go through all that, because me Da, was on that clinic and I didn't want to go through all that. I was better then. Sure all they do is give you tablets. That's what happened my Da, so I said "I'm not goin' to go on loads of tablets." At that time I wasn't into drugs. They don't even say "are you all right," or counsel you or anything. They give you tablets and say "see ya" and "hope you're alright in the future"."

Paula was admitted to the Mater as she tried to kill herself by taking an overdose.

"They could only keep me for a day so they sent me to Vincent's. In Vincent's they weren't talking to me or anything, I was just left ...walking around. I was in Vincent's for a week. But you could walk in and out, the door was open all the time, but I didn't want to, I wanted to come off them."

When asked if she was evaluated she said,

"No, no one was coming to see me (staff); all I had was me family up with me. They did give me my methadone and they discharged me after I week. I thought they were going to talk to me and all, and ask me why did I do it, and am I going to do it again. When I was leaving one of them says to me are you going to do it again? So, I says I don't know and I walked out."

Experiences of Health Services

Commerchants
Quay...I think
I'd have been
long dead
only for
them 99

David who currently is addicted to 'tablets', also tried to kill himself by taking an overdose and when found was taken in a semiconscious state to the Mater and admitted to the Intensive Care Unit

"The minute I came out of it, everything was whipped out of me (drips and tubes) and I was put into a ward. They could not wait to get me out of the hospital. I was brought by ambulance down to Vincent's psychiatric hospital. I was there for one day. I got psychiatric analysis, assessed, ye know, I got a full screen check up from a nurse. I got admitted, I was put in a room on me own. They kept me for one day and they discharged me. They sent me to the health centre here and I was given prothiaden and I was given zimovane. I was given a big bottle each and they had me on them for ages."

Mary had a more recent experience of the same Psychiatric hospital and was asked if her drug treatment was looked after in the hospital.

"I was there two weeks ago. I didn't get me 'phy', till 4 o' clock in the evening whereas I get it in the morning over here. But, they weren't givin' me medication until all hours."

Merchant's Quay

Merchant's Quay was praised by a number of participants, specifically the needle exchange and dental service. Not all participants knew about the dental service and were very interested in finding out more.

"I think I'd have been long dead only for them... from staying on the streets, I used to go in there in the mornings to get tea and something to eat off them. I was able to sit there from 10 till 12 and 2 to 4, whereas I couldn't do that anywhere else."

"They have actually a dentist service in it now and they're flying through people. You just go in and put your name down."

"I have to say it's very good... Now I got teeth taken out in prison. They just pull them out, that's it and send you back. Not a painkiller... forget about it. But up in Merchant's Quay now they have all this and a new dentist and they're trying to bring in a chiropodist"

Dentists

There were varying experiences dependent on individual dentists. However many participants found it difficult to get good dental care which they found distressing as one woman put it "your teeth are everything".

"I went into the Strand (health centre) and they told me there was a waiting list and I'd have to go on the list to get me teeth done. And I'm after loosen them ones" (indicates where teeth have fallen out), And I'm still waiting. I think when you go to a dentist and they see rotten teeth they just look at you and say "well he can wait another while", but all me teeth are caving in."

"Your man that I went to was very nice he even filled in my medical card form for me."

Not having a medical card was seen as an obstacle to accessing dental care. When one woman said she couldn't go because she had no medical card, one of the other participants told her she would still be seen by the dentist in Merchant's Quay without a medical card. Those that knew about the dental service in Merchant's Quay enthused about it, however few knew about it.

The link between no medical card and dental service was made by a number of participants.

"I was told I was getting it done and by the time my appointment came round my medical card was out of date."

"I couldn't get a dentist cause I had no medical card and no doctor would take me on."

There was an impression that if dentists knew you were an 'addict' or had HIV or Hepatitis C they would not want to treat you.

"I went to the dental hospital, they didn't treat me cause I'm an addict."

Frank felt his difficulty in getting dental treatment was because of his HIV diagnosis; however he felt he was treated well in hospital when he eventually was seen.

"I went to umpteen dentists and because I told the truth about my problem...
my disease.. you know ... and when I told them, they always came up with a
different story... an excuse. "Ah we couldn't touch that, cause we'd be afraid,"
and, "not with the medication you're on", and "we'd be very afraid."

Frank explained that he had to wait until the last case to be treated and complained about the length of the wait. When it was suggested that everyone experiences such a wait he said

"I thought it was because of what I have. In surgery your man putting in the syringe says " he has a history of drugs and he has hepatitis C and HIV so just be careful". So I couldn't wait till I was knocked out and just got me teeth out.



Needle exchange

No participant raised a complaint about 'needle exchanges'. In general they seemed to be regarded positively, however more were sought.

"They (staff in needle exchange) were real nice and supportive, they tell you what to do... to mind your self... what you're taking"

"They're all right (meaning good)."

"Merchant's quay, are all right. They keep you there, and bring you next door for a cup of tea and all, a sandwich and that."

Chemists

Some participants received methadone at the pharmacy on production of a prescription from their GP. There were a lot of complaints about treatment within pharmacies. There were isolated positive experiences with this service.

Some participants felt mistrusted and uncomfortable. They felt their treatment was discriminatory.

"They'd be watching every move, you wouldn't feel comfortable."

"You have to stand outside the door while the security guard gets it for you."

"I was collecting a normal prescription and I wasn't allowed go in and get it."

"This fella standin' on the door won't let you in, he says "what's your name" and he goes and collects your stuff, you're not even allowed in, you've to stand at the door while he goes in and collects your stuff for you."

Some participants spoke of signing contracts with pharmacies about rules and regulations; however they felt the contracts are there for the pharmacist and not the client. They state that the person cannot come in for the methadone if anyone else is in the chemist at the time.

"If there's any one else in the chemist that's on drugs you've to walk out, so I was getting kicked off because there was people in there when I was, that were on drugs."

GPs

Access to GPs arose as a big problem with many participants complaining that they were constantly being refused by GPs. Eleven of the 25 participants did not have a GP.

"I couldn't get a dentist because I had no medical card and no doctor would take me on."

The common reason participants were given for refusal by GPs was that their GMS list was full; however this is unlikely as participants pointed out that others were taken on after they had been refused. Others found they would be taken on by GPs if they lied about their drug status.

"I got three refusals and then sent the card and form away and they appointed me a doctor. Now the doctor they appointed me you should see the state of his surgery. It's a scandal. It used to be the old shoe repairs, the surgery is manky."

"My key worker is getting my medical card sorted out. I stuck to my old doctor because I found it hard to get one, even though he is out in Tallaght, but I'll just stick with him."

"Soon as they found out I was addicted to drugs in the past well one of them said "you wont be getting any sleepers off me" and that's when I stood up and said "stick your surgery"."



This participant had tried to get 3 or 4 doctors to take her on.

"Because when I've gone in I've said to the nurse is the doctor there? "Well eh he's busy at the minute come back." I'd come back the next day, or whatever... he just wouldn't see me, and it's been like that in other places too."

Access to medical cards was hampered by doctor's refusal to take on patients stating that 'their list was full'.

"I had one right (medical card), but it ran out and they never told me, every doctor I went to wouldn't take me on and they say if 3 Doctors refuse you the Eastern Health Board has to get you a doctor and I'm still waiting on one. That's a year."

"They just said they had enough patients, they're full"

"They got me a doctor, I had him for a year and when I went in to get him to sign the form he says "I won't be giving you anything", I say "I don't want anything, all I want is to go to the dentist and that's all. I only went down to the dentist that's all I used him for, and I went up to him one day for something and he says "your year is up," I said "it couldn't be up, once I was up with you and that's when you filled in the form and I haven't come near you since this is me second time." Says he "your year is up, and I can't take you back on". He put me off!"

"I've had (names doctor) for years right, and then when I went to her, I said "Doctor will ye take me back on? ..me and the little one, cause me ma's medical card is for her and (names two others)" She said, "ah no, I'm full up" and I was after hearin' she was after takin' people on. But I think it was because she knew that I was on drugs, that she didn't want to know. When I was younger and I wasn't on drugs, she had me. She just said 'I'm full' and she wasn't, so I just left it. I just kind of got annoyed; I just said ah "fuck it" I know I shouldn't, you know what I mean, I do need a medical card. So I'll just have to find a new doctor now."

Medical Cards

Participants were asked if they had medical cards. Only 12 of the 25 people taking part in the group discussions had current medical cards. Not having a medical card means that not only do vulnerable people not have access to GP services but they also do not have access to dental services and free medicines. To get a medical card, application forms have first to be completed then signed by a GP (indicating that the GP is willing to take the applicant on as a patient) then the form must be sent in to the medical card section of the Community Care area where it is returned if not completed correctly after which it is assessed and a decision made. The applicant is then informed of the decision by post. There are numerous points along this process which are potential obstacles to access to health care. By and large however the biggest obstacle seemed to be in getting a doctor to take drug users on, as indicated above. The health board can assign a doctor for someone who has been refused by 3 doctors; one participant reported waiting to be assigned for the past year.

"I don't have a medical card, I have the form I'm just waitin' on a doctor. Same as (names friend)... she's me family doctor for years. I'm still waiting for a doctor. My job has been ringing up looking for doctors as well."

When asked why she thought this was, the participant responded,

"Cause I'm on a clinic."

Other participants agree that this particular doctor's list is not full as

"She only took my ma on, just there a few weeks ago,"



Experiences of Health Services

66 that's my
doctor, he
goes around
the hostels >>

and another offers

"she only took my brother in law on"

"I've no medical card and I haven't had one in about 5 years because when I came out of Mountjoy I did put in for one and went to a few doctors and they just said "ah we're not taking you on, you'll want drugs off us"."

"I was refused by 3 doctors because I was a drug user and then you send it off and then they appoint you a doctor"

"I had to get mine under false pretences."

Some gave no specific reason but had just not managed to complete the process necessary to obtain a medical card:

"Because to be honest I just haven't went about it. Like I haven't filled out the forms, I have the forms and all I just haven't filled them in and sent them away."

"I wasn't getting taken on so the reason why I haven't got a medical card is because of the fact that I haven't got a doctor."

Not having an address was seen as a barrier to getting a medical card by homeless drug users.

"The medical cards (section) won't renew it on account of me not having a stable address. I'm not down as a corporation address so I can't go down as a family member, I'm goin down as a single bloke, homeless."

"I've been 16 years homeless so I haven't had one (medical card).. No fixed abode."

Patrick went on to say he had recently been housed and he had now applied for a card and had filled in all the forms. He had not managed to get a doctor; he said that one had refused him because of his drug use. When he was asked how this made him feel he just shrugged

"16 year on the streets, it's second nature now."

Homeless people in hostels who were visited by doctors sometimes had better access to services (e.g. Cedar House).

"In the hostel I'm in at the moment, the chap that's dealing with it told me that if I give him numbers or something he'll get the medical card in a week."

"I don't have a card but I'm covered by the hostel cover, the one card does the whole hostel. I don't have me own card that's just for emergencies...

I haven't went about it."

Another woman residing in a hostel did not have a problem getting a doctor

"I'm in the Simon and the doctor that comes in to the Simon, he stamped it for me."

"Well Cedar house have one and Simon have one .. it's the one, its (names doctor)."

Another participant,

"That's my doctor, he goes around the hostels."



Another obstacle was the renewal process. Some participants admitted that some parts of the form were difficult to fill in or that they

"Haven't got round to sending it back."

"Mine is out of date since last December.. Now it's to get renewed .. I've to get the form."

"I've sent out my form I had it stamped everything done with it, what ever I was to get done with it, I've sent it out six months ago.. Still waiting."

"I just put in for a medical card and I got a doctor to stamp it and I'm just waiting to get word. I sent it all back in."

"I sent it for renewal and I'm waitin for it to come back."

Is Methadone treating the problem?

There was an issue between the 'green and the brown' (methadone) and complaints that the green is not holding them and is rotting their teeth.

Participants felt that the current methadone maintenance was not addressing their needs. Though John was on methadone maintenance for years he saw drink rather than drugs as his problem.

"I'm not on drugs; I just get my methadone from there. I was on drugs a long time ago. The only problem I have is a drink problem. And that's on top of my Hepatitis C."

John says that the alcohol treatment centre (Stanhope centre) will not treat him because he is on methadone and the drug treatment centre is not helping.

"I can't do it through City Clinic. I'm walking out the door and I'm going back on the drink. Stanhope wouldn't take me in there cause I'm on methadone. There's nothing they can do until you get off the methadone."

Another participant sees 'tablets' as his main problem

"I was admitted to Beaumont for tablets and heroin. The heroin cleared up but not the tablets. When I came out of the hospital I had a slip and straight away they put me back to square one. He put me right back up to me full dose, but still wouldn't give me any valium. I was left to look after me own valium to buy them myself on the street.

The doctor I have, kept on saying "I know you can do it, I know by looking at you that you can detox yourself" it's like as if they didn't want to give me the tablets. So I went on and on and on and on, eventually I just said fuck this! So I had to try myself. So I was more or less sent out onto the street to buy valium and come down. So I tried them 3 or 4 times, didn't work.. I told him, so he only started me there. And this is going on about 3 year, and I was only started there a few days ago!

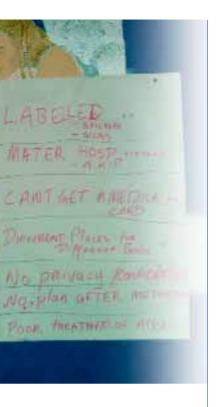
Detox, I flew through it, it was great I felt great in myself. They put me on Melleril 200mg a day. I went up to about 17 stone ..I stayed off it for about two months and then.. I couldn't ..because of the weight. I was down all the time. That's how I ended back over in City Clinic."

Participants expressed the desire to be free from drugs and seemed less than satisfied to continue on methadone without a long term plan asking

"So what's the plan are we to be hobbling in here to get methadone when we're 65?"

care we to be hobbling in here to get methadone when we're 65? >>

Experiences of Health Services



They felt there were not enough opportunities for detoxification or support to come down off methadone, as one young woman put it;

"I am asking them eight months to get me in to the hospital. I am after having problems with me kids and I am asking them for help to get me into hospital. I am on a 120mls of 'phy'. I've been on coke and I am asking them to get me into hospital to take me down to leave me on a certain amount that I'd be alright, to get me out of the environment for a while, so I stay away from cocaine. I don't want to lose me kids. I've had to give my youngest kid to my cousin, to take him for a couple of weeks. But that was arranged with her before someone reported me. They took one of my kids and left one of them with me. I've been asking them, eight months, nine months to get me in to hospital. They tell me to see counsellors, to see my doctor and I've done that and there's still no help. I am still going nowhere fast... there's nothing happening."

Another felt that the treatment centre could do more to help people come down off methadone

"They should encourage people to detox off their methadone, people who are doin' well on their methadone they should encourage them to get off it. Try to bring them on...

Where's the care in heath care?

In many of the experiences recounted it was evident that 'care' was missing. The lack of care as shown through staff attitudes throughout the services sometimes resulted in aggressive responses from the participants. They felt they were treated differently because they were drug users. Participants spoke positively about individual health care staff who showed real concern.

"I've a doctor called (names doctor) and she really is concerned about me medical problems, but there are doctors that don't give a shit."

"I have me own GP, I've me medical card, I've me family doctor for me kids. It's hard to get doctors sometimes, but now I've got one out in Darndale and he's brilliant and he's giving me a 3 month trial and that.. To see if everything is going well.

For this patient previous experiences were not as positive.

The last doctor up in (names practice) turned around and he says "well I won't be giving tablets". I said, "I don't want tablets. I don't take tablets". But he's one of them freaks, when the child would sneeze, and here he was, (imitates posh accent) "could you wipe that up, could you get some tissue, she got a little bit sick". Out with the cloths, he went out to the toilet came back in with all this sterilising stuff, he washed the floor.. (other 'jasus'). I said "you shouldn't be a doctor".

When asked how this made her feel she said

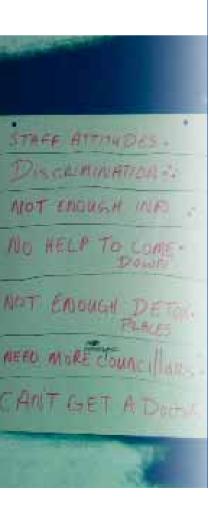
"I felt diseased, my child was diseased, we were filth."

"I had to pick up for this fella he got sick in the clinic one day and he had the virus. The GA's were running away and goin ... "well I'm not pickin' it up, I'm not pickin' it up", and I said, "put gloves on ye and pick it up it is your job, the young fella is too ill, he's too sick", so WE went and we helped him. His OWN, people helped him. But some other GA, went out to the door and said to me "no way was I pickin' it up". So I said, "come here it could be him, it could be me, it could be someone else,"

"But there's a lot of discrimination in the clinic anyway, and there are some good people there too ye know."

66 I have me
own GP,
....he's
brilliant and
he's giving
me a 3 month
trial > 2

Call the same >>



What Should be Done?

Participants were asked what advice they would give to health services managers

"There should be a lot more counselling for drug users."

"Services should be less discriminating."

"Treat every patient the same, like don't treat some rich person next to me any different then you would me. Treat each person the same don't discriminate against drug addicts. We're people too; we feel it when we're put down by doctors and hospitals."

"Its like, Jesus Christ, they just make you feel so low and this thing with the gloves on and they can't catch anything off you just taking your temperature. So I say to the doctors and management to treat us all the same."

"To try and integrate us into the main society."

"Right we're on drugs, we didn't set out to say right we're going to end up on drugs. Unfortunately we got strung out ...We're on methadone we're paying for it. I know that there's a lot of people payin' for it because we're on drugs ... We done bad and whatever but treat us equally."

"I think they need to stop thinking that throwing people into clinics and putting them on 'phy' is the answer to the problem...And leavin' them there."

"Not just put them on 'phy' and leave them there d'you know what I mean, help them like, Instead of just sayin "right they have their 'phy' they're not going to be going out robbing for gear or stuff like that."

"Treat us all with a bit of respect we are all human beings we're all equal, we're not asking for red carpets or anything like that."

"Treat us all the same. Give out more information about what's happening... on the 13 of July it is hepatitis day you know and I don't think many people knew about it."

"They think you are ignorant because you are a drug user they think you know nothing."

"They should explain themselves when they're talking to you and explain your medication."

"They've kind of tackled the drug problem, they have the clinics in the right places and people are getting treatment but they don't have the resources for people who don't want to stay on methadone. They haven't got the resources for counsellors, for when they want to come down off their 'phy' and if need be go to the country just to get out of the city for a while, to have a break you need more resources for that."

"There's no effort in treatment .. every one is the same across the board... The maintenance and that's it... "keep them on their 'phy' they'll be happy, there will be no robbing". But people don't want to stay on 'phy' for the rest of their lives. They need the resources for when people come down from their methadone so that there's something there for them."

Priorities and Conclusions

A feedback session was held at which participants had the opportunity to hear the main themes categorised as below. In general participants agreed with the following summary.

Participants wanted to be treated like everyone else and not discriminated against on the basis of drug use or associated health problems. Major problems with services were attitudes of staff, lack of confidentiality and inadequate treatment of the person as a whole (sent different places to get different health issues catered for). Respect was shown by some services and participants acknowledged this (i.e. James's and Merchants Quay). Participants felt that services and particularly the insensitive signs were discriminatory in the Mater Hospital.

The access to free health care through the provision of medical cards seems to be hampered by the reluctance of GPs to take on drug users, the difficult process in applying and keeping card updated and the lack of addresses for homeless people.

It seems apparent that services for drug users do not treat the client holistically, but rather treats part of his/her problem (i.e. drug dependency). While there was acknowledgement by some that they 'used' the clinic doctor as their GP this did not seem to be the intended system. If the client requires a GP, dentist or medical card s/he should access these outside the drug treatment clinic.

Participants felt that the current methadone maintenance was not addressing their needs. They expressed the desire to be free from drugs and seemed less than satisfied to continue on methadone without a long-term plan.

Participants were asked to prioritise the health service problems they had raised, for follow up action. There was a clear majority of participants who would like to see a change in the way the Mater hospital treated drug users. Discrimination and the desire to be 'normal' and treated like everyone else was a strong recurrent theme across experiences.

Participants were asked to rank current services in terms of better and worse. Clearly there was no consensus on some services e.g. treatment clinic and dentists were dependant on individual experiences. In general most ranked GP services towards the bottom and there was consensus around perceptions that the Mater should be ranked at the bottom.

Though the call back session aimed to focus on health services, participants insisted on registering the issue of homelessness for drug users as high on their agenda for action. During this session literacy problems were also noted which have a bearing on how health entitlements are accessed.

Conclusions

Drug users are service users and as such have the same rights and entitlements as other patients, service users and citizens of the state. These rights and entitlements are enshrined in international and national laws and implicit in policy and strategy documents.

Specific entitlements have been challenged by the accounts above including:

- Access to a range of free health services through the medical card system.
- Access to GP services in primary care
- Access to methadone maintenance in primary care
- The right to be treated with dignity and respect.

The needs of drug users are not dissimilar to the needs of patients as expressed by the Irish Patients' Association¹¹.

The fundamental principle outlined in the Methadone Treatment Protocol of a tiered treatment service which treats stable drug users in the primary care system in their own localities would conceivably bridge at least some of the gap between their treatment and the treatment of non drug using members of society and may reduce perceptions of, and actual discrimination. However if the majority of GPs are reluctant to treat drug users in the community it will be difficult to bridge this gap.

¹¹ The Irish Patients' Association have identified a number of basic needs of patients which include; treatment with dignity, equitable access to information, treatment and medication, explanation of alternatives to treatment, complaints procedures, safe system in a quality culture, ability to give informed consent and ability to trust the system.

This action research aims to facilitate the realisation of drug users' rights as members of the community to be involved in health service planning.

The health strategy places the patient at the centre of the health service and says the health system "listens to you and takes your views into account". We have presented the views of drug users. The challenge for the health system is now to take them into account!

Table 2. The main issues arising from the group discussions.

Service	Problems Identified	Comment
Acute Hospitals	Poor staff attitudesPerceived discriminationPoor 'care'LabellingSignage	Participants saw a difference between services provided in Mater and James's many spoke highly of James's
GPs	 Gate keepers of medical card Reluctance to take drug users on their lists Attitudes 	Majority consensus that GPs were reluctant to take on drug users Some used their family GP to get a medical card but did not use for health. Others lied about addiction to get 'taken on' by GPs. Some hostels had GP services
Dentist	 Some difficulties in accessing dentists Dental care identified as an important priority Not having medical card -an obstacle 	Varied experience
Drug treatment centres	 Confidentiality Lack of 'care' for the whole person Inadequate treatement of 'other' addictions and problems Some problems with access to counselling sometimes due to lack of privacy Some complaints about staff attitudes Sense that administering 'phy' was not solving the problem The one fit for all treatment does not fit the complexity of the underlying problems experienced by the client group 	Varied experience of 'clinics' Individual staff members praised. Consensus on privacy and confidentiality problems Some used complaints procedure others did not know it existed Appreciated counselling but lack of privacy in some clinics was a barrier Consensus that methadone is not the answer
Medical cards	 Difficulty in getting GPs to stamp application Some extended waiting once completed forms were sent in Poor information about process 	General consensus on GP barrier
Pharmacies	Perceived discriminatory treatment (e.g. not allowed in shop)	Minority reported good service

Actions and Outcomes

The Participation and Practice of Rights project, UISCE and Mountjoy street Family Practice will:

- Engage decision makers and lobby for change
- Raise awareness where necessary through the media
- Encourage more GPs to treat this patient group in their communities
- Feedback results of these actions to the drug using community
- Monitor actions and outcomes, identifying barriers and enablers

As the groups involved in asking drug users their views we recognise both our limited capacity to make change on many of the issues raised, as well as our duty to the participants who gave their time to share their experiences openly and honestly. In addition to the above specific actions we convened an informal meeting of service providers and key stakeholders to draw up an action plan to tackle the main issues arrising out of this consultation with drug users (see pages 26 and 27).

The following are the longer term outcomes expected as a result of initiated action:

- A realisation of the right to dignity of those on methadone treatment
- An identifiable change in policy and practice of health services with regard to their treatment of drug users
- An increased awareness among drug users of their rights as patients and citizens
- The voice of drug users is taken into accont by the health system



Consultation with Service Providers

28th June 2005: Merchant's Quay

Purpose

To identify the appropriate channels and necessary actions to make changes on specific issues raised by drug users in focus group discussions on their experience of health services.

Summary of consultation

Participants were sent a draft copy of the report which they had read prior to the meeting. A presentation of the main findings was made by Fiona O'Reilly and Emily Reaper. General comment and feedback was then invited from those in attendance.

The following points were made:

- The report represents drug users views. It is a stage in a process to improve services for this client group and will allow their views to be taken into account in the planning and implementation of services.
- 2. Participants welcomed the initiative taken to assess the views of drug users on services and felt it was important that the voice of the drug user was heard in the system. There were some comments that the report focused mainly on negative views and did not represent the many clients who are happy with services and treatment.
- 3. It was stressed that the issues raised were based on clients' perceptions. The provider group felt that findings may not be accurate reflections of reality but nevertheless were issues that needed to be addressed so that perceptions change.
- Providers do not necessarily concur with some of the views. A wide range of comprehensive addiction services exists. However these are sometimes challenged by limited resources and infrastructure.
- 5. People in acute hospitals and other health services should be treated equally and with dignity. A paradigm shift from medical to social model is necessary. Equity of services needs to be embraced.
- 6. There was a high level of non-medical card holders among this vulnerable group.
- 7. There are issues of security/confidentiality for services, which necessitate implementation of rules and regulations for clients.
- 8. Due to difficulties within central services, primary care services (e.g. pharmacies) are taking on unstable patients. This was not envisaged in original protocol.
- 9. There is a general difficulty in getting additional GPs involved in the methadone protocol.
- 10. The fifth pillar of the National Drugs Strategy emphasises rehabilitation.
- 11. Providers see continuation on methadone maintenance in a more positive light than do users.
- 12. Providers were eager to work together to solve problems raised.
- 13. It was suggested that the report should include this summary to reflect discussions and thereby minimise any possible defensiveness which might hinder future progress.

Meeting Participants:

Mary O'Shea (Merchant's Quay)

Noleen Dargen (Pharmacist Dargen's Pharmacy)

Ruth Gray (Dentist Merchants Quay)

Grainne Courtney (St. James's Hospital)

Eddie Matthews (Director for Social Inclusion HSE)

Johnny Connolly (Research Officer, Drug Misuse Research Division, HRB)

Gerry Reid (AOM Addiction Services)

Phil Dunne (Project Manager - Partnership in Primary Care)

Bernie McGuire (Information Officer Addiction Services)

Christina O'Connell (Manager Mountjoy Street Practice & Thompson Centre)

Ciara Mac Meel (GP Mountjoy Street Practice)

Austin O'Carroll (GP Mountjoy Street Practice)

Fiona O'Reilly (Research Associate Mountjoy Street Practice)

Emily Reaper (Project Worker UISCE)

Tom Redmond (Rights Worker Participation and Rights Project)

Table 3. Suggested Solutions and Routes for Redress

Issue raised	Possible Solutions	Route
Barriers to Medical Card access GPs Gate Keepers of Medical Cards	Separate application process from GP registration	National Social Inclusion Directors General Managers in CCAs
Difficult process to understand	Form in 'Clear English'	NALA
Hospitals Poor perception of treatment by acute	Share lessons from St. James's Hospital	Not identified at meeting
hospitals particularly Mater	Take down / change insensitive signage (Infectious disease)	Letter of Complaint to CEO NICP; Social workers
	Raise specific issues with Mater	CEO & New Infectious Disease Consultants
	Educate client group about what to expect as normal hospital procedure	UISCE
GPs Reluctance to be involved in methadone	Reduce 'fear' through introduction of peer led support systems.	ICGP and GP Coordinator (Addiction Services)
protocol	Raise awareness of need	NICP
Reluctance to register drug users	Explore 'why GPs are reluctant' Educate client group about rights,	Further Research (Mountjoy Street Practice)
	entitlements and appeals procedures	UISCE
Methadone Perception that it's not the answer	Involve clients in their own care plan (learn fro positive experiences in some centres)	Review research from international experience and identify best practice
	Systematic review of clients on methadone maintenance long term	Central Treatment List and National Drug Treatment Reporting System
	Review the message being sent out by treatment services, that clients will be on maintenance indefinitely	
	Devise different approaches for different client type groups (e.g. short term users)	
Confidentiality Perception that all staff knew 'their' business. Counselling rooms not sound proofed	Review best practice charter in this area and access reality against guidelines	Addiction Services
Pharmacies Unreasonable / unrealistic contracts devised by pharmacies	Agreed contracts developed with client group.	UISCE and Pharmaceutical Society
Dental Care Poor access to Dental care	Dental treatment centres attached to Drug Treatment Centres	Lobby Department of Health and HSE utilising this and other research (R.Gray)

People registered on Cer List by electoral division	
ARRAN QUAY A	11
ARRAN QUAY B	32
ARRAN QUAY C	39
ARRAN QUAY D	77
ARRAN QUAY E	45
ASHTOWN A	6
ASHTOWN B	4
BALLYBOUGH A	103
BALLYBOUGH B	33
BOTANIC A	5
BOTANIC B	4
BOTANIC C	16
CABRA EAST A	22
CABRA EAST B	31
CABRA EAST C	39
CABRA WEST A	13
CABRA WEST B	20
CABRA WEST C	50
CABRA WEST D	24
CLONTARF WEST D	8
CLONTARF WEST E	6
DRUMCONDRA SOUTH A	13
DRUMCONDRA SOUTH B	6
DRUMCONDRA SOUTH C	10
INNS QUAY A	13
INNS QUAY B	56
INNS QUAY C	54
MOUNTJOY A	164
MOUNTJOY B	73
NORTH CITY	45
NORTH DOCK A	7
NORTH DOCK B	20
NORTH DOCK C	89
ROTUNDA A	69
ROTUNDA B	37
Total	1244
NEIC EDs	640
NWIC EDs	217

Note: This data corresponds to map on page 5.

The Right to Health

Guidelines for Developing Health indicators in the Context of The Rights

Ill health both causes poverty and can result as a consequence of poverty. Ill health can inhibit an individual's educational achievements, their ability to work and their opportunities. Poverty can lead to reduced access to medical care, increased exposure to environmental risks and malnutrition, all of which contribute to ill health.

Good health is an essential element of the empowerment poor people need in order to escape from poverty. Enjoyment of the right to health is instrumental in securing other rights such as education and work. The right to health is protected by several international human rights instruments, including, the United Nations International Covenant on Economic, Social and Cultural Rights (ICESCR) and the European Social Charter (ESC).

The right to health implies the right to a variety of facilities, goods, services and conditions necessary for the realisation of the highest attainable standards of health. The right to health is not confined to the right to health care. The right includes both health care and other determinants of health such as access to potable water, adequate and safe food, adequate sanitation and housing, healthy occupational and environmental conditions, and access to health-related information and education.

In the Irish constitution there is no specific reference made to the right to health, however, article 45.4.1 states:

The State pledges itself to safeguard with especial care the economic interests of the weaker sections of the community, and, where necessary, to contribute to the support of the infirm, the widow, the orphan, and the aged.

Article 12 of the UN Covenant on Economic, Social and Cultural Rights encourages governments to ensure that medical services and medical attention are available to all persons in the event of sickness:

- 1. The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.
- **2.** The steps to be taken by the States Parties to the present Covenant to achieve the full realisation of this right shall include those necessary for:
- **3.** The creation of conditions which would assure to all, medical service and medical attention in the event of sickness

Article 11 of the Revised European Social Charter outlines the right to the protection of health: With a view to ensuring the effective exercise of the right to protection of health, the Parties undertake, either directly or in co-operation with public or private organisations, to take appropriate measures designed inter alia:

- 1. To remove as far as possible the causes of ill-health
- 2. To provide advisory and educational facilities for the promotion of health and the encouragement of individual responsibility in matters of health
- 3. To prevent as far as possible epidemic, endemic and other diseases, as well as accidents.

Article 13 of the Charter provides for the right to social and medical assistance: With a view to ensuring the effective exercise of the right to social and medical assistance, the Parties undertake:

1. To ensure that any person who is without adequate resources and who is unable to secure such resources either by his own efforts or from other sources, in particular by benefits under a social security scheme, be granted adequate assistance, and, in case of sickness, the care necessitated by his condition.

Excerpts from the Report of the Methadone Treatment Services Review Group (Undated) Department of Health and Children

Methadone treatment should continue to be a valid treatment for opiate dependence as part of a comprehensive programme of care [3.(a)]

Treatment for opiate misuse should be provided in the misuser's own local area wherever possible as recommended by the Pharmaceutical Society of Ireland the Medical Council and the Irish College of General Practitioners. [1.5 and 1.6]

General practitioners should provide methadone treatment to opiate misusers who reside in their local area in accordance with the terms of the proposed GP Contract as set out in this document and as endorsed by the ICGP [4.2]

Pharmacists should provide methadone treatment to opiate misusers who reside in their local area in accordance with the terms of the proposed Pharmacist Contract as set out in this document [5.2]

The review group recommends that the health board GP coordinator contacts the GP and informs him/ her of the details relating to the person. The health board designates a key worker for each patient and where necessecary a community addiction counsellor. The GP enters into a contract with the board to provide methadone in accordance with the protocol [6.1.1]

The Eastern Health Board (EHB)* should ensure that proper structures for effective working relationships between treatment centres and general practitioners and pharmacists are put in place [6.2]

Under Future plans of the methadone scheme the EHB and Drugs Treatment Centre in Pearse street would be responsible for on-going support to GPs and Pharmacists under the consultant psychiatrist area operations managers and GP coordinators with 2 liason pharmacists [6.2 (a)]

Patients will be supported from health board counselling and out reach staff [6.2 (b)]

Comprehensive treatment plan put in place for each patient; this will include medical social and psychological care – a regular review will be made of each patient's progress on methadone. [6.2 (f)]

* Now Health Services Executive

Addiction services provided directly by the NAHB on an area wide basis

NAHB Addiction Services

Phibsboro Tower, Phibsboro, Dublin 7. Tel: 8820300

Treatment Centres (North City)

- Cabra Clinic 121 Broombridge Close, Ballyboggan road, Dublin 11 Tel:8307051
- City Clinic, 108/109 Amiens Street, Dublin 1. Tel 8620298
- The Mews, 224 North Circular Road, Dublin 7. Tel 8380298

Satellite Clinics (North City)

- Buckingham Street, 42 Buckingham Street, Dublin 1. Tel: 8555311
- Thompson Centre, 53 Mountjoy Street, Dublin 7. Tel: 860 2000
- Mobile Clinic (Stops at Empress Place, Dublin 1)

Counselling therapy

- 2nd Floor, Phibsboro Towers. Head of Discipline area 7 - Kathy O'Flaherty 087 6862180

Outreach Services

- 2nd Floor, Phibsboro Towers. Head of Discipline - Jane Kenny 086 8543755

In and Out patient detoxification

- Phibsboro Tower. Consultant Psychiatrist in Substance Misuse
- Units Cuan Dara SWAHB, Cherry Orchard Ballyfermot
 - St. Michaels ward Beaumont Hospital

Information and education and prevention

- 2nd Floor, Phibsboro Tower. Contact Bernie Maguire

Soilse NAHB Addiction Rehabilitation

- Drugfree: 6/7 North Frederick Street, Dublin 1.Tel: 8724535 soilse@eircom.net
- Prescribed Medication: 1 / 2 Henrietta Place Dublin 1

Holistic service which responds to a range of recovery discovery and rehabilitation needs

Rehabilitation and integration service (RIS)

- 2nd Floor Phibsboro Tower. Contact: Cathal Morgan 086 3837278

Keltoi

Therapeutic Rehabilitation, c/o St Mary's Hospital, Phoenix Park, Dublin 20. Tel:6200040/41 marion.earle@erha.ie

Residential Rehabilitation

Drugs information help line: 1800 459 459

Talbot Centre

29 Upper Buckingham Street, Dublin 1 Tel: 8363434/ 8366746 Fax:8553910

To work with young people up to 20 years of age at risk of drug abuse, young people using drugs and their families. Acts as a resource to local community by participation in the community response, in the area of prevention and education.

Gay Men's Health Project

Baggot Street Clinic, 19 Haddington Rd, Dublin 4

Tel: 6602189 Ext:4221

Service: Sexual Clinic for gay and bisexual. Full STD screening, HIV testing, Hepatitis B testing and Vaccine.

Addiction services provided by other agencies in collaboration with NAHB on an area wide basis

Anna Liffey Drug Project

48 Middle Abbey Street, Dublin 1

Tel: 8786899 Fax: 8786828 E-mail: aldp@indigo.ie

Service: Education, training, guidance/counselling, childcare, arts, peer support group for recovering drug users, after-school clubs, summer projects.

Coolmine Therapeutic Community

Coolmine House, 19 Lord Eward Street, Dublin 2 Tel: 694822, Email: coolhse@eircom.net Service: Holistic drug free recovery programme

Drug Awareness Programme (Crosscare)

Crosscare, Clonliffe College, Dublin 3

Tel: 8360911 Fax: 8360745 E-mail: drugprev@eircom.net

Service: Training and support for those interested in preventing drug problems. Works in partnership with communities.

Dublin AIDS Alliance

53 Parnell Square West, Dublin 1

Tel: 8733799 Fax: 873 3174 E-mail:aids-alliance-dublin@hotmail.com

Service: Mediation, advocacy, referral and information on HIV related issues. Personal development training and customised training programmes on HIV, homophobia and related issues. Also campaigning on issues of social justice.

Open Heart House

2 Mary's Place, Dublin 7

Tel: 8305000 Email: Paula@openhearthouse.ie

Service: Range of services which challenge isolation of HIV/Aids and empower and enhance the lives of people living with the illness

Teen Counselling

Mater Dei, Clonliffe Rd, Dublin 3. Tel:8371892 email:materdei@teencounselling.com Ballygall, 19 Glasilawn Ave, Dublin 11. Tel: 8646014 email: ballygall@teencounselling.com Service: Adolescents 12-18 years are seen with parents, care worker or guardian

The Drug Treatment Centre Board

30/31 Pearse Street, Dublin 2. Tel:6488600

Service: Treatment prevention rehabilitation and aftercare. Guidance to other professionals. Drugs analysis lab services and research department.

Additional Addiction Services available in the North Inner City and DTF

North Inner-City Drugs Task Force

22 Lower Buckingham Street, Dublin 1. Tel: 366592 Fax: 8366286 E-mail:nicdtf@iol.ie

The role of the Drugs Task Force is to plan and implement an effective response to the drug problem in the North Inner City by improving co-ordination in service provision and utilising the knowledge and experience of local communities in designing and delivering those services. The Task Force is a partnership between the statutory, voluntary and community sectors.

Dublin Citywide Drugs Crisis Campaign

109 North Strand Road, Dublin 1. Tel: 8365090/8365039 Fax: 8364849 E-mail:info@citywide.ie Service: Specialist support agency to community development programmes. Also supports the network of Family Support groups.

After Care Recovery Group (ACRG)

176 North Strand Road, Dublin 1 Tel: 85577952 tkacrg@hotmail.com

Service: Practical support to those in recovery. Drug free project that offers a day programme. Non-therapeutic, non-medical, access to counselling, access to further education/training, care parenting skills, relaxation techniques, anger management, etc.

Crinan Youth Project

72 Sean McDermott Street, Dublin 1 Tel: 8558792 email:cproject@gofree.indigo.ie Service: Treatment and rehabilitation project for young people (15 – 21 years) from the North Inner City, with drug dependency. Educational, recreational and therapeutic programmes.

SAOL Project

58 Amiens Street, Dublin 1. Tel: 8553391/93 mob: 086 8266410 email:joan@saolproject.ie Service: Rehabilitation project for women drug users through personal development, education and support. Participants commit to a two-development programme attending 5 mornings a week.

UISCE (Union for improved Services, Communication and Education)

53 Parnell Square West, Dublin 1. Tel: 873 3799

Drug service Users Forum. Provides an opportunity for those in receipt of services to have a role in policy development. Services include: Hosting drug service users fora; providing information by regular newsletter; conductiong action research on issues with users.

ICON Drugs Support Project

15 North Strand Road, Dublin 1. Tel: 8550303/087 6537518.

Service: Drug referral, immediate response and support.

CAIRDE

19 Belvedere Place, Dublin 1 Tel: 8552111 Fax: 8552089 email: info@cairde.ie Service: Support for people infected or affected by HIV/AIDS. Crisis intervention, information, referral service, counselling, child and family service, volunteer support and befriending, advocacy and campaigning.

Oasis Counselling Services

Pastoral Centre, St. Laurences Place East, Seville Place, Dublin 1. Tel: 8364524

email: oasiscounselling@eircom.net

Service: Bereavement counselling on one to one basis and famillies

NIC Step by Step

Georges Hill National School Tel:878155 email stepbystep@dublin.ie Service:Education and prevention programes for young people

North Inner City ASESP

25 Spenser Dock, Lr Sheriff St, Dublin 1. Tel: 8554043 afterschools@indigo.ie Service Education and skills training to children age 13 to 18 years.

Snug

Macro, 1 Green St, Dublin 7 Tel 8786231 email: thesnug@eircom.net Service: Education and prevention programmes for young people

Chrysalis Community Drugs Project

27 Benburb St. Dublin 7 Tel: 6705544

Service: Drug related support and counselling to individuals and families. Provides links to health, social and welfare services. Support to drug using women working in prostitution.

North-East Inner City Community Policing Forum

Killarney Court, Lr Buckingham St, Dublin 1. Contact Marie Medcalfe. Tel:

Gateway

38 Arran Quay, Dublin 7. Tel 8720127 Fax 8720127 manager@gateway.iol.ie Service: Prepares women for employment.

Hope

49 North Strand D1 Tel 8878403 email afterschools@indigo.ie

Service: Education and prevention programmes for parents in relation to problem drug use.

North West Training and Development

Macro, 1 Green St, Dublin 7 Tel:8737014

Service: Education and prevention for young people

For more information on available addiction services in the Northern Area Health Board contact NAHB Addiction services Phibsboro Towers, Phibsboro, Dublin 7 Tel:8820300

Photos

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Page 21 & 22 Flip charts at call back session

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Photographs above by Fiona O'Reilly, 2004 & 2005

Page 3 Anti drugs march (compliments of The Folklore Group)

Page 25 Methadone March (compliments of Citywide)

Thanks to: Orna O'Reilly for report design and SIPTU for printing



Report available from:

UISCE c/o Dublin AIDS Alliance 53 Parnell Square West, Dublin 1 Tel: 8733799

or

Participation and Practice of Rights Project (PPR) c/o Tom Redmond ICRG, 57 Amien Street, Dublin 1 Tel: 8557207 email: icrg@iol.ie

