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A COMMUNITY ENGAGEMENT PROJECT

“SILENT VOICES”

A REPORT OF THE NEEDS AND ISSUES OF HIV+ WOMEN WHO HAVE OR ARE STILL USING DRUGS AND ALCOHOL CARRIED OUT BY THE INTERNATIONAL COMMUNITY OF WOMEN LIVING WITH HIV /AIDS (ICW) IN LONDON.

The research was carried out by: Carmen Tarrades, Elizabeth McKay, Moono, Leigh Neal and Beatrice.

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PERSONAL PROFILES:

The following people were involved in the development and delivery of this project.

Carmen Tarrades

Carmen has been a member of ICW for 7 years and was diagnosed as being HIV positive in 1989. She has been using drugs since the age of 15 and began working with ICW in 2001 as “Voces Positivas” project co-ordinator. When that project was completed, Carmen then became Membership Development Officer as well as continuing to think about the needs of HIV positive drug users and how ICW could support them. When the opportunity for funding arose, she grabbed it with both hands and presented the proposal for *SILENT VOICES* to the University of Central Lancashire. Carmen wants to develop this project further and take it nationally and internationally.

Liz McKay:

Liz has been a member of ICW for 6 years and a trustee member for 2 of those years. Liz has been HIV+ for 20 years and was a drug user from the age of 18 to 39. She has worked both with positive women and drug users over the years and believes that drug users should be heard and listened to at all levels. She particularly wanted to be a part of this research as she feels this is a beginning for other service users and providers to understand the difficulties these women face on a day-to-day basis. Liz has particularly enjoyed learning about the research side of this project. She is also a trained hypnotherapist.

Moono:

Moono has just recently joined as a member of ICW. She is currently reading Law. She has thoroughly enjoyed her work on the *Silent Voices* project – not only because of the opportunity it has provided for the women affected to tell their stories but also because it has brought the subject back to the fore.

Leigh Neal:

Leigh has been involved with ICW for over 10 years, originally as a Trustee and a volunteer and lately as a member whilst concentrating on her embroidery textile studies. Leigh was diagnosed HIV+ whilst serving a prison sentence for a drug-related crime 19 years ago. Leigh has got back involved with ICW as she feels that *Silent Voices* is an important and long overdue piece of research, as even within the HIV community there is invisibility and marginalisation of drug users.

Beatrice:

The researchers and all at ICW would like to express our sincerest appreciation to Beatrice, who sadly passed away May of this year. We would like to dedicate this report to her as she gave her fullest commitment and encouragement to make this report happen. We will always remember the passion, insight and inspiration that she brought to this important project.

ACKNOWLEDGEMENTS

ICW would like to thank the University of Central Lancashire for giving them the opportunity to be involved in such a significant project for HIV+ drug using women. ICW believes that HIV + women drug users often face triple discrimination which leads to prejudice, invisibility and marginalisation and hopes that this research will be a step forward in addressing these and many other issues HIV+ drug using women face.

ICW on behalf of the *Silent Voices* Drugs Research Team would like to thank all those who participated and contributed toward this research project.

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And the *Silent Voices* Steering Committee:

- Carmen Tarrades: Project Coordinator and ICW staff member.
- Mark McPherson: I Base
- Shona Flannigan: Membership and Development Coordinator – London Drug and Alcohol Network.
- Fiona Hale / Fiona Pettitt: ICW International Network Manager
- Chezerine Dhaliwal: - DAT Islington – Representative from the Community Safety Partnership Unit.
- Jax Shapter: Mainliners
- Alison Johnson: Hackney Drug Action Team
- Faith Mango: Support Worker from the University of Central Lancashire

The people involved in the steering committee were chosen for their knowledge of the issues affecting people living with HIV and their knowledge of issues affecting drug users. They all work in the relevant fields and because of their extensive experience, they were able to support and advise on the proceedings of the research.

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Executive summary

Introduction - *Silent Voices* is an ICW project, funded by the University of Lancaster, developed to research services available for HIV+ drug/alcohol using women living in London, UK, their experiences of such services as well as barriers to access and to find out what services the women felt they needed. The project also aimed to create links between positive women drug users, with the help of local partner organisations, to collate information on current policies and practice and to develop advocacy tools around gender, sexual reproductive health rights, access to care, treatment and support, harm reduction and possibly prevention. In line with the participatory approach focus groups and individual interviews were conducted by HIV positive former or current women drug users.

Prevalence - During 2005, a reported 112 people were diagnosed with HIV probably acquired through injecting drug use. By the end of December 2005, reports showed that 4,392 people had acquired HIV by this route (*Avert website: <http://www.avert.org/uksummary.htm>*).

Background of participants - The 20 participants in the research, all of whom were HIV positive women, were from a range of ethnic and religious backgrounds. They also varied considerably in age and number of years since their HIV diagnosis. Out of the 20 participants involved in this research 5 have been diagnosed since the year 2000 with 2 women having been diagnosed as far back as 1987. Nine of the 20 women have been either arrested or cautioned, 5 women have spent time in prison. 16 of the women had received their diagnosis in either clinics or hospitals and four were diagnosed in prison.

Diagnosis - An HIV positive diagnosis is life-changing often precipitating fear, shock, a sense of helplessness, forms of denial and occasionally self-blame. However, the impact and nature of this change can depend on the way in which a diagnosis is given and the level of support offered to women once they are diagnosed. Of all the women who were asked about the manner in which they were given their diagnosis, everyone has something bad to say, no matter which country they were living at the time. What is even more shocking is that nothing seems to have changed in 20 years.

Responses to how their diagnosis affected the women's lives varied from some who increased their drug use or started taking drugs to others drastically changing their lifestyle and starting a process of reducing their drug intake. The majority of women who have been living with HIV for many years expressed the psychological impact of originally believing that their lives would be cut short to now having to readjust their way of thinking about life and the future. A few women became involved in activism either in the HIV or drug field, such activism generally increasing feelings of self-worth.

Partners - Of the 14 women who gave in-depth interviews, 7 of these women are either married or in long-term relationships. Only one partner is HIV positive, the others being negative.

The testimonies from the participants show concerns over disclosing their HIV status and drug use, with the expectation that existing partners might leave them or that it would be difficult to find new partners. In fact partners generally (but not always) showed a fairly good level of support from ex and existing partners and varying degrees of support from new partners.

There were a diverse selection of answers to this question, yet it is evident that when thinking about a long-term relationship the women felt it was important to disclose as early as possible. However, a large proportion of women stated that after many years of diagnosis they tended not to disclose as readily as before. On the other hand women felt strongly that if it was going to be a one-night-stand it was important to practise safer sex. Some women in the early stages of diagnosis felt disclosure was far too difficult and made a decision to not have sex at all.

Family and friends - there were diverse examples of how, when and why women disclosed to their family and friends and the reactions they met. Reactions varied from shock and discrimination to full and loving support.

Disclosure to children similarly is fraught with concern related to possible reactions and the impact on the lives of their children. Acceptance by children of their mother's diagnosis was extremely important. However, one woman felt that telling her children would serve her needs more than those of the children.

Wider community/society - It was generally found that even the women who work within the HIV community and were open about their status did not disclose to the 'wider community'. A few women stated that they enjoyed being in environments where they could be anonymous and feel a part of normal living.

Silent Voices undertook this project because the researchers had experienced discrimination not only within society but more alarmingly actually by their own peers. Anecdotal evidence has been gathered by ICW of discrimination by male drug users who are HIV positive towards HIV positive female drug users wishing to become pregnant. Even during international events whose main focus is HIV rarely are the voices of drug users heard or their concerns even mentioned. This discrimination is particularly alarming given the close link with failed strategies to address HIV transmission and drug use and that many of the new infections in a number of countries, especially Eastern Europe, are due to injecting drug use.

At a local level the majority of women participating in this research stated that even though they felt able to discuss issues around their HIV status they felt that being honest about their drug use and lifestyles amongst their peers was very hard to do. Most had experienced at some point in their lives varying degrees of ostracism on disclosure; even marginalised and judged by other HIV positive women.

Professional lives - All but 2 of the women involved in the research have previously or still are working in various professions. Positions held have been as varied as teaching Spanish, painting and decorating, nursery nurse, to project workers, management and key development roles within both national and international HIV organisations and editing a harm reduction publication. A few of the women have returned to full or part-time study and a few do voluntary work. Various levels of qualifications are held by the women including BA's MA's and one PHD. '*Silent Voices*' feel strongly that this part of our research challenges the stereotypical picture quite often painted by society around drug users.

Whilst some women considered themselves disabled they still felt that they could work part-time but the main anxieties around work were disclosure to employers and the fear of losing their benefits and the worry that their health would later decline. Maintaining confidentiality at work is not easy given the need to take time off for appointments, treatment and illness. Apart from the few women who felt able to disclose their status as they were working within the HIV community, most women who are or have been in full-time employment did not feel able to disclose. In fact some of the women said they felt that they had been discriminated against at work after disclosure. Other concerns around maintaining confidentiality were related to pension schemes and health questionnaires.

General health - Three quarters of the participants have a dual diagnosis of HIV and Hepatitis C (HCV). As it stands at the moment there is no cure for either HCV or HIV and therefore is and will be a huge issue for the women and the National Health Service.

Silent Voices believes that more research needs to be carried out around living with HIV in the long term. As more and more women in this country successfully live with HIV they are now facing other health issues that they believed they would not live long enough to experience, for example, the menopause and various types of cancer.

Of the 20 participants, the majority of which have been diagnosed for longer than 10 years half were not on combination therapies. Other medications taken by the women for other various conditions include: anti-depressants, sleeping pills, tranquilisers, dihydrocodeine, antipsychotics, acyclovir, thyroxin and asthma ventilators.

All the participants have used and benefited from complimentary therapies. Although the majority of women have used them more in the past, many stated that they would definitely use them more if they were easily accessible today.

Sex and sexuality - The women's feelings around sex and sexuality varied greatly. Some women were still too scared around issues of disclosure and the fear of infecting partners to even think about a sexual relationship. Whilst others, especially women who have been living long term with HIV felt that these days they felt confident enough to have a casual relationship without disclosing as long as they practiced safer sex. A lot of the women felt that sex could no longer be as spontaneous as they would like due to having to practice safer sex.

Those women who felt their libido had changed said it was connected to issues such as when they were feeling ill, body changes due to lipodystrophy, general relationship problems or due to the menopause and not necessarily directly related to HIV. One woman felt that she had no concept of anything being different for her as she was only 15 when diagnosed.

Motherhood - Out of the 20 women participating in '*Silent Voices*' 9 are mothers, 3 have had a child since their diagnosis; 7 have 1 child each whilst 2 had 3 children. One of these children has subsequently died through an HIV related illness and another has died from addiction. Two of the children have been adopted by other families. One woman is currently pregnant.

Women who are diagnosed now can safely have children even when both partners are positive. Research has advanced incredibly in the last few years and so has the knowledge regarding how HIV is transmitted from mother to child and also regarding important steps to follow regarding minimisation of transmission. Having said that, from the experiences of the women participating in the research, not all health professionals are aware of these developments and therefore do not support the reproductive choices of HIV positive women.

Women and their partners also experienced anxiety during pregnancy and post-delivery.

For the women who decided to become pregnant there were different experiences within the health system. The HIV doctors were supportive and gave advice regarding how to become pregnant. Issues of serodiscordance and minimisation of transmission to the negative partner were also explained to couples. However, such supportive attitudes are not generally prevalent amongst the other professionals involved post partum.

The research seems to highlight that these attitudes are the result of the lack of information within health professionals in general and highlights the need for training at all levels of the NHS. And even when the consultants are supportive, they also seem to stick to the guidelines regarding mother to child transmission without listening to the concerns and desires of the women in their care and sometimes ignoring the latest data available regarding PMTCT.

Many of the women who have been living with HIV for many years felt that they had no choices. Most were actively discouraged from having children as in those days the belief was that both mother and child would die. Another woman who is currently still young enough to have a child but has been diagnosed for nearly 20 years and no longer accesses services other than her clinic had not been given any recent information around this issue. The *Silent Voices* team were concerned that this was because she was still taking drugs - judgmental attitudes around injecting drug users (HIV positive and negative) having children abound both outside of and within health services.

Alcohol and drug use - The majority of the participants drink alcohol and most say that they do so socially and that their drinking has lessened over the years. This could be because they are all getting older and wiser or maybe because the majority of us are also co-infected with HCV hence the need to take care of our livers. It should be noted that the women who do not drink (with the exception of one woman who is currently pregnant) the others all belong to an abstinence-based drug and alcohol self-help group. Only 3 of the women felt that their drinking was problematic.

Three quarters of the women smoke.

Just over half the women still use illicit drugs, although again most claim to have cut down dramatically. All the women interviewed had used drugs chaotically for long periods previously, but when asked if they felt that their current drug use was problematic only a very small percentage said yes. Two of the women said that the only problem was the expense. One woman felt her drug use was not a problem but others may view it in a different light. Another woman realised that whilst she was drug dependent, this was not a problem for her.

The drugs currently still being used are hash, cocaine, ecstasy, speed, methadone, injectable diamorphine and physeptone, diazepam, heroin and crack. Half of the women use on a daily basis. As most of the women claim not to have a problem now with drugs, it appears that cocaine, as opposed to crack, is being used recreationally. Hash use appears in this category also. The women who have or are still heroin users appear to have used for long periods, whilst crack users seem to reach 'rock bottoms' quicker. The use of crack appears do more damage more quickly.

When asked what their drug of choice was three quarters of the women said heroin whilst the remaining quarter said cocaine with the exception of one woman that felt hash was her drug of choice and the other said that heroin and crack (speedball) together was hers. Out of the 20 women 16 reported that their favoured method of use was injecting, 4 preferred smoking their drugs and 2 would rather snort theirs. The majority of women still using illicit drugs no longer inject.

When asked whether the women disclosed their drug use with any professional worker, for example, consultant, nurses, counsellors with the exception of one woman all replied yes. However, responses from these professionals were in many cases not particularly positive.

When asked if they felt, that continued drug using and drinking impaired their ability to adhere to their treatment regime the answers were quite conflicting ranging from women that were using cocaine heavily and being able to adhere totally to others who found that drinking especially affected adherence. One woman said that when she was using heavily she was aware that she might not be able to adhere if she started treatment. She was also beginning to get quite ill - yet her HIV specialist did not offer any help or even a referral to address her drug use.

Drug and alcohol services - When the women interviewed were asked what three drug and alcohol services they considered most important in regards their drug use the responses were: Drug Dependency Units (DDUs), needle exchanges and drop-ins.

It appears that the women who have managed to abstain from alcohol and/or drugs for any period of time checked out services themselves and used them according to their own needs. The services used were DDU's, crisis detox centres, rehabs and NA (Narcotic Anonymous) meetings. Quite a few women stated that they used their own initiative and stopped of their own accord when they felt that their use was out of control. Most of the women have stopped using chaotically and now use recreationally although a quarter of the women abstain from both drink and drugs and regularly attend NA meetings in their local area. These meetings are free and are not a government service.

When asked if the women felt they were given (directly) enough information on the use of illicit drugs whilst taking combination therapy almost everyone reported that they had never been given any information directly. Whilst at their local clinics although there was often literature in the waiting rooms it all seemed to be aimed at gay men and clubbing. The women felt that it was assumed by their doctors that if they had stopped using chaotically they did not use drugs at all.

Five of the women who gave in-depth interviews had spent time in residential rehabilitation centres since diagnosis. Although in some cases the women were not treated badly they felt that due to ignorance and lack of experience around HIV there was in the main no direct /comprehensive support. One woman was faced with the decision imposed by the staff of having to disclose to her peers or leave the facility. Another disclosed immediately to the group and to her surprise was hugged and accepted but later the same peer group brought up issues around her serving the food at meal times. Some women felt that the facilities didn't appear to have any real policies or strategies around HIV.

One woman returned to the same facility many years later after being their first patient with HIV and when staff did not know how to deal with her. She found on her second visit that they were more prepared and were very professional. She was completely happy with their level of support, confidentiality and treatment both psychological and medical.

HIV services - When the women interviewed were asked what three HIV services they considered most important in regards to their HIV the responses were: medical services that provide treatment along with treatment information and monitoring of treatment; complimentary therapies; peer support with information resources.

Although all the participants have used a variety of services in the past the majority of women now only use their clinics for their medical care. It should be noted that the women involved in the research were all able to access services locally – this is an advantage of living in the capital.

Although the participants may have shopped around until finding a service which they are comfortable with, it is worth adding that the majority have also decided their clinic is the only service where their needs are met.

There were various reasons for the women not accessing services as frequently as they may have done, for example, women returning to work and study. Many services do not have late opening hours. Unfortunately many of the complimentary therapy services are no longer in existence and those that are usually only open during the day. Due to long-term living with HIV many women are just getting on with 'normal living'. However, *Silent Voices* has exposed the isolation faced by HIV positive drug using women. They felt that present day services do not support them in their specific needs and in fact many expressed feelings of being invisible and discriminated even within the HIV community. The majority felt the need for peer support, although many said that having a space to meet together need not be as frequent as weekly and did not have to be that formalised.

RECOMMENDATIONS

Pre and post diagnosis:

- Pre and post counselling are very important for those who have just been diagnosed – they help in dealing with the shock, the fear, the sense of helplessness, the denial and occasionally the self-blame. It might help avoid some of the issues that a positive diagnosis might lead to, i.e. increase in drug use.
- Along with a positive diagnosis, information should also be given regarding the services which might be able to help – not just what the clinic has to offer.
- Ensuring that alternative therapies are available for all those living with HIV (regardless of whether they are still using or not). All the women interviewed benefited from them, and if we consider the range of conditions indicated by the participants, it would ultimately be of benefit to the health system.
- Develop better strategies for the management of pain for drug users – because of drug use, the tolerance can be very high – so when in need of painkillers the dosage should be discussed with the patient on the basis of their tolerance.
- More support regarding issues of adherence to treatment needs to be offered and in some instances DOT (Directly Observed Treatment) might be an option.
- ARV treatment needs to be offered to all those who need it, regardless of whether they are drug users or not.

Disclosure:

- Disclosure is a big issue with all the women who were interviewed. It would be really useful for women living with HIV to be able to have discussions/training about disclosure, how, when, where and what is the best way of disclosing. These can be facilitated by other people who can share their experiences regarding what worked and what didn't.
- Disclosure issues have been mentioned by all participants – disclosure has affected them in all spheres of their life. Realistic information has to be made available to the population in general – to dispel perceptions and misconceptions. This will not only help the issue of disclosure but will also help with the eradication of stigma and discrimination.
- The media has a big part to play – they can be instrumental in dispelling the perceptions that most of the time they have created within the community.

Reproductive and sexual health:

- Information and treatment is needed on sex and sexual health issues.
- Support and information needs to be made available to those HIV positive women actively seeking to have a child. Up-to- date information regarding PMTCT (Prevention of Mother to Child Transmission) needs to be made available to them – regardless of whether they are drug users or not.
- More information is needed by the community in general on issues of serodiscordance in couples.
- A lot of research has been done on PMTCT. This information has to be made available to all staff involved, both in the HIV clinic and in the hospital – and referrals made where necessary.
- All clinical staff needs to be trained around HIV (at all levels within the NHS). Knowledge would lead to the cessation of the discrimination experienced by many positive women when choosing to be mothers.

Drug Services:

- All those working within the drug services need to be informed around HIV and drug use and around the impact that HIV can have on their clients.
- Specific peer support groups between HIV+ women drug users should be encouraged as a way of supporting each other and exchanging information and experiences.
- Service providers need to be informed regarding the pharmacokinetic effects of drug using and ARV.

- Issues regarding harm reduction need to be revisited and information about sterilisation of injecting equipment needs to be stressed. Harm reduction is not just about needle exchange and provision of swabs.
- Harm reduction approaches to crack and stimulants users need to be researched.
- Drug users need to be offered the treatment they require for their HIV and their drug use – without assumptions by the staff that their drug use will interfere with adherence. Directly observed treatment might be an option when the user is too chaotic to adhere.
- Encouragement to participate in community engagement programmes to develop life skills which will help them integrate back into the community rather than just being given their substitution therapies with no other support.

Support groups:

- We recommend that specific peer support groups are established for HIV+ women who are drug users. This would lead to the greater participation of this specific group.
- We also recommend that the support groups, and all their clients, are trained and informed about specific needs of drug users who are HIV+. This would, hopefully, do away with the discrimination which drug users feel when attending these support groups.
- We want a place that is not judgemental, that gives practical support which looks at the issues in a holistic manner, one that is open for discussion, and where information is available.

Prison:

- We recommend that all prison staff has mandatory HIV awareness training.
- Need to do away with the segregation which has been reported in institutions – information regarding HIV has to be made available to all the community, and specifically to those working within public institutions so that there is an end to the prevalent discrimination which has been reported.

Service Providers:

- Need to provide different sessions to cater for different needs.
- Research is needed on living long term with HIV and the psychological impact this has on individuals.
- Drug use – and especially to look at the impact of different drugs and how they impact on the individuals living with HIV.

Employment:

- As well as legislation that do not discriminate against people living with HIV, employers should be encouraged to support their workers by means of offering alternatives like part-time, job share, flexi – time (to attend hospital appointments, etc).
- The Benefits Agency should take into account the ever-changing situation of individuals living with HIV so that they are not penalised and lose benefits if they need to start or stop working due to illnesses. This would actively engage those living with HIV who feel they are capable of some sort of work and encourage them to seek gainful employment.
- Pension schemes should not have questionnaires where disclosure of chronic illness or HIV needs to be stated. The same applies to mortgages, life insurance and travel insurance.
- There is diversity of drug users, and in the drugs they use – therefore providers need to have knowledge of the different issues that can arise when using and being HIV positive. This applies to HIV service providers and drug services alike.

Research

- Health issues on those living long-term with HIV.
- Health issues of those living long-term with HIV and Hepatitis C co-infection.
- Treatment for those also living with Hepatitis C – as yet there is little options for those whose genotype is 1 or 4.
- Health issues on those living with HIV, co-infection and drug use.

- Effects of long-term ARV treatment for those living with HIV.
- Particular pharmacokinetic effects of ARV treatment and substance use, for example, heroin, crack, cocaine, methamphetamine.
- Benefits of prescribed marijuana to aid physical side effects of ARV medication and conditions associated with HIV, such as peripheral neuropathy.

The Centre For Ethnicity and Health's Model of Community Engagement

Background

We often hear the following words or phrases:

- Community Consultation
- Community Representation
- Community Involvement/Participation
- Community Empowerment
- Community Development
- Community Engagement

Sometimes they are used inter-changeably to mean the same thing. Sometimes the same word or phrase is used by different people in the same meeting to mean different things. The Centre for Ethnicity and Health has a very specific notion of Community Engagement, and this paper is an attempt to describe it. The Centre's Model of Community Engagement evolved over a number of years as a result of its involvement in a number of projects. Perhaps the most important milestone however came in November 2000, when the Department of Health awarded a contract to what was then the Ethnicity and Health Unit at the University of Central Lancashire to administer and support a new grants initiative. The initiative aimed to get local Black and minority ethnic community groups across England to conduct their own needs assessments, in relation to drugs education, prevention, and treatment services.

The Department of Health had two key things in mind when it commissioned the work; first, the Department of Health wanted a number of reports to be produced that would highlight the drug-related needs of a range of Black and minority ethnic communities. Second, and to an extent even more important, was the process by which this was to be done. If all the Department of Health had wanted was a needs assessment and a 'glossy report', they could have directly commissioned a number of researchers who could have gone into local Black and minority ethnic communities, talked to them about their needs, written up a report, and produced yet another set of reports that potentially do not have any long term impact. This scheme was different however. The Department of Health was clear that it did not want researchers to go into the community, to do the work, and then to go away. It wanted local Black and minority ethnic communities to undertake the work themselves. These groups may not have known anything about drugs, or anything about undertaking a needs assessment at the start of the project; what they would have is proven access to the communities they were working with, the potential to be supported and trained and the infrastructure to conduct such a piece of work. They would be able to use the six month process to learn about drug related issues and about how to undertake a needs assessment. They would be able to benefit and learn from the training and support that the Ethnicity & Health Unit would provide, and they would learn from actually managing and undertaking the work. In this way, at the end of the process, there would be a number of individuals left behind in the community who would have gained from undertaking this work. They would have learned about drugs, and learned about the needs of their communities, and they would be able to continue to articulate those needs to their local service providers, and their local Drug Action Teams. It was out of this project that the Centre for Ethnicity and Health's model of community engagement was born.

The model has since been developed and refined, and has been applied to a number of areas or domains of work. These include:

- Substance Misuse
- The Criminal Justice System
- Sexual Health
- Mental Health
- Regeneration

- Higher Education
- Asylum

New communities have also been brought into the programme: although Black and minority ethnic communities remain a focus to the work, the Centre has also worked with:

- Young people
- People with disabilities
- Service user groups
- Victims of domestic violence
- Gay, lesbian and bi-sexual people
- Women
- White deprived communities
- Rural communities

In addition to the Department of Health, key partners have included the Home Office, the National Treatment Agency for Substance Misuse, the Healthcare Commission, The National Institute for Mental Health in England, the Greater London Authority and Aimhigher.

The Key Ingredients

According to the Centre for Ethnicity and Health model, a Community Engagement project must have the community at its very heart. In order to achieve this, it is essential to work through a **host community organisation**. This may be an existing community group, but it might also be necessary to set a real or virtual group up where one does not exist already. The key thing is that this host community organisation should have good links to the target community^[1] (whoever this is) such that it is able to recruit a number of people from the target community take part in the project and to do the work (see section on task below). It is important that the host community organisation is able to provide a co-ordination and infra-structure (e.g. somewhere to meet; access to phones and computers; financial systems) for the day to day activities that will be undertaken once the project is underway. One of the first tasks that this host community organisation undertakes will be to recruit a number of people from the target community to work on the project.

A Host Community Organisation	With Good Links To The Target Community	To Provide Basic Infra-structure For The Project (Recruit And Co-ordinate Project Team; Provide Office Space, Phones And Computers; Look After The Finances)	To Recruit A Number Of People From The Target Community To Do The Work
A Task	Time Limited Meaningful Manageable	A Piece Of Research Into Key Needs/Gaps/Issues For The Community	Learning And Development Of Key Individuals; Access Hard To Reach Groups; Raise Awareness and Debate; Community Ownership
Support	Financial (Typically Up To £20,000)	Training And Workshops; On-Going Support And Guidance; Personal Tutor	Statutory Partnerships; Steering Groups; Sustainability

The second key ingredient is the **task** that the community is to be engaged in. According to the Centre for Ethnicity and Health model, this must be something that is meaningful, time limited and manageable. Nearly all of the community engagement projects that we have run have involved communities in undertaking a piece of research or a consultation exercise within their own communities. Sometimes we have been met with an initial resistance to doing 'yet another piece of research', but this misses the point. As in the initial programme that we ran on behalf of the Department of Health, *the process (i.e. of getting ordinary people involved in doing the work) is as important*, if not more important, than the report that they produce at the end of the day. The task or activity is something around which lots of other things will happen over the lifetime of the project. Individuals will learn and new partnerships will be formed. Besides, it is important not to lose sight of the fact that it will be *the first time that these individuals have undertaken a research project*.

The final ingredient, according to the Centre for Ethnicity and Health's model, is the provision of appropriate **support** and guidance. We do not expect community groups to become involved for nothing. Typically we would make in the region of £15-20,000 available to the host organisation.

^[1] The target community may be defined in a number of ways – in many of the Community Engagement Projects that we have run we have defined it by ethnicity. We have also worked with projects where it has been defined by some other criteria however, such as age (e.g. young people); gender (e.g. women); sexuality (e.g. gay men); service users (e.g. drug users or mental health service users); geography (e.g. within a particular ward or estate) or by some other label that people can identify with or rally around (e.g. victims of domestic violence, sex workers).

We would expect that the bulk of this money would be used to pay people from the target community as community researchers^[2]. We then allocate a named member of staff from our Community Engagement Team as a project support worker. This person will visit the project at for at least half a day once a fortnight. It is their role to support and guide the host organisation and the researchers through the project. We also provide a package of training – typically in the form of a series of accredited workshops. The accredited workshops give participants in the project a chance to gain a University qualification whilst they undertake the work. The support workers will also assist the group to pull together a steering group for the project^[3]. The steering group is an essential element of the project: without one, it is difficult to see who the community are engaging with and it is unlikely that anything out of the project will be sustained in the longer term. The group will be doing a needs assessment or a consultation exercise, but for what purpose? It is the role of the steering group to ensure that the work that the group undertakes sits with local priorities and strategies, and that there is a mechanism for picking up the findings and recommendations that the group may make. It is also their role to help to pick up the key individuals who are developed through the project process to help them to take their ‘next steps’.

The Community Engagement Team

The Community Engagement Team comprises of 25 members of staff. They work across a range of Community Engagement areas of specialism, within a tight regional framework.

National Programme Directors			
Northern Team	Midlands Team	Southern Team	Senior Programme Advisors
Senior Support Worker	Senior Support Worker	Senior Support Worker	
Support Workers X 3	Support Workers X 3	Support Workers X 6	Drug Interventions Programme
			Regeneration
			Mental Health
Teaching And Learning Team			
Administration Team			
Communications Officer			

Programme Outcomes

Each group involved in any of our Community Engagement Programmes is required to submit a report detailing the needs, issues or concerns of the community that it consulted with. The qualitative themes that emerge from the reports are often very powerful, particularly when taken together with other reports produced by groups involved in the same programme. Such

^[2] This is not always possible, for example, where potential participants are in receipt of state benefits and where to receive payment would leave the participant worse off.

^[3] Very often we will have helped groups to do this very early on in the process at the point at which they are applying to take part in the project.

information is key to commissioning and planning services for diverse and 'hard to reach' communities. Often new partnerships between statutory sector and hard to reach communities are formed as a direct result of community engagement projects.

The capacity building of the individuals and groups involved in the programme is often one of the key outcomes. Over 20% of those who are formally trained go on to find work in a related field.

The Focus Of This Particular Report

Since 2000 over 200 community groups have taken part in one or other of the Centre for Ethnicity and Health's Community Engagement Work Programmes. ICW were one of 40 community groups who took part in the Department of Health's Substance Misuse Community Engagement Programme in 2005. The specific objectives of this programme were:

- To research services available for HIV+ drug / alcohol using women;
- To find out the level of use of such services by these women;
If not accessed why not?
- What are women's experiences in using these services
- What services the women think they need;

- Create links between positive women drug users, with the help of local partner organizations;
- Conduct participatory research with HIV+ drug/alcohol using women;

- Collate information on current policies and practice;
- Develop advocacy tools around gender, sexual reproductive health rights, access to care, treatment and support, harm reduction and possibly prevention.

Silent Voices is the only drug project that ICW has developed and the only project which is UK based, and is a starting point for ICW to collate and document women's experiences so we can reflect the priorities, needs and interests that are so often ignored amongst services providers, policymakers, and governments.

This research is imperative as so many HIV+ drug using women face triple discrimination (being a woman, a drug user and HIV positive) which leads to marginalization and invisibility.

In addition to the research findings, *Silent Voices* aims to explore and challenge the myths and preconceptions surrounding drug and alcohol using women living with HIV and AIDS.

About the International Community of Women Living with HIV/Aids

ICW is the only global network run by and for HIV positive women and young women. It was founded in 1992 due to a desperate lack of support, information and services available to women living with HIV, and the need HIV positive women felt to influence policy development. The founding members were a group of 56 HIV positive women from around the world attending the 8th International Conference on AIDS held in Amsterdam in July 1992.

ICW's Vision is a world where all HIV positive women:

- Have respected and meaningful involvement at all political levels, local, national, regional and international, where decisions that effect our lives are being made;
- Have full access to care and treatment, and
- Enjoy full rights, particularly sexual, reproductive, legal, financial, and general health rights, Irrespective of our culture, age, religion, sexuality, social or economic status / class and race.

ICW has adopted a human rights framework for all our work. We campaign currently to promote gender equity, universal access to care, treatment and support, and solidarity with and involvement of HIV positive women at all levels of decision-making affecting our lives.

The views expressed in the report are those of the group that undertook the work, and are not necessarily those of the Centre for Ethnicity and Health at the University of Central Lancashire.

Introduction

An important part of the research that ICW carried out aimed to look at “How has HIV affected the lives of the women who had participated”. It looks at how HIV has affected emotionally, physically, economically and how HIV services and drug services have supported, ignored or exacerbated the issues that they have to deal with.

Background to HIV epidemic in the UK

Risk groups

Since 1985, three routes of infection - sex between men, heterosexual sex and injecting drug use - have been the main determinants of HIV infections in the U.K. Up until 1998, men who have sex with men formed the main exposure category for new HIV diagnoses. However, in 1999, heterosexually-acquired HIV became the largest category, and has continued to be so ever since. The proportion of HIV infections acquired through injecting drug use has been much smaller in the U.K. than in many other European countries.

Heterosexuals

The number of heterosexually-acquired HIV infections diagnosed in the U.K. has risen hugely over the last 15 years. In 1999, for the first time, the rate of heterosexually-acquired HIV diagnoses overtook the rate of diagnoses in men who have sex with men. During 2005, there were 2,878 reports of heterosexually-acquired HIV, and a total of 30,381 had been reported by the end of December 2005. Many of the new diagnoses are in people who probably acquired HIV in other countries. However, the number of infections probably acquired in the U.K. from heterosexual sex with a heterosexually-infected partner has soared from 141 in 1998 to 474 in 2004.

Injecting Drug Users

During 2005, a reported 112 people were diagnosed with HIV probably acquired through injecting drug use. By the end of December 2005, reports showed that 4,392 people had acquired HIV by this route. In this exposure category there have been differences within the U.K.. Scotland experienced rapid HIV spread through injecting drug users in the early 1980s, which was not the case in the rest of the Kingdom. Probably as a result of the introduction of harm reduction measures such as needle exchange programmes in the mid-1980s, localised epidemics on the scale of Scotland have not occurred elsewhere in the U.K.

(Source: Avert website: <http://www.avert.org/uksummary.htm>)

These statistics show that the number of women that acquired HIV through injecting drugs has reduced over the years. However the relationship between HIV and injecting drug use is not solely confined to transmission. One has to take into account the change of behaviours when using other substances, for example with alcohol use. Moreover, drug use was identified in our research as one coping mechanisms of dealing with an HIV diagnosis.

How HIV infection was probably acquired	Country of diagnosis						%
	England	Wales	N. Ireland	Scotland	UK total	Channel Isles/ Isle of Man	
Sex between men*	33,477	552	206	1,499	35,734	33	47%
Sex between men and women	28,455	393	160	1,341	30,349	32	40%
Injecting drug use	3,080	46	10	1,245	4,381	11	6%
Blood/tissue transfer or blood factor	1,605	58	21	121	1,805	3	2%
Other/undetermined**	4,175	53	11	216	4,455	6	6%
Total†	69,241	1,076	384	4,191	76,765	85	100%

* Includes 768 men who had also injected drugs

** Includes 1,349 children of HIV infected mothers

† Includes 41 unclassified cases with sex not stated on the report

How people probably became infected by year

Year of HIV diagnosis	How HIV infection was probably acquired		
	Sex between men*	Sex between men and women	Injecting drug use
1989 or earlier	9,379	1,073	1,866
1990	1,705	536	201
1991	1,717	649	242
1992	1,644	780	188
1993	1,512	777	203
1994	1,485	794	167
1995	1,477	854	181
1996	1,556	839	174
1997	1,416	1,016	161
1998	1,372	1,170	132
1999	1,373	1,445	113
2000	1,520	2,021	114
2001	1,769	2,899	133

2002	1,892	3,800	115
2003	2,024	4,503	149
2004	2,214	4,347	131
2005	1,712	1,878	112
Total	35,767	30,381	4,392

** Includes 768 men who had also injected drugs*

Notes

- Numbers, particularly for recent years, will rise as further reports are received.
- Due to rounding to the nearest whole number, percentage columns may appear not to total 100%.

(Source: 1 HPA Communicable Disease Surveillance Centre (HIV and STI Department) and the Scottish Centre for Infection and Environmental Health: Unpublished Quarterly Surveillance Tables No. 69, 05/4, January 2006)

Methodology

The idea of “*Silent Voices*” began with Carmen (lead researcher) and Liz (ICW researcher). They both felt very strongly that ICW should be involved in a project concerning drug users. Carmen was instrumental in submitting the proposal with support from ICW fundraiser Corinne Miele. Funding was received from the University of Central Lancashire and the project began.

Initial talks began with representatives from the University and ICW staff in January 2006 and agreement was finalized on the University project offer and at this point support was secured from Islington and Hackney Drug and Action Team. A steering group was then formed and met every 6 weeks with the researchers and ICW staff involved to support and advise the project and researchers. The group also contributed to the development of an ethics form and Service Providers questionnaire.

Researchers were recruited from the HIV community; this was done by networking with other HIV and Drug organizations and ICW targeting women living with HIV and with personal drug/alcohol experiences. The researchers then attended 6 days of “Community Research Training” held by The University of Central Lancashire. The training focused on Drug Awareness and Methodology and Research. None of the researchers had any previous experience of formal research and 2 of the women had little knowledge of drug use – although all the researchers were HIV+ women – in this respect the training was invaluable. A participatory approach was used throughout this project. (See appendix 2 for more information about The Centre for Ethnicity and Health’s Model of Community Engagement).

The researchers – with the input of the steering committee – started to think about the best way to attract participants and together they also started thinking about ethical issues that might impact on the project. Therefore an ethical form (Appendix 2) was devised for submission to the internal ethics committee of the university before research began.

It was decided that the way forward in developing the questions and issues which would later form the questionnaire for the in-depth interviews would be by holding focus groups whose members would be HIV+ women who had or were still using drugs. ICW sent out flyers (Appendix 3) to various drug and HIV services and also advertised the focus group and *Silent Voices* project through ICW News. Researchers also contacted individual women known to them through their membership. (The majority of women targeted at this point were through word of mouth).

To begin the research, it was decided to hold 2 focus groups. In order to find the women to participate in the first group, a flyer was designed which was mailed to all ICW members who live in the U.K. Copies were also left at various London HIV clinics such as the Harrison Wing at St Thomas Hospital and the Kobler Centre at the Chelsea and Westminster Hospital. The nurses were asked to point out the flyer to women who they knew had been drug users or were still using drugs. The flyer was also sent to various drug services such as Phoenix House which is a rehabilitation centre in South London. The flyer was left at alternative therapy organizations such as The Lighthouse in West London and The Helios Centre in Central London. The project was also discussed with other women in support groups who then passed the information to their friends about the research and our first focus group was held.

Both Carmen and Liz facilitated the group, Carmen taking comprehensive notes on a flip chart and Liz ensuring that everyone in the group had their say. The group consisted of 6 women ranging in ages from 34 to 58 and coming from countries as far away as America and Italy and local London women. They told their stories willingly and gladly and two hours flew by with everyone participating and enjoying being with other women who understood what they were

saying. What came out of that first focus group was the isolation which was felt by all the women and how good it felt to be with other like-minded women.

From notes from the flip-chart and hand written notes which had been taken, the most important issues were discovered (see appendixes 4 and 5) - which would later be used in the questionnaire. One main point to come through was that most of the women had stopped using chaotically many years ago and had been diagnosed for a long time apart from one woman who had been diagnosed in prison about 3 years previously. Most of the participants were quite settled in their lives, working, studying and 2 of the women were busy trying to get pregnant! It was felt to be very important to speak to women who were newly diagnosed and still using drugs to find out the relevant issues for them. It was also realized that so far no black women had come forward for the research.

With all this in mind, contact was made again with Positively Women which is the only national organisation, based in North London, and who hold a monthly drug and alcohol group for positive women. Through this group participants for the next focus group were found. The information gathered at both focus groups was collated. The main issues were disclosure and sexual and reproductive rights. The questionnaire was born.

Although the notes taken by both facilitators for both focus groups are reprinted in the appendix, it was felt that some comment of them was necessary. The notes highlight many issues and make interesting reading in themselves. It was obvious that the women enjoyed the discussion and felt at ease meeting other women who they could identify so easily with. Most of the women had used HIV support groups in the past but now felt that there was nowhere for them to go as cultural issues had become so important. HIV positive women drug users feel stigmatized by the other members of support groups and feel it is very difficult to be honest about their past and sometimes present drug use. Society's stigma follows them into the support group. From the issues raised at these focus groups the researchers then formed the basis for the questionnaires to be used for the in depth interviews (included in the appendix are 3 of the completed in depth interviews – see appendix 6,7 and 8).

Once again through advertising and word of mouth women were found who would be willing to give in-depth interviews and these women were contacted and given a range of options as to where these meetings would take place (the ICW Office), the interviewee's homes or a venue of their choice. At this point it is important to stress that 2 researchers were involved in the interviews when going to the interviewee's home.

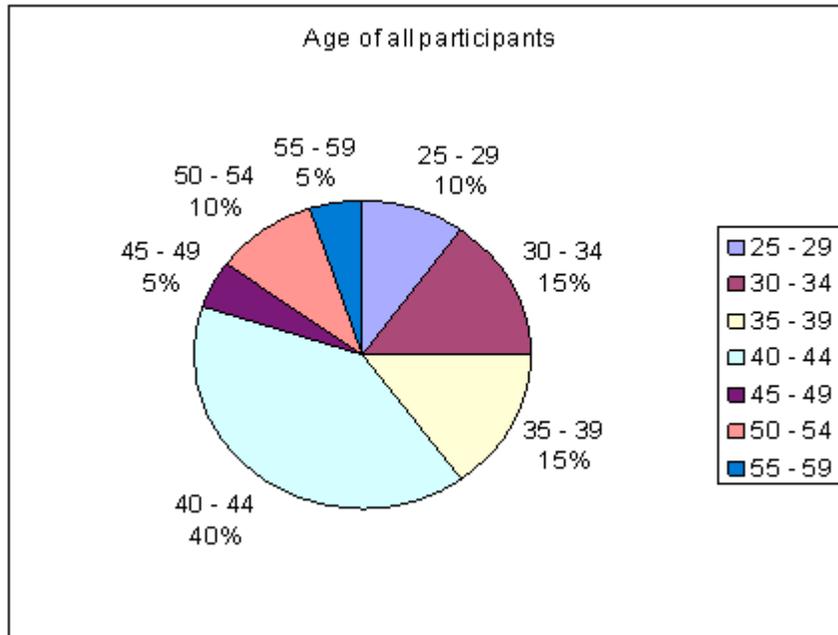
It was agreed that all participants would remain anonymous and could feel free to abstain from answering any questions which they felt uncomfortable with. It was estimated that the time of the interview would be approximately one hour but this varied depending on the circumstances. ICW has always experienced that "real, accurate honest" research most often occurs when Interviews are carried out by their peers – in this research other HIV+ women who have or are still using drugs/alcohol.

During The International Strategic meeting of ICW that was held in October 2005 Carmen presented the project and brainstormed with the staff and International Board of Trustees of ICW to try to ascertain the amount of knowledge with relation to harm reduction that the participants - of which the majority were HIV+ themselves - had. This highlighted the desperate lack of knowledge that prevails amongst the HIV + community and therefore validated the need for this research. (See appendix 1 for more information).

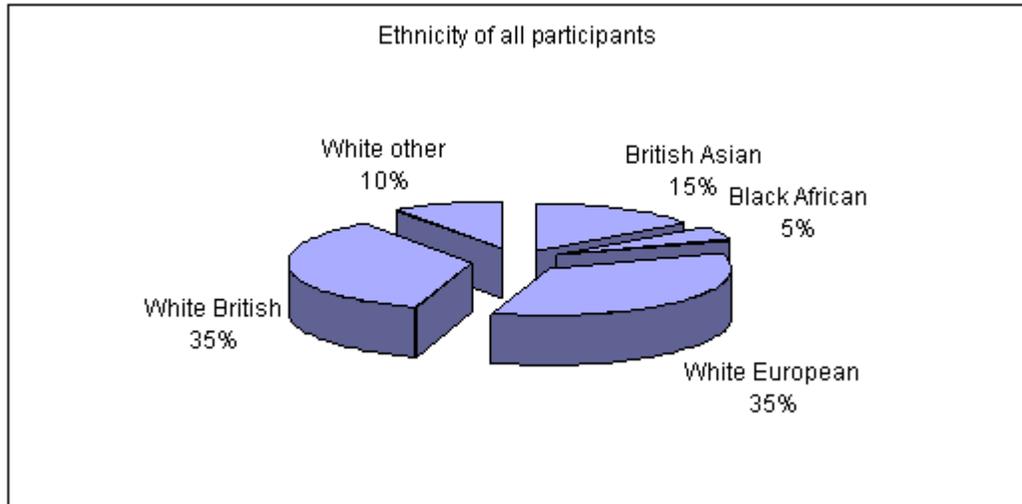
FINDINGS

These charts reflect the findings obtained from either all the participants which include the in-depth interviewees plus the members of the focus groups or just the interviewees only.

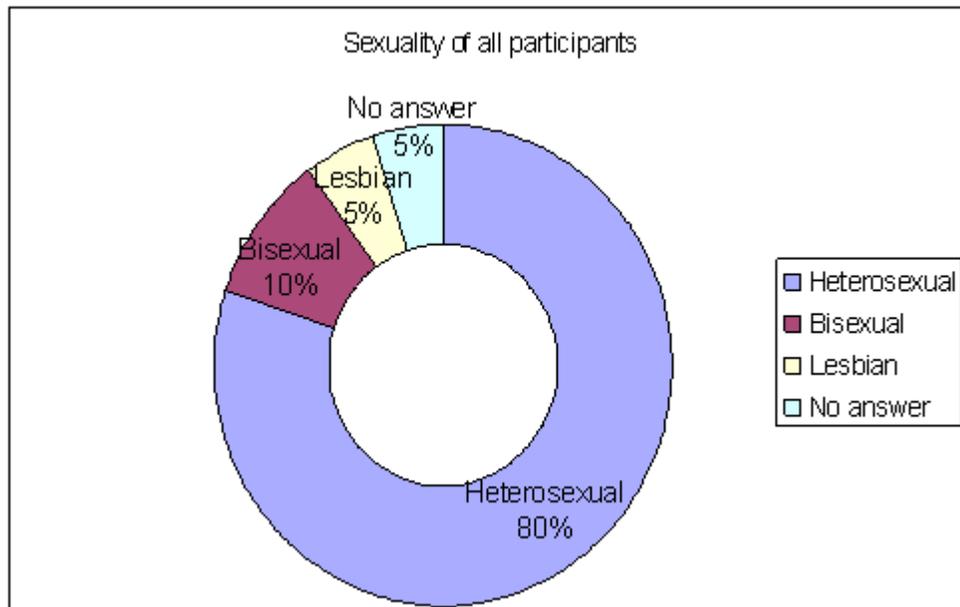
Silent Voices would like to take this opportunity to state that the reason for many of the questions being asked is to highlight how diverse drug using women can be.



25-29	30-34	35-39	40-44	45-49	50-54	55-59
2 women	3 women	3 women	8 women	1 woman	2 women	1 woman

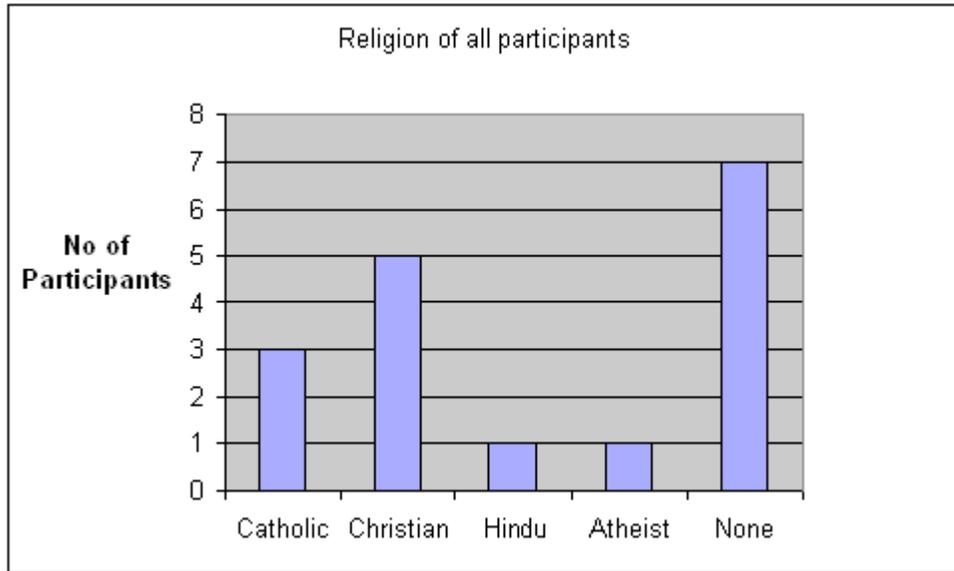


The White European group comprised 7 women in total - 3 Italian, 1 Portuguese and 3 Spanish. The White Other group comprised 2 women in total – 1 from Australia and 1 from USA.



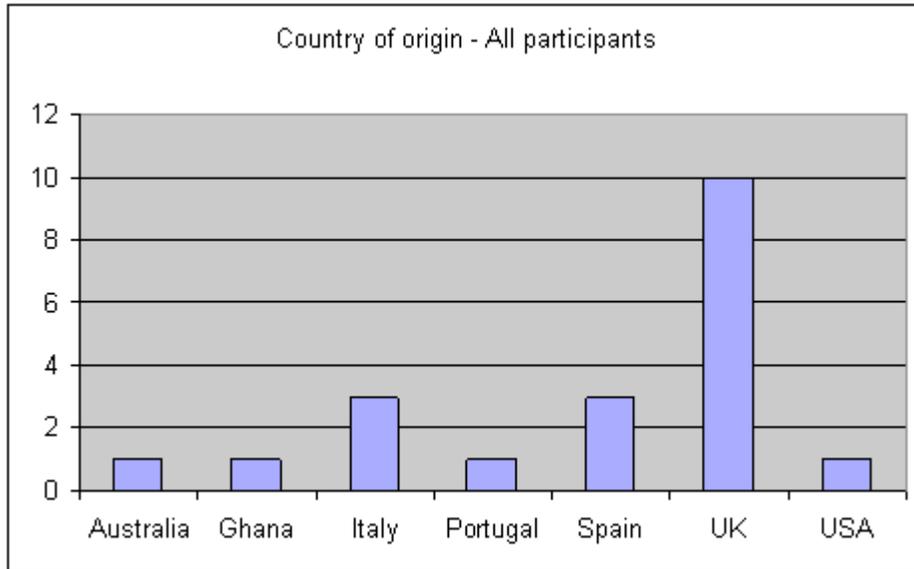
Sexuality of all participants

Heterosexual	16
Bisexual	2
Lesbian	1
No answer	1



Religion of all participants

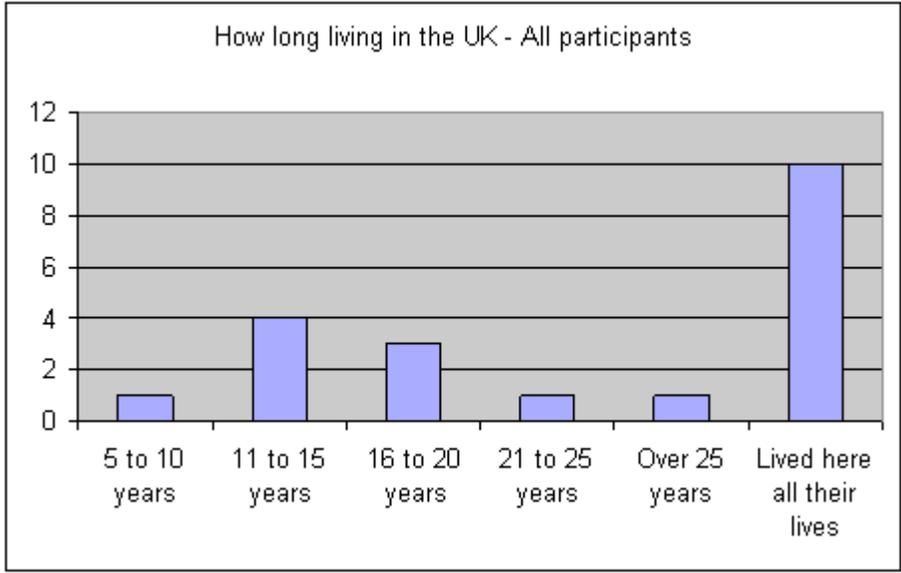
Catholic	3
Christian	5
Hindu	1
Atheist	1
None	7
No answer	3



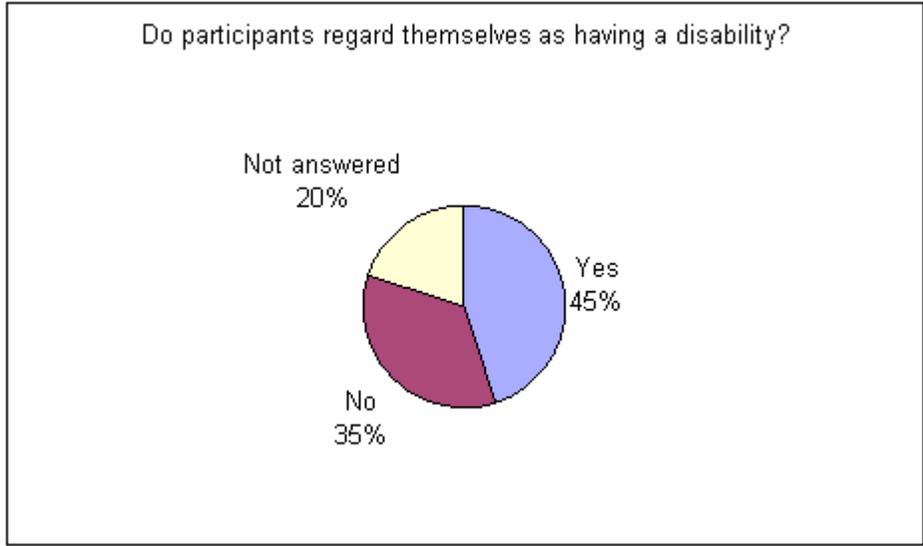
Country of origin - All participants

Australia	1
Ghana	1
Italy	3
Portugal	1
Spain	3
UK	10
USA	1

None of the participants fell under the category of asylum seeker or refugee. 7 of the participants are from countries belonging to the European Union.

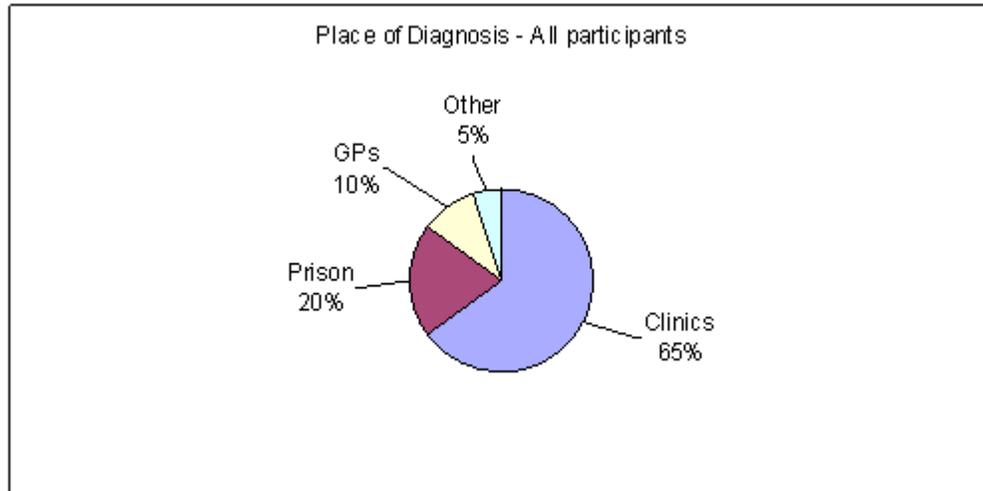


Languages that are spoken fluently within the participant groups are English (20), Spanish (6), Italian (3), Catalan (2), German (2), Portuguese (1), Bengali (1), Tamil (1), and Twi (1).



Do participants regard themselves as having a disability?

Yes	9
No	7
Not answered	4

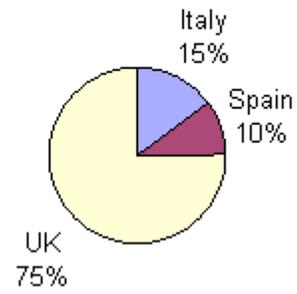


Place of Diagnosis - All participants

Clinics	13
Prison	4
GPs	2
Other	1

All 4 of the women that were diagnosed in prison were in Holloway prison at the time. From the 14 in - depth interviews it is noted that 9 of the women have been either arrested or cautioned, 5 women have spent time in prison. Out of all 20 participants 4 women received their diagnosis in prison. 3 of them were diagnosed since the year 2000. (See recommendations.)

Which country were you living in when you received your diagnosis



Which country were you living in when you received your diagnosis

Italy	3
Spain	2
UK	15

Dealing with diagnosis

Of all the women who were asked about the manner in which they were given their diagnosis, everyone has something bad to say, no matter which country they were living at the time.

"It was appalling, I was in care in a secure unit and I was tested against my will, I didn't ask to be tested so I was just told, I was only 15." (3)

"I was put in an isolation cell" (7)

"I was told I had 2 years to live" (8)

An HIV positive diagnosis is life changing often precipitating fear, shock, a sense of helplessness, forms of denial and occasionally self blame.

Responses to how their diagnosis affected the women's lives varied from some who increased their drug use or started taking drugs to others drastically changing their lifestyle and starting a process of reducing their drug intake. A few women became involved in activism either in the HIV or drug field.

"I feel that HIV has changed my life as it put my life on hold. I used to travel and do an awful lot more and those things changed because I think I was in shock for quite a few years. And now after living with what seemed like a death sentence it is hard to change my mind set and get my head round the fact that may now live a lot longer."(4)

"Cause I wasn't doing crack or coke before I got diagnosed. It was 2-3 months after that I started doing them. At the end it was the only thing that would keep me going. I smoked all day – I lost all the weight – I didn't have nobody. I had no friends. No family."(13)

I got a lot more active and focused my activism a bit more around drug using issues" (5)

"Well, it helped me clean up" (7)

The majority of women who have been living with HIV for many years expressed the psychological impact of originally believing that their lives would be cut short to now having to readjust their way of thinking about life and the future. (See recommendations).

Relationships and disclosure

Partners (casual and long-term)

14 women gave in depth interviews, 7 of these women are either married or in long-term relationships. Only one partner is HIV+ himself, the others partners been negative.

The testimonies from the participants show concerns over disclosing their HIV status and drug use, with the expectation that existing partners might leave them or that it would be difficult to find new partners. In fact partners generally (but not always) showed a fairly good level of support from ex and existing partners and varying degrees of support from new partners.

Its hard. It's very hard – disclosure is the key – and some people they won't understand like to use a condom and, sexual relationship is hard.... And then disclosure is massive, it's a massive problem. It's a big issue. It's more easy to say, or well I am a recovering addict because its like to say, 'I been naughty once but I am ok now than to say I have HIV. Because when you say HIV, Wow!! People they judge you, straight away, its like, or my God! (9)

A large proportion of women stated that after many years of diagnosis they tend these days not to disclose as readily as before. There were a diverse selection of answers to this question, yet it is evident that when thinking about a long-term relationship the women felt it was important to disclose as early as possible. On the other hand women felt strongly that the feeling was that it was going to be a one night stand it was important to practise safer sex and disclosure was not necessary. Some women in the early stages of diagnosis felt disclosure was far too difficult and made a decision to not have sex at all.

“Stops me from meeting other people and it scares me” (11)

Disclosure to family and friends

Again there were diverse examples of how and when women disclosed to their family and friends.

“I've tended to disclose the Hep C first to use it as a tester” (3)

“You never know what's going to happen once you tell. Maybe that person in few weeks is not your friend anymore.” (1)

“For 15 years I didn't tell my parents about my drug use, my HIV” (1)

Disclosure to children

Disclosure to children similarly is fraught with concern related to possible reactions and the impact on the lives of their children. Acceptance by children of their mother's diagnosis was extremely important. However, one woman felt that telling her children would serve her needs more than those of the children.

“We have a very loving relationship – I am very lucky – history of my drug use - since he was a small baby” (6)

"I knew it was hard enough growing up in London – no services available for the kids – they worried enough about me (drug use) so I chose not to tell them until they were grown up" (8)

"Where would they go? Who would they tell?" (8)

"I had a son. He died last year – really painful – to deal with a child who is HIV+. It is a big thing" (9)

"I did tell him when he was 12 that he was HIV+. Can you imagine?" (9)

Disclosure within the wider community

It was generally found that even the women who work within the HIV community and were open about their status did not disclose to the 'Wider community'. A few women stated that they enjoyed being in environments where they could be anonymous and feel a part of normal living.

"I still haven't said it to anyone because I am scared to have a label – and for my son to be discriminated" (1)

"Life tells you that it's ok to tell some people but not other people" (1)

"It's like you have a double life" (1)

"It really freaked some people out" (3)

"They have got really upset – either because it was so big or outside their own experience, more that they were upset for me" (3)

"My family wouldn't be too keen on telling my extended family" (3)

". I don't go running around telling mummy's friends" (4)

"With a really nice group of people - someone said that they had cancer - talked about her immune drugs-so thought I would drop in that I was HIV+ It was like dropping a bomb in the conversation" (5)

Economic issues

Work and qualifications



All but 2 of the women involved in the research have previously or still are working in various professions. Positions held have been as varied as teaching Spanish, painting and decorating, nursery nurse, to project workers, management and key development roles within both national and international HIV organisations and editing a harm reduction publication. Other jobs held have been retail management in the food industry, working for the United Nations and a high profile position within a well known British Institution.

Various levels of qualifications are held by the women including BA's MA's and one PHD. '*Silent Voices*' feel strongly that this part of our research challenges the stereotypical picture quite often painted by society around drug users.

Decisions about working

One of the things that became apparent during the interviews is that whilst some women considered themselves disabled they still felt that they could work part time but the main obstacle was disclosure to employers and the fear of losing their benefits and the worry that their health later declined.

Obviously the issue of disclosure at work came up and the concerns of needing time off for appointments, treatment and illness.

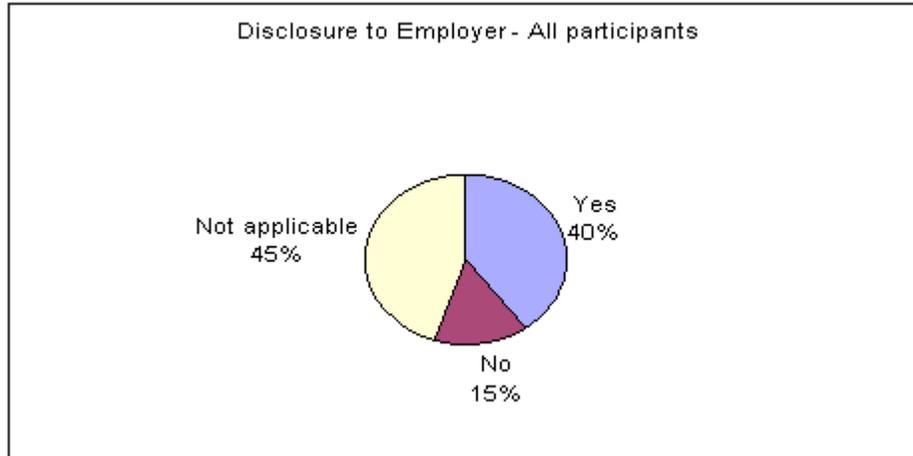
Other concerns mentioned were pension schemes and health questionnaires. A few of the women have returned to full or part time study and a few do voluntary work.

"Even if they say now that you have your rights..... I don't believe it. I would be very scared to disclose" (1)

"I had just been offered my dream job and was asked to fill in a pension health questionnaire. If I filled this in truthfully would it be taken away?" (3)

"I've got disability benefits through being HIV but I feel like it's hindered me a bit because it's very hard to get these benefits and I feel if I go out there and get work I'll never get them back again if I need it" (5)

Disclosure at work



Apart from the few women who felt able to disclose their status as they were working within the HIV community, most women who are or have been in full time employment did not feel able to disclose.

One of the women felt that disclosure led to her being pensioned off and another woman did not know if her hours were reduced by her boss due to lack of work or was it due to her disclosure? She subsequently left her job.

"I had just been offered my dream job and was asked to fill in a pension health questionnaire. If I filled this in truthfully would it be taken away?" (3)

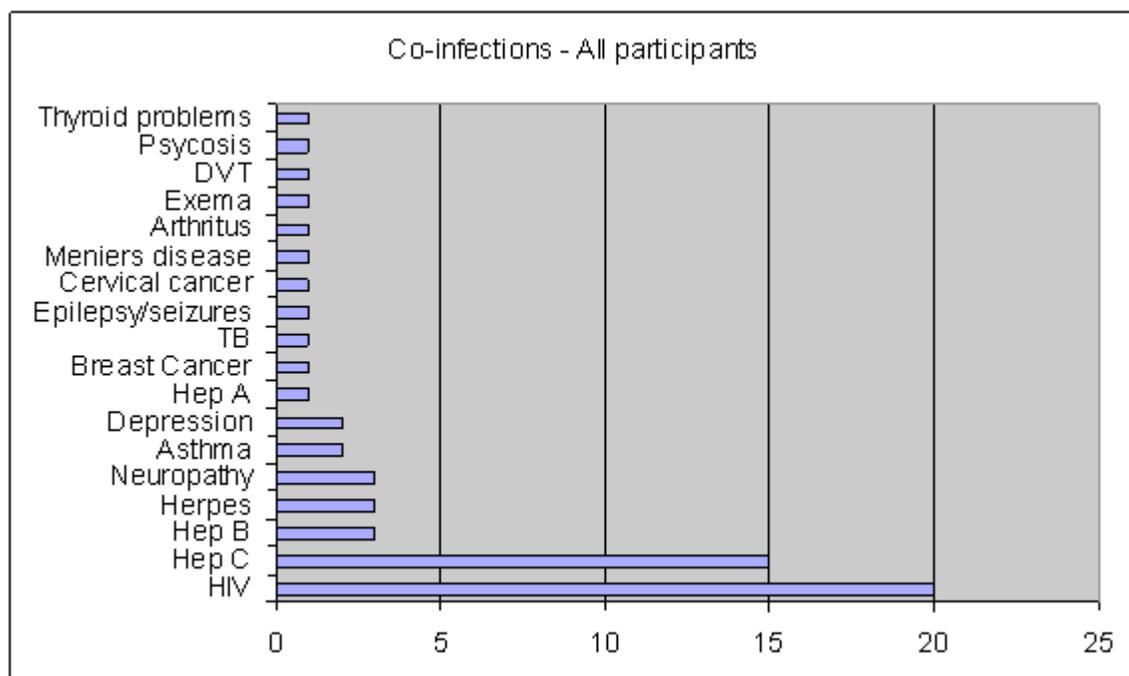
"Even if they say now that you have your rights that you are entitled to not be discriminated.... but I don't believe it. I would be very scared to disclose it" (1)

Physical well-being

General Health

As the chart reflects, three quarters of the participants have a dual diagnosis of HIV and Hepatitis C. Although HCV can be transmitted by other routes the majority of the women involved in 'Silent Voices' were IV users which leads us to the assumption that this was the way HCV was acquired. As it stands at the moment there is not a cure for either HCV or HIV and therefore is and will be a huge issue for the women and the NHS.

A common complaint by many women was the recurrence of herpes which can be very irritating as well as debilitating. Shingles is also very common among HIV positive women and much more research is needed around this subject.



'Silent Voices' also believes that more research needs to be carried out around living with HIV in the long term. As more and more women in this country successfully live with HIV they are now facing other health issues that they believed they would not live long enough to experience, for example, the menopause and breast cancer. One of the women developed breast cancer and was unable to access chemotherapy (her doctor told her this was imperative for her recovery) due to her lowered immunity. She was also unable to access any information on HIV and breast cancer.

Out of the 20 participants, the majority of which have been diagnosed for longer than 10 years, half were not on combination therapies. Other medications taken by the women for other various conditions include: anti-depressants, sleeping pills, tranquilisers, dihydrocodiene, anti-psychotics, acyclovir, thyroxin and asthma ventilators.

Considering the stresses in the lives of HIV+ drug using women it is surprising that not more take anti-depressants. One woman stated that when seeking help for menopausal sleep problems her

GP actively encouraged her to take anti-depressants stating that “Everybody with a life threatening illness is depressed”. (7)

“I think my menstruation changes are linked to the menopause. I am currently having slight lipodystrophy problems but have just reduced one of my combinations so hopefully that will sort that out.” (4)

“Body changes have been huge – huge weight loss. But it is 20 years down the line and we all have body changes then, sometimes difficult to tell whether it is HIV related, Hep C or just related to getting older. How do you disentangle all that?” (2)

Complimentary Therapies

“Prevention is better than cure” (3)

“They helped with controlling symptoms and sustained me generally” (2)

All the participants have used complimentary therapies. Although the majority of women have used them more in the past, many stated that they would definitely use them more if they were easily accessible today. All the women stated that they had benefited from the various therapies that they had experienced...

“Complimentary therapies are important if you are isolated and not having sex – It’s nice to have that touch and closeness” (2)

(See recommendations)

Sex and sexuality

“I stopped being such a party girl which used to suit me just fine as I wasn’t really into serious relationships. So the ‘tarting’ days are over and I wouldn’t now sleep with someone without disclosing.” (4)

The women’s feelings around sex and sexuality varied greatly. Some women were still too scared around issues of disclosure and the fear of infecting partners to even think about a sexual relationship. Whilst others, especially women who have been living long-term with HIV, felt that these days they felt confident enough to have a casual relationship without disclosing as long as they practiced safe sex. A lot of the women felt that sex could no longer be as spontaneous as they would like due to having to practice safer sex.

“In the early days I did feel very afraid of infecting people, now it doesn’t so much because I don’t feel as infectious but I think it affects me when I’m not well and also with body changes as they affect how I feel about myself so that affects my sexuality” (2)

“Before HIV I was more sexually active – I liked sex. But now what’s the point you have to be careful and watch out” (13)

When asked if women felt that their libido had changed in any way it was apparent that if it had it was not necessarily connected to HIV but other issues such as feeling ill, body changes due to lipodystrophy, general relationship problems or due to the menopause. One woman felt that she had no concept of anything being different for her as she was only 15 when diagnosed.

Silent Voices were pleasantly surprised that as stated previously that out of all the women who were in long term sexual relationships all but one were in serodiscordant partnerships.

Reproductive lives and choices

Out of the 20 women participating in *Silent Voices*:

- 9 are mothers
- 3 have had a child since their diagnosis
- 7 have 1 child each whilst 2 had 3 children.
- One of these children has subsequently died through an HIV related illness and another has died from addiction.
- 2 of the children were adopted at birth.
- 1 woman is currently pregnant.

Choices to have children

The information available at the moment regarding HIV and pregnancy is extensive. Women who are diagnosed now can safely have children even when both partners are positive. Research has advanced incredibly in the last few years and so has the knowledge regarding how HIV is transmitted from mother to child. There are also guidelines regarding important steps to follow regarding minimisation of transmission. Having said that, not all health professionals are aware of these developments and therefore do not support – in their capacity – the choices made by HIV+ women.

“HIV has changed the way I think (about pregnancy) because I suppose before I was diagnosed I thought that I would get pregnant when and if I was ready and now I think I still would. If I decided that it was something I wanted to do I think I would probably still go ahead with it seeing as it is really quite safe now but it makes it into a huge issue and the thought of taking all those drugs whilst pregnant – there a lot of issues and it has coloured how I feel about that.” (5)

Pregnancy and labour

For the women who decided to become pregnant there were different experiences within the health system. The HIV doctors were supportive and gave advice regarding how to become pregnant. Issues of serodiscordance and minimisation of transmission to the negative partner were also explained to the couples.

“When I was pregnant – we did plan the baby – we tried for a baby for many months, in the artificial way, using syringe. (1)

“Yes. I wasn’t sure if I could have a baby, because of the HIV. I wasn’t sure at all if it was possible. But as soon as I found out from the doctors that I could – my viral load was so low that I could get pregnant. We started planning. We had been married for 2 years. Before, I thought it was impossible.” (13)

They were quite supportive. The Royal Free was quite for it. And they did offer me counselling especially for my husband because he wasn’t sure. He didn’t want to have even a 1% risk. For him it was too big even if it was a small percentage. They put us in contact with another couple who had just had a child and been through the same

situation. That was quite helpful. The two husbands have ended up been very good friends. And after the years they still are. (1)

"Yeah, the doctors were OK. I knew the doctors already. I had been dealing with them for some time. And all of them were OK. And the ones that did the caesarean – they were nice." (13)

Anxiety was also one of the issues that the women (and their partners) experienced through this period (pregnancy) and post – delivery:

"Then when I got pregnant, he [partner] was very stressed. He was very worried about the child, and he started becoming violent. I remember in that time we had to wait 18 months to see if the child was positive or not. And when we got the clear result and I said: "Let's celebrate that he's OK" – my husband said: "I have nothing to celebrate". He was really stressed and pissed off" (1)

"I started a big depression. I don't know if it started as post-natal depression or just the stress, been scared of not been able to cope, of feeling unwell...not physical complications."(1)

The treatment received by the women interviewed seems to indicate that although the consultants are supportive of the decision made by the HIV positive women to have a child; this is not generally prevalent amongst the other professionals involved post-partum.

When I had the baby, the nurses there – because you're in a general ward – the nurses there, they were not very friendly. They were not very nice. I needed help and they wouldn't help me. I had a caesarean done" (13)

"I had an awful experience when the baby was born, because I was in hospital for 5 days and the midwives were absolutely horrible to me. I wanted to make a complaint but I never had the time...I was tired. And I thought: "when I feel better" and I didn't fill the papers or the letters. But I had a terrible experience." (1)

The research seems to highlight that these attitudes are the result of the lack of information within health professionals in general and highlights the need for training at all levels of the NHS

"And then I used to have a midwife coming to the house after the CS. They were nice but they were too naïve. Asking very basic questions about HIV. I knew 100 times more. I thought it was fine because they needed information but it wasn't what I needed at that time." (1)

And even when the consultants are supportive, they also seem to stick to the guidelines regarding mother to child transmission – without listening to the concerns and desires of the women in their care and sometimes ignoring the latest data available regarding PMTCT.

"I did have a CS. I wasn't happy because I asked the doctor: can I have the CS once the baby is due?" but they wanted to do it a month before, have everything ready, and I don't know...I think my child was borne with a lot of anxiety. He didn't sleep as a baby. It was awful, very, very stressful" (10)

"Quite stressful. Always my CD4 count and viral load were good, high T-cells and low viral load. At that time I was going to the Royal Free and they wanted me to take a combination of 3-4 drugs and I refused it. I thought my body didn't need it. Now, after a few years they know babies are OK with some drugs, but at that time they didn't really know. And the doctors pushed me a lot, and it was very stressful. I just took some AZT. It made me feel awful. I had a lot of side effects. The baby was taking it for 3 months. I felt

very guilty as well. My husband, at that time wasn't supportive at all. I started getting very stressed when I was 5-6 months pregnant. Found it hard!" (10)

Deciding not to have children

Many of the women who have been living with HIV for many years felt that upon diagnosis they had no choice. Most were actively discouraged from having a baby as in those days the belief was that both mother and child would die. Since the introduction of ARV's and research regarding mother to child transmission things have changed, but for those original women the age factor has played a big part in their decision not to have a child.

"The first thing he (doctor) said to me, promise me you won't get pregnant and I said Why? and he said, well you've got the HIV virus and if you get pregnant you will die and your baby will die." (2)

Another woman who is currently still young enough to have a child but has been diagnosed for nearly 20 years and no longer accesses services other than her clinic had not been given any recent information around this issue.

"I have never ever had any interest before in having a baby and I don't know what is going on but now I am getting slightly interested. Haven't really seriously thought about it and wouldn't ideally have one on my own but I have grown up thinking because of my HIV I couldn't have a kid, because although years ago I did see women that I knew having kids but back then the majority of them died. I haven't been given any up-to-date information by my clinic and I think that they assume that I wouldn't think of having one even though we have never had that discussion. They have never at any point spoken to me about it and I remember once just out of interest broaching the subject and they didn't really know what to say, although at the time I was using a lot and they knew I had a lot of other things to deal with but I wasn't given any information." (3)

Although one woman had been diagnosed for a very long time, about 10 years ago she considered the possibility of getting pregnant and talked to her consultant who gave her support, encouragement and referred her to a consultant gynaecologist and to a counsellor. The 3 clinicians involved gave her all the relevant information that was available at that time. On the basis of this she made an informed choice not to have a child.

"There was one point when I was about 35 I seriously considered having a child - and that was a strange one having to talk about what he (partner) wanted. I knew he was quite keen and I knew that it would affect us as a couple and if we did have a child what would the future hold. It was 10 years ago and it was certainly more difficult and of course being co-infected with Hep. C also brought that deeper on to me. And also given the fact of what I am like, - that I worry about things whether they are going to happen or not - it just implied what my relationship to a child would be - so I think that was the one difficult issue we had to consider as a couple" (10)

Drug and alcohol use

The majority of the participants drink alcohol and most say that they do so just socially and that their drinking has lessened over the years. This could be that we are all getting older and wiser or maybe that the majority of us are also co-infected with HCV hence the need to take care of our livers. It should be noted that the women who do not drink (with the exception of one woman who is currently pregnant) the others all belong to an abstinence-based drug and alcohol self-help group. Only 2 of the women felt that their drinking was problematic. It could be construed from our research that the women who do still drink do so safely.

'*Silent Voices*' finds it an interesting statistic that three quarters of the women smoke tobacco considering the health risks and the modern no-smoking culture. It needs to be noted that a few of the women who do still smoke only do infrequently, one of the women only smokes tobacco with hash.

Just over half the women still use illicit drugs, although again most claim to have cut down dramatically. It should be assumed that all the women interviewed had used drugs chaotically for long periods previously, but when asked if they felt that their current drug use was problematic only a very small percentage said yes. Two of the women said that the only problem was the expense. One woman felt that she didn't feel her drug use was a problem but others may view it in a different light and one woman realised that whilst she was drug dependent she felt that this was not a problem for her.

The drugs currently still being used are hash, cocaine, ecstasy, speed, methadone, injectable diamorphine and physeptone, diasepan, heroin and crack. Half of the women use on a daily basis. As most of the women claim not to have a problem now with drugs, it appears that cocaine, as opposed to crack, is being used recreationally and not viewed as a problem at all the use of hash appears in this category also. The women who have or are still heroin users appear to have used for long periods, whilst crack users seem to reach 'rock bottoms' quicker. The use of crack appears do more damage more quickly and the researchers are aware that more research is need around the use of crack cocaine and the issues surrounding this.

When asked what their drug of choice was three quarters of the women said Heroin whilst the remaining quarter said cocaine with the exception of one woman that felt hash was her drug of choice and the other said that heroin and crack (speedball) together was hers.

Out of the 20 women 16 reported that their favoured method of use was injecting, 4 preferred smoking their drugs and 2 would rather snort theirs. The majority of women still using illicit drugs no longer inject.

When asked how long they had used drugs for, two women didn't answer this question and no one had used continually for less than 9 years - the majority used for longer than 20 years. When asked whether the women disclosed their drug use with any professional worker, i.e. consultant, nurse, counsellor with the exception of one woman all replied yes. '*Silent Voices*' felt that this was good news considering that in many cases the responses from these professionals were in many cases not particularly positive.

"Within medical services you always got treated very differently I suppose, they never trusted you they always treated you like a bit of shit on the bottom of their shoe pretty much."(2)

"I have lied – It's very rare that I said that I was an injecting drug user" (1)

"I was on a waiting list to see a psychologist for years and when I finally saw someone she said she wouldn't see me because I was still using." (3)

When asked if they felt that continued drug using and drinking impaired their ability to adhere to their treatment regime the answers were quite conflicting ranging from women that were using cocaine heavily and being able to adhere totally to others that found that drinking especially affected adherence. One woman talked about the fact that when she was using heavily she was aware that she might not be able to adhere if she started treatment and was beginning to get quite ill and yet her HIV specialist did not offer any help or even a referral to address her drug use.

"One of the reasons that I didn't take medication for so long and was really ill was that the doctors were resistant to me starting treatment because of my drug use" (3)

Services

Drug and alcohol services

When the women interviewed were asked what 3 services they considered most important in regards their drug use the responses were:

- Drug Dependency Units (DDU)
- Needle exchanges
- Drop Ins

Another interviewee stated the importance of going to places such as Tony's Holistic Centre which is an establishment where clients are registered and prescribed compounds of hash/grass and tinctures for pain, insomnia` and various other medicinal complaints" (7)

It appears that the women who managed to abstain from alcohol and/or drugs for any period of time checked out services available in their area themselves and used them according to their own needs. The services used were DDU, crisis deter centres, rehabs and NA (Narcotic Anonymous) meetings. Quite a few women stated that they used their own initiative and stopped of their own accord when they felt that their use was out of control. Most of the women have stopped using chaotically and now use recreationally although a quarter of the women are abstinent from both drink and drugs and regularly attend NA meetings in their local area. These meetings are free and not a government service.

"I have never directly been given any information - I have always done my own research."

"I have noticed that all the posters are geared towards gay men and clubbers (the implication is that gay men don't have a problem with drugs)"

When asked if the women felt that they were given (directly) enough information on the use of illicit drugs whilst taking combination therapy almost everyone reported that they had never been given any information directly. Whilst at their local clinics although there was often literature in the waiting rooms it all seemed to be aimed at gay men and clubbing. The women felt that it was assumed by their doctors that if they had stopped using chaotically they did not use drugs at all.

"I think that it is outrageous that gay men may be given information because they are happy middle class clubbers who may use recreational drugs – It's all so black and white." (3)

"I think I found out more by talking to people that were using than from doctors"

5 of the women who gave in-depth interviews had spent time in residential rehabilitation centres since diagnosis. Although in some cases the women were not treated badly they felt that due to ignorance and lack of experience around HIV there was in the main no direct support. One woman was faced with the decision imposed by the staff of having to disclose to her peers or leaving the facility. Another disclosed immediately to the group and to her surprise was hugged and accepted but later the same peer group brought up issues around her serving the food at meal times. Some women felt that the facilities didn't appear to have any real policies or strategies around HIV.

"At the rehab I didn't come across any of the staff being really, really bad - it was just ignorance" (3)

"It's not that they were not sympathetic but they wanted to push the subject away, some days I had a fever or wasn't feeling well and I was pushed to carry on as normal. I wasn't given any allowances, any extra counseling for that. They just wanted me to cope with that. I didn't find much support in that area." (3)

ISSUES THAT STILL NEED ADDRESSING:

Concerns around harm reduction were expressed by some of the participants – in that although syringes and swabs were given – there was in fact not much more information other than that given by the services. More information was needed regarding the safety of all the injecting paraphernalia, especially in view of the high risk of transmission of HIV and Hepatitis C.

Harm reduction issues need to be looked at because obviously there is a huge Hepatitis C explosion, everybody is Hep C positive and apparently people have got it within their first 2 years of using so the needle exchanges are stuck a bit in the 1980's in the HIV sort of mind set, where they are just giving out needles and swabs and really now that won't work they need to sterilise all the paraphernalia – the water and the tourniquets and the filters I think it's almost negligent now in a way not to be giving out that sort of information and equipment if you're only giving out a bit of it and not the rest of it, there are so many procedures involved in hitting up you need a selection of equipment and if one of them is clean and the rest of it isn't it's just not going to work. That is definitely the future now. (5)

Another concern was the lack of research around crack use and living with HIV – there is no established or tested procedure for coming off stimulants – the norm is to treat as in opiates.

The future way to proceed and I think there's issues now with crack and stimulants users that there needs to be more focus with that and looking at that and what sort of harm reduction approaches can be employed there. Especially for women it brings up a lot of issues especially around the sex industry and that sort of work, and can be really fraught with all sorts of complex issues that really need to be focused on more in the future and I think women's issues have been generally dodged because they are hard and so big and complex issues so I think they've been glossed over and tokenistic.(5)

HIV services

When the women interviewed were asked what 3 services they considered most important in regard to their HIV the responses were:

- Medical services that provide treatment along with treatment information and monitoring of treatment.
- Complimentary therapies
- Peer support with Information resources

“Peer support is really key; I don’t think that I would be here if it wasn’t for the support of my peers - that is really what has sustained me.” (2)

Although all the participants have used a variety of services in the past the majority of women now only use their clinics for their medical care. It should be noted that all the women involved were able to access services locally - but of course this is due to living in the capital.

As regards women changing services it should be noted that as far as the clinics were concerned, originally women may have shopped around until they found somewhere where they were comfortable. It might also be worth adding that the majority found that this was the only service where they felt their needs were met.

There were various reasons for the women not accessing services as frequently as they may have done in the past. For example, women returning to work and study, as many services do not have late opening hours. As previously stated unfortunately many of the complimentary therapy services are no longer in existence and those that are usually only open during the day. Due to long term living with HIV many women are just getting on with ‘normal living’. However, *Silent Voices* has exposed the isolation of HIV+ drug using women and whilst the majority feel the need for peer support - many have said that having a space to meet together needn’t be as frequent as weekly and didn’t have to be that formalised – the need was still there. They felt that the present day services did not support them in their specific needs and in fact many expressed feelings of being invisible and discriminated even within the HIV community.

Discrimination

Silent Voices undertook this project because the researchers had experienced discrimination not only within society but more alarmingly by their own peers. Anecdotal evidence has been gathered by ICW of discrimination by male drug user who are HIV+ towards HIV+ female drug users wishing to become pregnant (Eastern Europe – ICW News). Even during international events whose main focus is HIV it is rare that the voices of drug users are heard or even mentioned. One example would be the lack of sharp bins during the International AIDS Conference in Barcelona. This is not acceptable especially as we should all be aware that at present many of the new infections, in many countries, especially Eastern Europe, are due to injecting drug use. In order to combat this there is the need for the involvement of drug users in the planning and implementation of programs.

At local level the majority of women participating in this research stated that even though they felt able to discuss issues around their HIV status they felt that being honest about their drug use and lifestyles amongst their peers very hard to do. This is due to experiences where by disclosure of their drug use led to ostracism. They felt marginalised and judged by other HIV+ women.

“Being a drug user has put me off going to services” (5)

"I can't find any organizations that I can fit in. I know there are places but they don't seem to do anything for us. I can't see how I can benefit from going to the places that we have today." (1)

"Being invisible or treated disdainfully because I was a drug user" (5)

"Maybe it's because you can't be honest and everyone else is being honest and it's not so easy to launch into the conversation and say you are an injecting heroin user and smoke crack at the weekends" (5)

"When I was first involved with setting up Positively Women we were all ex drug users in those early days so that's why it took us a bit of time really to get accepted by the professionals and by other groups of people with HIV. Social workers actually refused to refer people to us, we got women coming along who had wanted to come for about 6 months but the social workers had been stopping them by saying you can't because they are all drug users we had lots of experiences like that so it took a long time to get that recognition and respect but we did." (2)

Services: the way forward

What appears to come through in all the interviews is the need for a place that it is not judgemental, and where issues can be looked at in a holistic manner. A place where open discussion, information and practical support is available. This need for practical support was highlighted

"I'd like to see a women's- only treatment centre that focuses not just on heroin addiction but stimulants and benzo addiction and some more avenues so you can move on from treatment or at least start contributing back to life while you are in treatment instead of ending up in a sort of methadone limbo land - where you're just going in to pick up your dose everyday and going home - with maybe support and networking opportunities to get back into school or volunteering or maybe even developing your skills in the drug field and using all that knowledge that drug users pick up over the years." (5)

"And I think that services should be – not just a drop-in – but more practical- having people to help you out, really, when you need it. Like when you are in hospital and you need something and you are so lonely – you have no family here. you need help .I had to leave my bed on a couple of occasions to go and pick up my son from school and bring him back with me to the hospital. That's how sad it is, you know!" (1)

Recommendations

Pre and post diagnosis:

- Pre and Post counselling are very important for those who have just been diagnosed – they help in dealing with the shock, the fear, the sense of helplessness, the denial and occasionally the self blame. It might help avoid some of the issues that a positive diagnosis might lead to, i.e. increase in drug use.
- Along with a positive diagnosis, information should also be given regarding the services that might be able to help – not just what the clinic has to offer.
- Ensuring that alternative therapies are available for all those living with HIV (regardless of whether they are still using or not). All the women interviewed benefited from them, and if we consider the range of conditions indicated by the participants, it would ultimately be of benefit to the health system.
- Develop better strategies for the management of pain for drug users – because of drug use, the tolerance can be very high – so when in need of pain killing the dosage should be discussed with the patient on the basis of their tolerance.
- More support regarding issues of adherence to treatment needs to be offered and in some instances DOT (Directly Observed Treatment) might be an option.
- ARV treatment needs to be offered to all those who need it, regardless of whether they are drug users or not.

Disclosure:

- Disclosure is a big issue with all the women who were interviewed. It would be really useful for women living with HIV to be able to have discussions/training about disclosure, how, when, where and what is the best way of disclosing. These can be facilitated by other people who can share their experiences regarding what worked and what didn't.
- DISCLOSURE issues have been mentioned by all participants – disclosure has affected them in all spheres of their life. Realistic information has to be made available to the population in general – to dispel perceptions and misconceptions. This will not only help the issue of disclosure but will also help with the eradication of stigma and discrimination.
- The media has a big part to play – they can be instrumental in dispelling the perceptions that most of the time they have created within the community.

Reproductive and sexual health:

- Information and treatment is needed on sex and sexual health issues.
- Support and information needs to be made available to those HIV positive women actively seeking to have a child. Up to date information regarding PMTCT needs to be made available to them – regardless of whether they are drug users or not.
- More information is needed by the community in general on issues of serodiscordance in couples.
- A lot of research has been done on PMTCT (Prevention of Mother to Child Transmission). This information has to be made available to all staff involved, both in the HIV clinic and in the hospital – and referrals made where necessary.
- All clinical staff needs to be trained around HIV (at all levels within the NHS). Knowledge would lead to the cessation of the discrimination experienced by many positive women when choosing to be mothers.

Drug Services:

- All those working within the drug services need to be informed around HIV and drug use and around the impact that HIV can have on their clients. Silent Voices recommends quarterly training for all staff and for the staff to understand that the physical conditions related to HIV need to be addressed regardless of the drug treatment policies that that particular service adheres to.

- Specific peer support groups between HIV+ women drug users should be encouraged as a way of supporting each other and exchange information and experiences.
- Service providers need to be informed regarding the pharmacokinetic effects of drug using and ARV.
- Issues regarding Harm Reduction need to be revisited and information about sterilisation of injecting equipment needs to be stressed. Harm reduction is not just about needle exchange and provision of swabs.
- Harm reduction approaches to crack and stimulants users need to be researched.
- Drug users need to be offered the treatment they require for their HIV and their drug use – without assumptions by the staff that their drug use will interfere with adherence. Directly observed treatment might be an option when the user is too chaotic to adhere.
- Encouragement to participate in community engagement programmes to develop life skills which will help them integrate back into the community rather than just been given their substitution therapies but no other support.
- A standard of care needs to be drafted for all drug service providers throughout the United Kingdom so that there is consistency of care everywhere.

Support groups:

- We recommend that specific peer support groups are established for HIV+ women who are drug users. This would lead to the greater participation of this specific group.
- We also recommend that the existing support groups, and all their clients, are trained and informed about specific needs of drug users who are HIV+. This would go a long way towards the stigma and discrimination that drug users feel when attending this support groups.
- We want a place that is not judgemental, that gives practical support that looks at the issues in a holistic manner, one that is open for discussion, and where information is available.

Prison:

- We recommend that all prison staff have mandatory HIV awareness training.
- The segregation which has been reported in institutions needs to stop now. Information regarding HIV has to be made available to all the community, and specifically to those working within public institutions so that there is an end to the prevalent discrimination that is been reported.

Service Providers:

- Need to provide different sessions to cater for different needs.
- Living long term with HIV and the psychological impact this has on individuals.
- Drug use – and especially look at the impact of different drugs and how they impact on the individuals living with HIV.

Employment:

- As well as legislation that do not discriminate against people living with HIV, employers should be encouraged to support their workers by means of offering alternatives like part-time, job share, flexi – time (to attend hospital appointments, etc).
- The Benefits Agency should take into account the ever changing situation of individuals living with HIV so that they are not penalised and lose benefits if they need to start or stop working due to illnesses. This would actively engaged those living with HIV and feeling that they could do some work to engage in looking for jobs that they feel they can do.
- Pension schemes should not have questionnaires where disclosure of chronic illness or HIV needs to be stated. The same applies to mortgages, life insurance and travel insurance.
- There is diversity of drug users, and diversity in the drugs they use – therefore providers need to have knowledge of the different issues that can arise when using and been HIV positive. This applies to HIV service providers and Drug services alike.

Research

- Health issues of those living long term with HIV.
- Health issues of those living long term with HIV and Hepatitis C co-infection.
- Treatment for those also living with Hepatitis C – as yet there is little options for those whose genotype is 1 or 4.
- Health issues of those living with HIV, co-infection and drug use.
- Effects of long term ARV treatment for those living with HIV.
- Particular pharmacokinetic effects of ARV treatment and substances use, for example, heroin, crack, cocaine, methamphetamine.
- Benefits of prescribed marihuana to aid physical side effects of ARV medication and conditions associated with HIV, such as peripheral neuropathy.

Appendix 1: ICW's staff's understanding of Harm Reduction

HARM REDUCTION as understood by participants at the International Strategic Planning Meeting of ICW

- *“harm reduction – a proven, known, and unfortunately still controversial approach to lots of issues, for example, safer sex, drug use, etc. To me it implies (maybe naively) that communities themselves are involved in solutions – needle exchange in communities or prisons, whatever. Not having policies for projects demanding (or expecting) 100% safe sex. For example, not taking into account human behavior – i.e. we all fuck up from time to time. This does not mean we are horrible or failures. Microbicides could be a huge harm reduction product – i.e. it might be easier for positive women to use than overt condom use. So, even if it “fails” more than condoms it would protect women”.*
- *“harm reduction: safe needles; safer sex practices; drug use/healthy lifestyle; HIV drugs/Recreational drugs”*
- *“harm reduction = reduce the harm attached to drug use, to protect drug user's life not from drug use but the condition in which they use drugs, ex. needle exchanges”*
- *“harm reduction: Before Carmen's presentation regarding Silent Voices, harm reduction meant safe injecting. Afterwards I would like to know more about other HR areas: alcohol use, condom use. If we have problems explaining harm reduction, how about looking at a more accessible term? How do we advocate globally? Need to inform ICW members about these issues; raise awareness that harm reduction is needed everywhere as drug use is everywhere; raise what might be taboo topics in some regions? Bushbash; lobby for safe drug user”*
- *“an approach consisting in looking at prevention as a continuum (no a 0% v 100%), taking into consideration people's choices, situations, strengths and so on”*
- *“I think this is the creation of programs, and availability of resources, measures, etc to make as safe as possible potentially harmful activities, i.e. safe sex, needle exchange programs, reduction of stigma and discrimination”*

Appendix 2

Ethics Form

Proforma: for submission to internal ethics committee before research with human subjects begins: examples of how to complete the form are in italics. To be completed jointly by project leads (see point 2 of guidelines) and project support workers.

Section 1:

Name of Group	International Community for Women Living with HIV/AIDS (Silent Voices)
Address	Unit 6 Canonbury Yard 190a New North Road London N1 7BJ
Name of support worker	Faith Mango
Date:	13 th July 2005

Section 2:

What kind of work does the group intend to do as part of this project?	The group intends to carry out research into the drugs/substance misuse service needs of women who are HIV positive. The group intends to find out whether HIV positive women need specific or specialised services. The group also wants to carry out an audit of the services currently available in the study area to assess whether these are fulfilling the needs of the women as indicated by the women themselves. The group also intends to find out the level of take-up of services available and to investigate the reasons for any apparent lack of take-up of the services provided.
How do they intend to do this?	The group intends to carry out work in four overlapping main stages. The stages are preceded by the calling of a steering group whose role will be to oversee all aspects of the work. The steering group is currently made up of representatives from the Drug Action Teams in the target area, representatives from HIV groups, and some people who have been invited because of third-hand knowledge of issues in this area. The four stages are as follows: - Focus Group: Mapping of women's needs and experiences <i>The group intends to hold one or maybe two focus groups with 8 to 10 participants in each (these will</i>

be women who are HIV positive and will have to be current or ex substance misusers).

The aim of the focus groups will be to elicit from the discussions the key service provision issues in relation to drugs and alcohol as perceived by the women. It is aimed that this discussion will, in line with the research focus, inform the content of questionnaires that will be used to carry out this research. The group intends to use these focus groups as a way of gathering data, arising themes and issues pertinent to the research. . The sample for the focus group will be gathered through a snowballing technique beginning with contacts known to the researchers through support groups they attend at various centers. With permission, the group intends to take notes and an audio recording of the meetings.

- **Provider Audit form – mapping of available services**

A simple self-completing audit form (Appendix I) will be sent to the service providers in the target area to collect data on the services currently being provided. . The form will require the service provider to list all services currently provided and to indicate the level of take up by women. It is intended that this will provide quantitative as well as qualitative data – the service providers will be asked to provide current statistics on service take up and also impressions on any gaps perceived.

- **Development and Administering of questionnaire**

Using the information gathered in stages 1 and 2, the group intend to develop a questionnaire that will be used to gather the information for the research. It is intended that this questionnaire be completed by at least 35 – 50 women. To gain this sample the researchers will seek the help of Service Providers who have support groups for the target sample. A draft questionnaire will be used for piloting and then revised based on the results of the pilot. A number of articles about the project will be posted into such publications as Positive Nation, the Mainliners Newsletter, the Big Issue and others as appropriate. Given the sensitivity of the subject, it is anticipated

that a proportion of the questionnaires will be self-completing via an online questionnaire posted on the ICW website. Potential participants for the questionnaire will also be identified as part of the focus group phase i.e. respondents will be asked if they are willing to fill a questionnaire. Those who are willing will be contacted later. Women who come to the ICW centre to take part in the research will have a researcher on hand to assist with the completion of the form if they so require. Once all the questionnaires are collected, an elimination process will be conducted to eliminate from the research questionnaires completed by people who do not fit the target sample.

- In-depth Qualitative Interviews and Information Analysis

At each of the stages above – participants will be invited to indicate whether they are interested in taking part in in-depth qualitative interviews. This will be done without the anonymity of the particular stage being jeopardised. These interviews will be conducted without the participant being linked into their earlier participation. The aim of the qualitative interviews is to get in depth information on the themes arising from the completed questionnaires.

Analysis of the information and writing of the report will follow this process.

Who will the respondents be?	Women who are HIV positive and are currently drug misusers or were drug/alcohol misusers at the time of their HIV diagnosis. For this research, only women aged over seventeen will be recruited for the focus group and for completion of the questionnaire.
Who will they get to do the work?	A team of 3 women have been recruited from the HIV positive community using fliers and posters. In addition, Carmen, an employee of ICW is coordinator of the work and also part of the research team.
Where they will undertake the work?	All the focus groups will be conducted within the ICW International Support Office, in Central/North London. One of the researchers already does work in prisons

	<p>and using this contact, permission to visit the prison for the purpose of recruiting women to complete the questionnaire will be sought.</p>
<p>How will those who are doing the work be supported and supervised?</p>	<p>Carmen, who is an employee of ICW, is the lead researcher and project coordinator. She will have over-sight of the project on a day-to-day basis. She will also be the main contact between the research team and all the other stakeholders. As coordinator, she will meet with the team both individually and as a team once a week. .</p> <p>The 3 researchers and the Coordinator will all be attending the training workshops that the University is providing. The researchers have agreed to dedicate at least three hours a week to the project for the nine-month duration of the project. They will each be paid £10.00 per hour for all the work on the project.</p> <p>The university has appointed a support worker who will be visiting the project on a fortnightly basis. The support worker will help in the planning of the work and advise on all aspects of the project. In between visits, either the coordinator or any other member of the team will all be able to telephone or e-mail the support worker for support around any issues that they are unclear about.</p> <p>The researchers will only carry out work as agreed in this document and other work plans that will have been agreed by the coordinator and project support worker.</p>
<p>How they will ensure that participants in the project have given consent?</p>	<p>An information/consent form has been prepared (see attached). The information sheet will be explained and the participants invited to ask questions to ensure that they understand. The researchers will read this to potential respondents in order to get consent. Respondents will be asked whether they are happy to proceed with the interview based on the information that they have been given. The same will apply to participants of the focus group. It will be clearly explained to all participants that they can discontinue completing the questionnaire or leave the focus group at any time. .</p>

<p>How they will ensure the project confidentiality?</p>	<p>Names will not be recorded on the questionnaires. Interviews will be conducted in private rooms (if they so wish) within International Support Office. Completed questionnaires will be stored in a locked filing cabinet in an office within the centre. Only staff working on the project will have access to them.</p> <p>Data from the questionnaires will be analysed and presented in the final report (and any interim reports) in such a way to ensure that it is not possible to attribute any particular response to any specific individual.</p> <p>The names of participants/respondents where known, will not be revealed to anyone outside of the research team.</p> <p>Any recording of the focus group will be destroyed once the tape has been transcribed.</p>
<p>How will data generated by the project be handled and stored?</p>	<p>Completed questionnaires and notes from focus groups/interviews will be stored in a locked filing cabinet in an office within the centre. Only staff working on the project will have access to them. All interview notes/questionnaires will be destroyed by shredding once the final report has been written and accepted.</p>
<p>What risks are there? How will risks be identified and managed?</p>	<p>A number of forums exist to identify possible risks: individual workers may identify them on their own; they may be identified as part of weekly team meetings; they may be identified during discussion with the support worker; they may be identified at steering group meetings. Risks will also be identified during the preparatory work for the focus group and during the running of the focus group. Where any risk is identified it will be the responsibility of the project coordinator to ensure that measures are taken to manage the risk appropriately. The project coordinator will be supported in doing this by the University Support Worker, the Steering Group, and their own line management structure within ICW.</p> <p>So far the following risks have been identified –</p> <p>Managing prejudice and judgmental attitudes - The research team has been trained and supported to be aware of potential prejudices and how to manage</p>

these so that they do not manifest into judgmental attitudes towards the respondents and participants in the focus group.

Managing anger/violence/distress within the centre from respondents – The focus groups and interviews will be held in the premises of ICW. The risk of anger and violence will be minimized by involving the group in setting ground rules that ensure that participants respect each other. Some participants in the focus groups will be known to the researchers and to the organisation – thus further reducing the risk of violence. However, it is possible that respondents may become agitated during an interview due to the nature of the sensitive discussions around drugs. The researchers have all received training in interview techniques – including body language and non-verbal communication. Researchers have been instructed to make sure that they are always seated in a position that allows them to have a clear view of the whole room to dispel any side disagreements that could lead to violence.

Managing disclosure of self-harming behaviour – It is possible that respondents disclose self-harming tendencies or behaviour. The research team are clear that they are not counsellors. Prior to any interview or focus group – the researchers will collect information of support services available in the area and make these leaflets available and accessible.

Managing disclosure of criminal activity – Drug use is (in most cases) a criminal offence. Sometimes those involved in taking drugs are also engaged in other criminal activities (e.g. theft, shop-lifting). It is important that respondent confidentiality is maintained, and disclosures of criminal activities will not be passed on to the police except in the case of a threat of harm to others, or child abuse. This is explained to respondents at the beginning of the interview as part of the information sheet that is read out to obtain consent. The responsibility of reporting such incidences will be with the project coordinator and support worker who will do this in accordance with ICW's criminal disclosure policy.

Please confirm the make up of

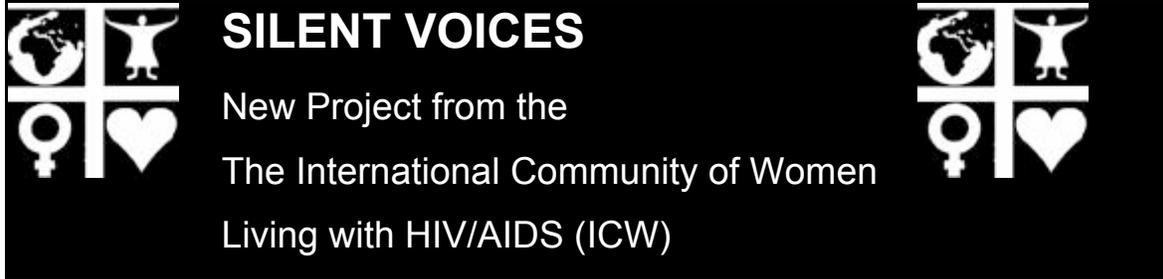
The steering group is currently made up of the

<p>the steering group.</p>	<p>following:</p> <ul style="list-style-type: none"> - Carmen Tarrades, Project Coordinator and ICW member of staff. - Chezerina Dhaliwal - DAT – Hackney – Community Action Coordinator - DAT – Islington – Representative from the Community Safety Partnership Unit - Faith Mango - University appointed Support Worker - Shona Flannigan – Membership and development Coordinator – London drug and Alcohol Network - Alison Johnson - Hackney Drug Action Team - Jax - Mainliners - Mark McPherson – I –Base – <ul style="list-style-type: none"> • Chris Galloway – Positive Futures – UK Coalition of People living with HIV & AIDS • Fiona Hale – International Network Coordinator – ICW – (HIV Community) • Julian Hows – GNP+- Europe
<p>How often does the steering group meet?</p>	<p>It is intended that the steering group will meet every six weeks. In between these meetings, members have indicated a willingness to be contacted by email to give an opinion on matters pertaining to the research.</p>
<p>Is the steering group clear that it has a responsibility for helping to manage the ethical issues that may arise as a result of running this project?</p>	<p>Yes. This was explained to each member at the time of being invited to join and also reaffirmed at the first steering group meeting held on 24/08/05.</p>

Section 3: To Be Completed By UCLan internal ethics committee

Date received:	
Reviewed by:	
Decision:	

Appendix 3 - Flyer



“Let Your Voice Be Heard”

HIV Positive Women and Drug Use

SILENT VOICES – a new project about positive women and drugs run by HIV positive women who have been or are drug users themselves.

The aim of Silent Voices is to research and collate information on drug and HIV related services, especially as they relate to women. Services, where they exist at all, are often geared towards men and do not meet the needs of women who could benefit from such services. This project will start with a London-based focus and will move on to look at the international situation at a later date.

We aim to illustrate how different drug use policies have an impact on positive women and the services they access or not. This will form the basis of recommendations to governments and policy makers.

Come to our Focus Group

Phone Carmen Tarrades on Tel: +44 (0) 20 7704 0606 to confirm and get the address. You will be reimbursed for your time

Appendix 3 – Notes from Focus Group 1



FOCUS GROUP 1 – 3RD October 2005

BEING IN THE MINORITY IN LONDON. HIV SERVICES MAINLY FOR BLACK WOMEN AND GAY MEN. THIS BRINGS IN CULTURAL DIFFERENCES – DIFFERENT LANGUAGES – DIFFERENT ISSUES SUCH AS IMMIGRATION RIGHTS –

– THERE IS AN ASSUMPTION THAT ALL WHITE WOMEN ARE DRUG USERS

WHAT HAS HAPPENED TO HOLISTIC THERAPIES? – NOT MANY AVAILABLE THESE DAYS – WESTMINSTER STOPPED FUNDING OUTSIDE THE BOROUGH - HELIOS IN KINGS CROSS UNFRIENDLY TOWARDS WOMEN AND ALSO NOT ADVERTISED – ONE WOMAN THOUGHT IT HAD CLOSED DOWN YEARS AGO – GLOBE CENTRE HAS A VERY LONG WAITING LIST – PRACTICALLY IMPOSSIBLE TO GET AN APPOINTMENT

DRUG SERVICES AND HIV – WHY DID THE GRIFFIN PROJECT CLOSE DOWN ?- ONLY SERVICE IN LONDON WHERE DRUG USERS COULD GET RESPITE CARE WITHOUT BEING LOOKED DOWN ON – POSITIVELY WOMEN NOT WELCOMING TO DRUG USERS. ROMA ALSO CLOSED DOWN – ONLY SERVICE IN LONDON WHERE DRUG USERS COULD GO TO STAY AND BE CARED FOR AND LEARN HOW TO LIVE ON THEIR SCRIPT AND NOT USE OVER IT.

SEEMS AS IF FUNDING TAKEN AWAY IN LONDON ANYWAY WHEN COMBINATION MEDICATION CAME ALONG - DO WE ONLY GET ONE OR THE OTHER BUT NOT BOTH?

ONE WOMAN WAS URGED TO DISCLOSE HER STATUS WHILST IN A REHAB (ST LUKE'S) BY COUNSELLORS – IT WAS FELT THAT DRUG WORKERS DID NOT HAVE ENOUGH TRAINING TO DEAL WITH HIV CLIENTS AND WERE GIVING OUT THE WRONG ADVICE

ALSO CONFIDENTIALITY WAS BREACHED IN ANOTHER REHAB (PHOENIX HOUSE) – THERE CAN BE RESENTMENTS FROM THE OTHER CLIENTS WHEN HIV PEOPLE NOT ALLOWED TO WORK IN KITCHEN – CAN BE SEEN AS GETTING TREATED AS SPECIAL AND DIFFERENT – THIS IS STILL HAPPENING TODAY – DRUG WORKERS AND DRUG SERVICES (REHABS) DO NOT HAVE SPECIALISED TRAINING

THE JUNCTION WHICH IS IN ANNERLEY ROAD IN SOUTH EAST LONDON WHICH IS A SPECIFIC HIV SERVICE FOR BOTH MEN AND WOMEN WAS CONSIDERED VERY GOOD – THEY HAVE A FAMILY DAY AND CHEAP LUNCHES – A GOOD MIX OF MEN, WOMEN AND GAY MEN

CLIENT NUMBER ONE USES NO SERVICES AT ALL THESE DAYS – ONLY HER CLINIC.

SHE DID USE IDT AND LIGHTHOUSE, BUT NOW THERE IS NO FUNDING FOR THEM. HER DRUG HISTORY WAS NOT AN ISSUE AT HER CLINIC – YOU ARE EITHER CONSIDERED TO BE A USING DRUG ADDICT OR YOU ARE NOT ONE. THERE IS NO MIDDLE LINE WHERE YOU MIGHT RELAPSE. INFORMATION CONCERNING THE EFFECTS OF

COMBINATION THERAPY WITH STREET DRUGS WAS NOT GIVEN IN CASE SUCH AS THIS – ONLY TO GAY MEN AND WOMEN WHO WERE OBVIOUSLY USING DRUGS.
ICARE – ISLINGTON CARE – GAVE GOOD SERVICE WHEN YOU FIRST WENT THERE AND DID NOT HAVE BENEFITS – ONCE YOU GOT THEM THEY IGNORED YOU AND THERE WAS THE ASSUMPTION THAT THERE WAS NOTHING MORE YOU NEEDED – AT CLINIC FOR FERTILITY NO ONE TO RELATE TO – NURSES HAD SAID TO HER HOW COULD SHE DO THIS – HAVE A BABY WHEN YOU WERE POSITIVE – MORE TRAINING NEEDED

CLIENT NUMBER TWO USES ONLY HER CLINIC – VERY HAPPY WITH THAT SERVICE – CALDICOT CLINIC AT KCH

CLIENT NUMBER THREE USES HER CLINIC, POSITIVELY WOMEN AND THE JUNCTION - WAS DIAGNOSED IN PRISON AND MET WORKER FROM PW – SHE SAYS SHE WOULD NOT HAVE ATTENDED GROUPS AT PW IF THAT WORKER HAD NOT BEEN THERE - THE REASON FOR THIS IS BECAUSE THERE WERE NO OTHER WHITE WOMEN AND SHE FELT VERY ISOLATED.

CLIENT NUMBER FOUR USES ONLY HER CLINIC AND BREAST CANCER HOSPITAL AND THEIR SERVICES – DID USE LIGHTHOUSE A LOT BUT THEN FUNDING WAS STOPPED FOR KENSINGTON AND CHELSEA. SHE DID USE HELIOS FOR COUNSELLING BUT ONLY FOR A SHORT PERIOD – SAYS IT IS TOO FAR TO TRAVEL FOR A MASSAGE

BROUGHT UP THE ISSUE AROUND PAIN CONTROL – BECAUSE HER GP KNOWS HER DRUG HISTORY THEY ARE VERY LOATHE TO GIVE PAIN KILLERS AS THE ASSUMPTION IS THAT THEY WILL MISUSE THEM – ANOTHER BIG ISSUE AROUND PAINKILLERS IS THAT MAYBE DRUG USERS NEED MORE THAN A PERSON WHO HAS NEVER USED THEM BUT THIS IS NEVER TAKEN INTO CONSIDERATION AND YET AGAIN ACCUSATIONS OF MISUSING THEM ARE EITHER SAID OR INSINUATED

CLIENT NUMBER FIVE USES HER CLINIC AND LOCAL HIV SERVICE (RIVERHOUSE) – FEELS VERY OUT OF PLACE THERE AS ONLY AFRICAN WOMEN SEEM TO USE IT AND THEY ARE NOT FRIENDLY (THEY SPEAK IN THEIR OWN LANGUAGE WHICH CAN COME ACROSS AS RUDE). SHE THINKS THAT SHE WILL STOP USING THIS SERVICE

CLIENT NUMBER SIX USES HER CLINIC – IS GETTING HELP WITH GETTING PREGNANT (SPERM DONOR) HAS GONE PRIVATE - COSTS £1000 EACH TIME – WILL ONLY TRY TWICE – WANTS INFORMATION ABOUT FOSTERING AND ADOPTING BUT DID NOT KNOW HOW TO FIND OUT THIS INFORMATION (ABOUT BEING POSITIVE AND AN EX-DRUG USER, BOTH PARTNERS HAVE BEEN IN PRISON)

IT APPEARS THAT MUCH MORE TRAINING AND INFORMATION IS NEEDED ABOUT ASSISTED FERTILITY FOR HIV POSITIVE WOMEN AND MEN. SHE HAS TO BE THE LAST ONE OF THE DAY TO GET THE SERVICE. ALSO CLIENT WITH BREAST CANCER HAD TO BE THE LAST PERSON TO BE OPERATED ON - WHY IS THIS STILL HAPPENING?

IN HOLLOWAY PRISON TRAINING IS NOT GIVEN TO STAFF – ONE POSITIVE WOMAN WAS

A SELF-HARMER AND THE NURSE PUT ON FIVE PAIRS OF GLOVES BEFORE SHE WOULD TOUCH HER.

HOLLOWAY IN GENERAL WAS THOUGHT TO BE GOOD IN DEALING AND SUPPORTING POSITIVE WOMEN AND SHOULD BE HELD UP TO THE OTHER PRISONS IN ENGLAND.

FOR DRUG USERS THE SERVICES NEED TO BE TAKEN TO THEM – WHEN YOU ARE USING HIV IS NOT CONSIDERED A PRIORITY

NEED MORE WOMEN DROP-IN SERVICES

THESE WOMEN WOULD LIKE TO HAVE THE CHOICE TO GO SOMEWHERE TO MEET OTHER POSITIVE WOMEN WHO HAD USED DRUGS – THEY WOULD LIKE TO GO TO A GYM BUT FELT TOO EMBARRASSED BECAUSE OF THEIR BODIES (LYPODYSTOPHY) BUT WOULD GO TO A CLASS WITH OTHER LIKE WOMEN. SOME SAID THEY WOULD LIKE A SUPPORT GROUP - IT SEEMS AS IF LONG TERM DIAGNOSED WOMEN HAD USED THE SERVICES THEY NEEDED IN THE BEGINNING THEN GOT ON WITH THEIR LIVES (MANY WERE AT UNI OR HAD GOOD JOBS OR HAD CHILDREN OR WERE TRYING TO HAVE BABIES) AND NOW AFTER SO MANY YEARS FELT THERE WERE ISSUES WHICH THEY WOULD LIKE TO TALK ABOUT BUT MANY HAD LOST TOUCH WITH OTHER HIV WOMEN.

ONE ISSUE WAS THEIR PARTNERS WHO WERE NEGATIVE – WHO DID (PARTNERS) THEY TALK TO? – THEY THOUGHT IT WOULD BE A GOOD IDEA TO HAVE AN INFORMAL EVENING WHERE THEY COULD TAKE THEIR PARTNERS

SERVICES

THERE WAS NO INFORMATION THAT THEY WERE THERE

THE RESEARCH MIGHT BE USEFUL TO TAKE TO DOCTORS AND CLINICS TO BE MADE AWARE

FEELINGS OF FEELING ALIENATED, ALONE, NO ONE TO SHARE HER PAST EXPERIENCES – ONCE A MONTH SUPPORT GROUP

ISSUES ABOUT POSITIVE PEOPLE BEING AT DIFFERENT STAGES OF USING – MIGHT BE DIFFICULT

DRUG AND ALCOHOL GROUPS IN DIFFERENT BOROUGHES

DIFFERENT STAGES OF HIV/DEALING WITH DIAGNOSIS - APPLIES TO ANY STAGE OF HIV

HOLISTIC THERAPY – SERVICES ARE NOT BALANCED

DIFFERENT ISSUES FOR WOMEN – BLACK AND WHITE

NEED FOR DRUG USERS TO BE PART OF THE SUPPORT GROUP
ATTITUDES FROM OTHER CLIENTS WHO ARE NOT DRUG USERS
JUDGEMENTAL ATTITUDES

DO DRUG SERVICES PROVIDE THAT SUPPORT?
SERVICES NEED TO ACCEPT CHOICES PEOPLE MAKE i.e. MAYBE NOT CLEANING UP

SERVICES THAT PROVIDE 24 HOUR SUPPORT FOR BOTH DRUG USERS AND HIV PEOPLE

DISCLOSURE OF USE – SOMETIMES FORCED TO DISCLOSE

ONCE DISCLOSED – FEAR OF LOSING CONFIDENTIALITY

TREATMENT CENTRES HAVE NO EXPERIENCE EITHER OF HIV OR OF DRUG USE

NEED OF PEER SUPPORT – NO ONE UNDERSTANDS IT

“THE JUNCTION” – TRYING TO EXPAND SERVICES
DROP-IN FOR HIV PEOPLE
NEED FOR PEACE AND QUIET
FAMILY DAY
FRESHLY COOKED MEAL AND CHEAP
A VERY GOOD MIX OF PEOPLE

ASSUMPTIONS THAT IF YOU ARE WHITE AND HIV YOU MUST BE A DRUG USER

MORE BLACK AND ETHNIC MINORITY COMING OUT OF PRISON WHO ARE BOTH HIV AND DRUG USERS

NEED OF CONTINUITY OF SUPPORT

SERVICES, WHEN AWARE OF DRUG USE, MIGHT NOT BE ABLE TO REFER

CLINICS DON'T ADVERTISE SERVICES FOR DRUG USERS

FEAR THAT IF DISCLOSING DRUG USE TREATMENT MIGHT NOT BE OFFERED (ARV)
NOT ENOUGH KNOWLEDGE ABOUT INTERACTING BETWEEN DRUGS AND ARV
ADDICTS AT TIMES LIE TO DOCTORS
CHAOTIC USERS ARE TAKEN OFF MEDICATION
COMBINING METHADONE AND ARV DAILY DOSE
IF DRUG USERS DON'T DISCLOSE USE – NO INFORMATION ABOUT INTERACTION
OUTREACH WORK IN PRISON – HELPED IN RECOMMENDING AND PROVIDING SUPPORT AFTER RELEASE
WORD OF MOUTH ABOUT SERVICES IS WHAT ENCOURAGES ATTENDANCE
DRUG USERS – MOSTLY WHITE – CULTURAL ISSUES (FELT THAT THIS NEEDED TO BE SAID)
PAIN RELIEF WHEN IN HOSPITAL – STAFF DO NOT UNDERSTAND LEVELS OF TOLERANCE AFTER HAVING USED
GP – ALSO FAIL IN ABOVE – THINKING THAT WE JUST WANT TO USE THE SYSTEM. NEED FOR TRAINING CLINICIANS
TREATMENT ALSO DEPENDS ON RELATIONSHIP WITH DOCTOR
SERVICES AT TIMES ARE MORE FOCUSED ON BALANCE OF NUMBERS THAN PROVISION TO THOSE NUMBERS
LOSS OF SERVICES – AND ALSO WHEN AVAILABLE TOO FOCUSED ON OTHER GROUPS
BODY IMAGE SOMETIMES AN ISSUE WHEN APPROACHING GYM ETC

ARV THERAPY ARE ONE OF THE CAUSES FOR LOSING HOLISTIC THERAPY

IVF-
GYNAECOLGY – SELF EXAMINATION – JUDGEMENTAL ATTITUDES BY STAFF
HAMMERSMITH – SUPPORT FOR IVF – BUT LAST ONE OF THE DAY FOR TREATMENT

PRISON
TEST
NO COUNSELLING
LOCK-UP
INCREASED NUMBER OF POSITIVE WOMEN IN PRISON AT PRESENT
STAFF NEED TRAINING

ALL PRISON POLICIES NEED CHANGING – IE POSITIVE EXAMPLES OF HOLLOWAY
HAVING TO DEAL WITH DIAGNOSIS
RESETTLEMENT INFO – HOUSING SERVICES
STIGMA IN PRISON – ISOLATION – BEING PICKED ON FROM INMATES AND STAFF
STIGMA CAN ALWAYS BE BROKEN WITH INFORMATION
NEED TO EDUCATE
NEEDS THE INVOLVEMENT OF POSITIVE PEOPLE
LACK OF POSITIVE PEOPLE CHALLENGING THE STATUS QUO – POSITIVE ACTION

NO CONSTANCY IN REGULATIONS – CHANGES OF GOVERNOR = CHANGE OF
APPROACH
PW SUPPORT (HMP STYLE) HELPS WOMEN IN PRISON AND HELPS RE-INTEGRATION
AND ACCESSING SERVICES ON THE OUTSIDE

SERVICES MIGHT NEED TO BE TAKEN TO THEM
REACHING ADDICTS AN ISSUE – NEED OUTREACH AND INFO ON SERVICES
HIV POSITIVE DRUG USERS ARE DISCRIMINATED IN THE SYSTEM

IUI NOT FUNDED BECAUSE OVER 38 – NEED TO GO PRIVATE – SPERM DONOR
TWO TREATMENTS

FOSTERING AND ADOPTION FOR POSITIVE WOMEN/COUPLES – CRIMINAL RECORD? IS
THIS AN ISSUE?

IN GROUPS – ISOLATION – WHEN TALK IS ABOUT ISSUES WHICH ARE NOT RELEVANT
TO INDIVIDUAL

NEED FOR LONG-TERM SURVIVORS MEETING

YEARS AGO ALL ROUND SUPPORT WAS AVAILABLE

NEED TO TALK ABOUT RELEVANT ISSUES TO THE GROUP
ISSUES ABOUT DISCORDANT COUPLES
SEXUAL HEALTH AND USING CONDOMS
LONG TERM SURVIVAL GROUPS – NECESSARY

Appendix 4 – Notes from Focus Group 2

FOCUS GROUP 2 -
Even though I have stopped (drugs) , they are still very present in my mind
Have to be careful of not relapsing as I am aware that it (drugs) is there
Able to connect with positive women but certain things are more difficult with the “norm” – don’t want to be judged
Relationships – broken – considered going to score
Need to be able to be in dual diagnosed groups
After diagnosis I started to use crack – every week going to a street agency but unable to talk about HIV - shared diagnosis with counselor but not with group - because of drugs, I started to lose self-esteem “and on top of that I was positive”
“with the baby I have no time to be smoking”
Fear that stopping smoking (spliff) might bring even more emotions – bringing up the issues of breast feeding
In groups there is a lot of denial – drinking, anti-depressants, yet, judgmental of drugs
Healing process – whole: physical, emotional (sometimes we use drugs to deal with emotions)

Getting a diagnosis made me use more drugs
Family rejection at first. counseling help
Every week there is something I have to deal with
GP. Newly registered. Nurse questioned why access to treatment – baby
Different experiences of GP's. Sometimes very helpful
Came off by myself
Got it through sex-not drugs
Unable to negotiate condoms – very insecure. Used sex in order to obtain love, security. HIV as realization that this had to be solved
Impossible to talk to a group about these issues
Feeling of been judged
In specific group (drug and alcohol) feeling comfortable. Not judgmental
Feeling support from co-workers and friends
Not able to access alternative therapies – have to pay – have to pay for all my support
Need free counseling services – difficult to access counseling once you have been diagnosed for a while <ul style="list-style-type: none">- long waiting list- drastic circumstances (killing oneself) you might get it (counseling) straight away – 2 attempted suicides
Baby – didn't think it was possible. I thought I would do it quickly before starting therapy
Royal Free: felt very supported. Went there before the break up of the relationship. Explained all the options. Self-insemination. Hormone tests. Sperm count. Supportive all the way.

Judgmental attitudes from a doctor when asked about getting pregnant
Feelings of joy at the realisation I can have a baby
Need to change treatment in order to have baby – Efavirez
Not contemplating a family on her own. Wanted a family
Parenthood was his idea. “I am too lazy”
Sex –normal
I got pregnant before but lost the baby. This time was fine. The father is negative
Being HIV is not that bad. Life is beautiful, whether positive or not
Need more friends who are positive. Peer support
Acceptance by other people is useful
Need to cut off from some friends who are still smoking (crack) but I don't have any other friends
Don't enjoy sex at the moment. Scared he might get it. Fear
At birthing nurses wouldn't help – started bleeding from caesarean – nurses would not help. Discrimination by black nurses – even from own country. Had to fend on my own, show that I could make it
Lack of confidentiality in wards
What's worse, the patronizing or the rejection?
Rather be in a room by myself – (hospital)
Common room – although for all – not allowed for positive women (was told it was not for patients)

Dentists – community dentists for HIV
Co – infection: with depression – not taking medication because of smoking and drinking
Co-infection – with Hep C, B – Liver Clinic at King’s College – reluctance to offer genotype testing
Initially, feeling that we will die because of AIDS, now, will die of Hep C before of AIDS <ul style="list-style-type: none">- better to have integrated care – co-infection clinic- fibro-scan- HIV treatment depending on liver function – clear guidelines for same standard of care-
Doubly emotional to be living with both diagnosis
Herpes – connections with periods
Side effects can/are very humiliating <ul style="list-style-type: none">- diarrhoea- sweats- mental health- fatigue – been overcome with fatigue-
How would I pay for alternative treatment, i.e. yoga, if I wasn’t working? Organic food, diet
Working keeps me focus
Sex: not on your mind after diagnosis
Starting all over again (relationships) <ul style="list-style-type: none">- dating- disclosure- fear of rejection- fear that by disclosing – they tell every one- easier to say it straight away
Everyone that matters knows
Always practicing safe sex – always comfortable with condoms
Stressing – do you tell before, after, at all?

Inform him before telling
Get a professional to talk to them to reassure
Anxiety – I don't want to hide. I am proud of how I live with it
However you disclose is not fun
Better at the beginning, that way I know how I stand
Sometimes I forget , it's just not all that I am about
By talking about the work I do I am already introducing the subject
Early menopause
HIV messing up periods
Drugs also (messing up periods) so maybe we don't notice for a while
Still horny all the time
If I weren't positive I would be messing around more – but disclosure – much freer with my favours
One night stand – might not be telling at all
Partners get worried when other people knows about our status – they hide it from other people
“I want to be a slut again”
Giving birth, I got a caesarean in case of tearing. First baby it might be a difficult delivery. - getting pregnant was the easy thing - will disclose to the child. Talking about all things is good - want one more child -
Need to feel ethically and morally right – telling about diagnosis

Appendix 5: Answers to questionnaire

QUESTIONNAIRE FOR SILENT VOICES

INFORMATION FOR INTERVIEWEES: THIS IS AN IN-DEPTH INTERVIEW WHICH IS PART OF ICW'S *SILENT VOICES* PROJECT. IT IS ABOUT SERVICES PROVIDED FOR WOMEN WHO ARE HIV POSITIVE AND ARE, OR HAVE BEEN, DRUG AND ALCOHOL USERS. WE WILL BE ASKING YOU QUESTIONS ABOUT THE SERVICES YOU HAVE USED IN RELATION TO YOUR DRUG/ALCOHOL USE AND WHETHER YOU FEEL THE SERVICES PROVIDED ARE MEETING YOUR NEEDS.

THE INTERVIEW WILL TAKE ABOUT AN HOUR AND I MAY BE JOTTING DOWN A FEW NOTES AND MAYBE ASKING YOU TO ELABORATE ON SOME OF THE THINGS YOU SAY. IF YOU NEED TO TAKE A BREAK AT ANY

PLEASE FEEL FREE NOT TO ANSWER ANY QUESTION, BUT THE ANSWERS YOU PROVIDE WILL BE HELPFUL

Personal Details																																								
<p>How old are you?</p> <p>What age group? <u>If the interviewee is reluctant to share age – ask for an age range.</u></p> <table border="1"> <tr> <td>18-20</td> <td>20-25</td> <td>25-30</td> <td>30-35</td> <td>35-40</td> <td>40-45</td> <td>45-50</td> <td>50-55</td> <td>55-60</td> <td>60-65</td> <td></td> </tr> <tr> <td></td> <td></td> <td></td> <td></td> <td>X</td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> </table>										18-20	20-25	25-30	30-35	35-40	40-45	45-50	50-55	55-60	60-65						X							I am 39								
18-20	20-25	25-30	30-35	35-40	40-45	45-50	50-55	55-60	60-65																															
				X																																				
<p>What ethnic group do you belong to? – How would you describe your ethnic group?</p> <table border="1"> <tr> <td>White</td> <td></td> <td>Black</td> <td></td> <td>Asian</td> <td></td> </tr> <tr> <td>British</td> <td></td> <td>British</td> <td></td> <td>British</td> <td></td> </tr> <tr> <td>European</td> <td>X</td> <td>African</td> <td></td> <td>Pakistan</td> <td></td> </tr> <tr> <td>Irish</td> <td></td> <td>Caribbean</td> <td></td> <td>Indian</td> <td></td> </tr> <tr> <td>Other</td> <td></td> <td>Other</td> <td></td> <td>Other</td> <td></td> </tr> </table>										White		Black		Asian		British		British		British		European	X	African		Pakistan		Irish		Caribbean		Indian		Other		Other		Other		Mediterranean
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<p>What country were you born in?</p>										Spain																														
<p>How long have you lived in the U.K.? (Only ask this if the person was born overseas)</p>										About 18 years																														
<p>What languages are you fluent in?</p> <p>Spanish, English, German, and learning Arabic now.</p>																																								
<p>What is your religion?</p> <table border="1"> <tr> <td>None</td> <td>Christian</td> <td>Muslim</td> <td>Jewish</td> <td>Hindu</td> <td>Buddhist</td> <td>Sikh</td> <td>Other (specify)</td> </tr> <tr> <td></td> <td>X</td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> </table> <p>I was born catholic but I don't really practice.</p>										None	Christian	Muslim	Jewish	Hindu	Buddhist	Sikh	Other (specify)		X							Christian														
None	Christian	Muslim	Jewish	Hindu	Buddhist	Sikh	Other (specify)																																	
	X																																							
<p>Are you in employment? What is your occupation?</p> <p>Were you working before?</p> <p>I was doing a lot of catering. And teaching Spanish.</p>										No																														
<p>Have you disclosed your status to your employer or anybody that you work with?</p>										No																														

<p>No. terrified. Even if they say now that you have your rights. That you are entitled to not be discriminated. But I don't believe it. I would be very scared to disclose it.</p>	
<p>Has your HIV status affected you financially in anyway?</p> <p>Very much. Even now that I couldn't take up an 8 hours job daily to earn enough money to pay my rent and to live with a child. I do feel trapped in that way, because...I don't know how to say it...if I was healthy, if I wasn't positive I would fight much harder to get a job...or probably I wouldn't even live in England. But here is where I get some support and some help. It's very difficult because I don't think you could get a job if you're struggling day by day with your health, if you're not feeling well. It's not just calling your employer and saying: "look, I am not feeling well" or every week you have appointments, or your system is not feeling strong enough. I think I would die of stress if I had to keep a job on top of my ordinary living.</p>	<p>Yes</p>
<p>Sexuality?</p>	<p>heterosexual</p>
<p>Disability?</p>	
<p>About Your HIV Diagnosis and other general health issues</p>	
<p>When were you diagnosed with HIV?</p>	<p>In 1987</p>
<p>Where were you diagnosed? hospital, clinic, prison? other?</p> <p>It was a clinic.</p> <p>What made you go for an HIV test?</p> <p>I was using drugs and wanted a check up, a general check up. I didn't really ask for an HIV test.</p>	<p>Clinic</p>
<p>Which country where you living when you received your diagnosis?</p> <p>In Spain, Bilbao.</p>	
<p>Are you co-infected with Hepatitis C?</p> <p>I did have Hep B and C but I cleared them completely about 10 yrs ago. The consultant said I was really, really lucky.</p>	<p>no</p>
<p>In what ways has HIV affected your life?</p> <p>Many, many ways. Something positive I could say is that I stopped using drugs, and that I have learned that we are all mortal. I think people today think that they are immortal – they don't really enjoy life. When you struggle a lot in life I think you appreciate it more and you realise that you have to make the most of it. I am more understanding and open to people.</p>	

<p>But the negative part is so huge. I was diagnosed when I started in my first year at university and I thought: "I don't know why I am doing this" because I thought I was going to die within a year, but I kept going to university and I did finish it. But whilst my friends were trying very hard to get work experience I had no interest. I thought it's not worth it, I am going to die.</p> <p>I have learned to hide in life. That's very stressful. There was a point I was panicking so much, I was having so many panic attacks about everything that I couldn't even go out of the house. All these have stopped me doing many things that I wanted.</p> <p>I am a very different person to what I could be. You start thinking that you have no time. Sometimes I get very anxious and I want to do everything right now because I think in a few months I might not be here. It's difficult. It's hard.</p>	
<p>Do you have other conditions/ infections that concern you? E.g. Hepatitis A or B, T.B, Cancer. MS or peripheral neuropathy</p> <p>Not now.</p>	No
<p>Do you want to say how you manage with having HIV and these other conditions?</p> <p>I have had a little trouble with anxiety and panic attacks – psychologically. I think now is one of my best times. This year has been one of the best years. I still find it very stressful.</p>	
<p>Are you on combination therapy?</p> <p>I stopped last year. I was taking tablets for 1 year.</p>	No
<p>When starting combination therapy did you suffer any side effects?</p>	
<p>Are you on any other medication?- Please give details</p> <p>I am on anti-depressants, sleeping tablets and tranquillizers.</p>	Yes
<p>Do you use alternative therapies? If so please specify which therapies you have used.</p> <p>Not now. I have had acupuncture in the past, but not now.</p> <p>Why don't you use them now?</p> <p>Because I cannot access the services. I have called a lot of groups and organisations. I used to have Reiki, homeopathy, reflexology. But I cannot access these services any more.</p> <p>If you could afford them, would you?</p> <p>Oh yes, definitely.</p>	

Why do you use alternative therapies?	
Do you pay for alternative therapies or any other therapies? No, I can't afford them.	No
Do you have to travel far to get to your clinic or to access any therapies or services? if so, how long does the journey take? Yes. There is nothing around here. I think the closest one is the Globe Centre, but still, it's not so close. And there is a waiting list for months, years, and I don't get to be called. Where do you go for your clinic? Bart's Hospital, but I don't think they do any therapies there.	
About your substance use/ Misuse	
Do you drink alcohol? If yes, how much do you drink –how regularly? Sometimes. Not much. I'll say once a week.	
Do you smoke cigarettes? If yes, how much do you smoke – How regularly? Yes, lots. 20 a day.	Yes
Are you currently still using illicit (illegal) drugs? If yes, how regularly? I am using hashish. That's it, really.	yes
What do you use and how regularly Yes. Everyday. I mean, every evening. I smoke 2-3 joints and that helps me to go to sleep and relax.	
How long have you or did you use drugs? I started when I was about 14. I have never given up hashish.	
What was your drug of choice? I did have a lot of trouble with heroin. I have tried many other things – I have tried LSD, ecstasies, speed, amphetamine. But that was in my early years. I was using heroin since I was 15 then I stopped, more or less, when I was 20. Then I had a relapse when I was 27...I can't remember... The last time I used was 4 years ago and I went to a rehab clinic in Spain and since then I have been fine.	Heroin
What do you use now?	Hashish

<p>What was your favoured method of use? <u>Tick as appropriate or enter given answer</u></p> <table border="1" data-bbox="240 346 690 478"> <tr> <td>Injecting</td> <td>X</td> </tr> <tr> <td>Smoking</td> <td></td> </tr> <tr> <td>Snorting</td> <td></td> </tr> <tr> <td></td> <td></td> </tr> </table> <p>I injected. And smoked as well. But mainly injecting.</p>	Injecting	X	Smoking		Snorting				<p>Injecting</p>
Injecting	X								
Smoking									
Snorting									
<p>Do you consider your alcohol use to be problematic? <u>Please say how.</u></p> <p>No. I have drunk a lot in the past. I lived in Germany for 1 year, about 8 years ago. And I was drinking very heavily that year.</p>	<p>No</p>								
<p>Do you consider your drug use to be problematic? <u>Please say how.</u></p> <p>No. only that it's very expensive!</p>	<p>No</p>								
<p>What issues can occur around using drugs in relation to any other service you use or have used?</p> <p>I have lied. I have lied very often because for me it's much easier to say that I got infected through a boyfriend that was using. It's very rare that I have said that I used to inject or be a drug user – because people do look down on you and they have an idea of you, or they make an idea of you. That's not real for me. It's not that I want people to feel pity for me, you know... if I have been infected by somebody else. But it's easier because you don't have to describe your whole life. If you say that you have been a drug user you're making a picture of yourself that I don't want many people to know.</p>									
<p>If using drugs or drinking heavily, do you disclose this to any professional worker? E.g. Consultant, Nurse, Counselor?</p> <p>To the doctors, or hospital.</p>	<p>Yes</p>								
<p>If so, what response have you had?</p> <p>I have found some problems with GP's or maybe sometimes when you go to consultants and they ask you questions that they shouldn't ask. It is okay to ask you how long have you been infected. But, if you go to a dermatologist or some other consultant and they start asking questions: how did you get infected? and they are not relevant to them.</p> <p>Have you had any bad responses from your HIV clinic to the fact that you had used before?</p> <p>Not really. I think the worst experience was when I got diagnosed, the first time in</p>									

<p>Spain because I didn't ask for the test, and then, the consultant treated me quite badly. He said; "well, you have 6 months to 1 year to live. And don't cry, because the people outside will see you crying". And that was it. No support at all. That was my worst experience.</p> <p>No sort of counseling? Or anything?</p> <p>No. nothing. No sympathy at all because I was using at that time.</p> <p>Did they recommend you went somewhere for support?</p> <p>No. nothing. At that time I think people were taking some AZT. They didn't even know if you could get it through tears and sweating and things like that. It was quite early years.</p> <p>At that time I did go to a dentist in Spain and I felt that I had to say that I was HIV positive. And I really had a bad experience. He told me: "okay, you come tomorrow, the last person in the clinic". He didn't wait for the anesthetic to work. He was in a really bad mood. And then I thought: "if he tells me to come as the last person it's because they are not cleaning the stuff properly and that means that I am getting any other infection that people has". And I thought that was really unfair. And I am not going to say it again! And that made me keep quiet for other visits.</p>	
<p>Were you ever on treatment and still using drugs /drinking?</p> <p>No. when I was taking anti-retroviral I wasn't using heroin. I was still using hash.</p> <p>And that didn't affect your adherence?</p> <p>No</p>	
<p>Were you able to adhere to your treatment regime? If not, please tell me what you thought where the causes of your failure to adhere.</p> <p>Yes. I did feel very sick. I felt very worried. My stomach was so bloated I was looking pregnant! I did have diarrhoea. I was quite regular at taking the tablets but I found it very difficult. I was in and out of hospital all the time.</p>	
<p>If you faced problems with adherence, <u>where you able to discuss these with your doctor?</u></p> <p>I went to see a specialist nurse, in a hospital in East London. We did have time to talk and discuss the different options. I didn't feel that I had many options!. But we did talk about it.</p>	yes
<p>Do you believe you are given enough information about your combination therapy and the use of illicit drugs?</p>	
<p>If you have managed to abstain from alcohol and/or drugs after a period of using, how have you managed this? - What services are there available for you to get enough support?</p> <p>Rehab</p>	

Did you tell them you were positive?

I did. I think it's the hardest thing I have ever done in my life – being there for a year. Away from my child! It's not that they were not sympathetic but they wanted to push it away, that subject, I wasn't allowed – let's say – some days I'll have fever, or wasn't feeling well – and I was pushed to carry on as normal. I wasn't given any allowances, any extra counseling for that. They just wanted me to cope with that. I didn't find much support in that area.

What was it like? (I have never been to rehab).

That was my first and only time, rehab. I was there for 11 months. I used to go home for the weekends. My parents were looking after my child during the week. It was very hard. You have to live with another 20-25 people and they all have a lot of problems because of drug use. Community living was very tough. We'll start at 7 o'clock every morning, running in the mountains. They did give you a lot of responsibilities. All the work was organised by us. We had therapies, family groups, once a week. And 2-3 days within the group. You do learn a lot of things – you learn to be hard, to be able. You think you cannot cope anymore, and you are been pushed all the time. Now when I go back to Bilbao I usually pay them a visit...you can see yourself a few years ago and now...I don't think I would have survived if I hadn't gone there...because I wasn't eating, I wasn't sleeping, I wasn't doing anything...it was hard. Very hard.

About the Services you use

What services/support networks do you use – please specify in relation to – HIV,

I can't find any organisations that I can fit in. I know there are places but they don't seem to do anything for us. I can't see how I can benefit from going to the places that we have today.

And why do you think that is?

Well, I think that the government doesn't pay enough money towards the alternative therapies. And the groups are very closed – like if you go to the Lighthouse – it will be mainly for gay people. All I see when I go there is people having meetings, having conferences and things but I don't actually see many service users.

Why is that? Where does it come from?

Because I think that most of the people who use these services have a very different background. Many Africans. Many gay people. I don't know. I don't seem to fit.

How about the staff in these services – were they supportive?

Yes. I would say that so...so...

So, what was the reason for you accessing these services – or that you tried to access these services?

I was feeling very lonely. It used to be my meeting point for other friends that I only see them when I used to go to PW. I used to meet other people that I otherwise

<p>couldn't meet somewhere else. I used to go to Body and Soul because they did help me with looking after my child. Giving me a break. Meeting other mums.</p>	
<p>Drugs, Alcohol</p>	
<p>Please tell me about services you have used in the past</p>	
<p>How did you find out about these services?</p>	
<p>Would you like to talk about the attitudes you have encountered from staff and other service users.</p>	
<p>What services have you used where you have felt that BOTH the HIV and drug use have been dealt with in a satisfactory manner?</p>	
<p>Have you ever changed services (e.g. your clinic) and if so, why?</p> <p>Well, I have when I couldn't find therapies – or enough support</p> <p>And what about other clinics?</p> <p>I have changed from the Royal Free Hospital. No, first I used to go to the North London Hospital. And changed that from the Royal Free. And after a few years I changed to Bart's Hospital. Because at the Royal Free they did have good consultants but you never got to see them because they were always busy in conferences. I kept on seeing different doctors all the time. I felt the service was overcrowded as well. The community nurse recommended me Bart's.</p> <p>And do you feel happy with that?</p> <p>Yes. I think so, yeah.</p>	
<p>What was your reason for accessing the services that you used?</p>	
<p>Did you find that your needs were met by these services?</p> <p>The clinics, yeah, but the support groups...not with the support groups and not with the therapies.</p>	
<p>What needs, if any, do you think still need addressing?</p> <p>Being HIV+? I don't think that we have the support that we should. As I said in the beginning I am feeling quite well now but when I was feeling very unwell last year and the year before, I had no support and no help at all with my child. I was actually in hospital, very unwell, with a lot of drips, and I was worrying how I was going to pick up my son from school. Social Services said that HIV wasn't a priority anymore! I couldn't even go shopping. I was feeling so sick, in bed...and that worry! And I think that services should be – not just a drop-in but having people to help you out, really, when you need it. Like when you are in hospital and you need something and you are so lonely – you have no family here. You need help.</p> <p>I had to leave my bed in a couple of occasions to go and pick up my son from school and bring him back with me to the hospital. That's how sad it is, you know!</p>	

<p>Is there anything else you want to say about the services you have used or are still using? _____ What services would you like to see available?</p> <p>Well, the thing is that I got so fed-up and tired of knocking on doors here and there, that at the end I decided not to count on anybody else. I couldn't. What I would like to see is places where I could go and talk freely, where my son is also welcome. You need people with the same background. I think today everything is for the African communities. I have no problem with them getting what they need but we have been pushed out a bit. I think. I think there are a lot of people like me who are not getting any support at all. You are either African or you are gay...!</p>	
<p>In relation to drug use, please tell me what 3 services you consider to be the most necessary.</p> <p>The first one is the hospital (the doctors). I have tried in the past to go to user services in Hackney, or Harringey. They didn't work for me. I just didn't want to see people who were in the same position. I didn't like going to the drug services. I don't know where I could go if I had problems, I would probably go back to Spain. I don't think here I can rely on....obviously the doctor.</p>	
<p>In relation to HIV care and support, please tell me what 3 services you consider to be the most necessary.</p>	
<p>Would you like to receive support and care around HIV in the same place that you receive support and care around drug use?</p> <p>Yes, that would be great.</p>	
<p>About your family and other relationships</p>	
<p>Are you married or in a long-term relationship? - Please give details.</p> <p>No. I have been divorced for the last 3 years. Happily divorced.</p> <p>How long were you in that relationship?</p> <p>For 15 years. I was married for 11 years. My partner wasn't positive. But at the end the relationship was very, very stressful. Especially when the child was born.</p>	
<p>Do you have children? Please give details.</p> <p>Yes. He's 7 years old. He's not positive. He is OK.</p>	<p>yes</p>
<p>Does your partner know about your HIV status?</p> <p>Yes</p> <p>What issues have arisen in your relationship due to your status?</p> <p>Many, many. He was understanding. I told him after 3 months when we met. But, he</p>	

couldn't understand completely how stressful it is with an illness like that. When I was pregnant – we did plan the baby – we tried for a baby for many months, in the artificial way, using syringe. – the doctors explained to us. Then when I got pregnant, he was very stressed. He was very worried about the child, and he started becoming violent. I remember in that time we had to wait 18 months to see if the child was positive or not. And when we got the clear result and I said lets celebrate that he's ok – my husband said: I have nothing to celebrate. He was really stressed and pissed off. He was very abusive with me for 3 years and I, it was very difficult to break up the relationship, but I did....

How do you disclose to family, friends etc?

Are you open about your status? If so, how does your partner, friends, family feel about this?

You have disclosed to your family. What about your friends?

Friends. I choose who to say to and who not. I remember when I was diagnosed – 20 years ago. I told my university friends and they had a very bad reaction. We were planning at that time to have a holiday trip altogether and they said very clearly that they didn't want me to go. And since then I have realised that even if they feel sorry for you, they don't understand, they don't support enough. Today I still keep very quiet, as much as I can. Sometimes I really feel the need to tell someone because if you have very close friends it is very difficult to have a double life, to have a secretive life. And I try to tell whenever I can. But it's not easy.

What about your child?

My child doesn't know anything. I think he senses the atmosphere. He's seen me many times in hospital and not very well...he's a very, very insecure child. He always thinks that something is going to happen to me. I know that kids act like this sometimes but I think he has got reasons. He's very scared to lose me. But he doesn't know anything about my status.

How do you cope with feeling like this?

Awful. He has seen me crying. He has seen me not been able to move from bed. I was away from him when I was in the rehab – he was 3-4 yrs old. Extremely hard. But I do worry that soon I will have to talk to him when he's a bit older. I worry a lot about that.

How did your parents feel about you telling other people about your status?

They didn't want ANYBODY to know. My mum said there is a lot of discrimination and I shouldn't tell anyone. She doesn't want anybody in the town to know. So, when I have been feeling unwell we put it down to depression, crisis, because I had a bad relationship with my husband – but never disclose.

What about your partner?

He did want me to be more open. He did want to tell his family but I always said no. Eventually he did, when we got divorced. He did tell his employer because when I was very unwell he had to miss work. His boss was quite understanding and supportive.

As regards disclosure – did you have any support from services?

<p>Not really. For many years I kept it a secret from my parents and there was no one really to tell me how to tackle it. No, I didn't get any advice. I have seen a lot of counsellors and psychologists but they helped me more to keep it a secret! More than to disclose it!</p>	
<p>Do you have any coping mechanisms for dealing with these issues? _What support, if any, have you had around these issues?</p> <p>Well, what happen at that time is that I started using heroin – that was about 4 years ago, something like that. That's the only thing I did.</p>	
<p>Have you found sexual relationships are different since your diagnosis?</p> <p>Yes. I was very scared. I was very frightened of rejection, to pass the virus to somebody else. Now I don't worry so much because I know if I use a condom or preservative I don't have to disclose it. But I'm always thinking that I am going to be rejected and....very difficult.</p>	
<p>Has your diagnosis changed the way you feel about sex?</p> <p>Yes</p> <p>In which way?</p> <p>Because you are always thinking – if you do start a relationship, or you meet somebody new...the first day it's ok because you don't give much information about yourself. But I panic when I meet someone that I might have a relationship with, because you think they are going to start asking questions about your life, how you get your money, what do you do...and I am just very scared. I would say that if I meet somebody for 1 day, it is fine. But when you want to carry on with the relationship...I just freak and don't want to.</p>	
<p>Has your libido changed in any way?</p> <p>It did, when I was 18. I had a partner for many, many years. I wasn't so worried because he knew. I remember a lot of friends telling me about the problems of meeting new people and blah, blah...but because I always had the same partner...it was easier in that way.</p> <p>And this is the partner you divorced?</p> <p>Yes. English.</p>	
<p>What is your Partner's HIV status?</p> <p>negative</p>	
<p>Does your partner know about your drug use?</p> <p>yes</p>	

<p>Did/do you and your partner use drugs together?</p> <p>No. Occasionally he did smoke some hash. He never used any class A drugs.</p>	
<p>Please tell me any concerns, if at all, you may have faced with regards to disclosing your drug use or HIV status to your partner.</p> <p>For instance, now I have met new friends at my son's school and I do get on very well with them. I really like them. And most of them are doctors, amazingly. So they are quite open-minded but I still haven't said it to anyone because I am very scared to have a label and for my son to be discriminated. You never know! Life tells you that it's ok to tell some people but not other people.</p> <p>Some people are very supportive, but maybe they have problems. They can't keep their mouths shut. You never know what's going to happen once you tell. Maybe that person in a few weeks is not your friend anymore. I don't know. It is a million things. So, I do keep...it's like you have a double life...it's very stressful in that way. It's something important – for 15 years I didn't tell my parents. I never told hardly anyone. It's only in the last 3-4 years that my parents have known about my drug use, my HIV.</p> <p>Did you tell them when you went to rehab?</p> <p>Yes. It was a big bomb when I disclosed all these. I always had a very secretive life. Very stressful! Just simple questions: where did you go to the dentist? You always have to be very witty, answer quickly...something that is a lie. And when you lie, and lie, and lie, it's very stressful.</p>	
<p>What response did you get?</p>	
<p>Have you had a baby since your diagnosis?</p>	<p>Yes</p>
<p>How was your pregnancy dealt with?</p> <p>Quite stressful. Always my CD4 count and viral load were good, high T-cells and low viral load. At that time I was going to the Royal Free and they wanted me to take a combination of 3-4 drugs and I refused it. I didn't want to because I thought my body didn't need it. Now, after a few years they know babies are ok with some drugs, but at that time they didn't really know. And the doctors pushed me a lot, and it was very stressful. I just took some AZT. It made me feel awful. I had a lot of side effects. The baby was taking it for 3 months. I felt very guilty as well. My husband at that time wasn't supportive at all. I started getting very stressed when I was 5-6 months pregnant. Found it hard!</p>	
<p>Did you have a natural birth?</p> <p>I did have a CS. I wasn't happy because I asked the doctor, can I have the CS once the baby is due? But they wanted to do it a month before. Have everything ready and I don't know...I think my child was born with a lot of anxiety. He didn't sleep as a baby. It was awful, very, very stressful.</p>	

<p>Did you have any complications/concerns</p> <p>I started a big depression. I don't know if it started as post-natal depression or just the stress, being scared of not been able to cope, of feeling unwell...not physical complications.</p>	
<p>Have you ever tried to get pregnant? Please tell me about your experience Are you presently trying to get pregnant?</p>	
<p>How did you feel your clinic dealt with your decision to get pregnant?</p> <p>They were quite supportive. The Royal Free was quite for it. And they did offer me counseling. Especially for my husband because he wasn't sure. He didn't want to have even a 1% risk. For him it was too big even if it was a small percentage. They put us in contact with another couple who had just had a child and been through the same situation. That was quite helpful. The two husbands have ended up being very good friends. And after the years they still are.</p>	
<p>What would you like to say about your experiences whilst pregnant and having your baby?</p> <p>I had an awful experience when the baby was born, because I was in hospital for 5 days and the midwives were absolutely horrible to me. I wanted to make a complaint but I never had the time...I was tired. And I thought: when I feel better and I didn't fill the papers or the letters. But I had a terrible experience.</p> <p>What were they like?</p> <p>The midwife, American black lady – and she was there during the nights. She just treated me and the baby very badly. “of course the baby is crying, you don't feed him properly” and I said “well, I don't know how to feed it!” she wasn't nice at all. And then I used to have a midwife coming to the house after the CS. They were nice but they were too naïve. Asking very basic questions about HIV. I knew 100 times more.</p> <p>So, you were teaching them?</p> <p>Yes. I thought it was fine because they needed information but it wasn't what I needed at that time. I suppose things have changed after all these years.</p>	
<p>If you have made a decision not to have a baby what influenced this decision?</p>	<p>Not applicable</p>
<p>Other Issues</p>	
<p>Have you ever been arrested or cautioned?</p> <p>No. I have never had trouble with the police.</p>	<p>No</p>
<p>Have you ever been in prison?</p>	<p>No</p>
<p>If you have been in prison, or in a police station/cell, did you declare your HIV</p>	

<p>status</p> <p>Personally, have you been aware of any changes in your body since your diagnosis or since starting combination therapy (e.g. menstruation, menopause)</p> <p>Many, many. Something positive I could say is that I stopped using drugs, and that I have learned that we are all mortal. I think people today think that they are immortal – they don't really enjoy life. When you struggle a lot in life I think you appreciate it more and you realise that you have to make the most of it. I am more understanding and open to people.</p> <p>But the negative part is so huge. I was diagnosed when I started in my first year at university and I thought: I don't know why I am doing this because I thought I was going to die within a year, but I kept going to university and I did finish it. But whilst my friends were trying very hard to get work experience I had no interest. I thought it's not worth it, I am going to die.</p> <p>I have learned to hide in life. That's very stressful. There was a point I was panicking so much, I was having so many panic attacks about everything that I couldn't even go out of the house. All these have stopped me doing many things that I wanted.</p> <p>I am a very different person to what I could be. You start thinking that you have no time. Sometimes I get very anxious and I want to do everything right now because I think in a few months I might not be here. It's difficult. It's hard.</p>	
<p>Is there anything else you would like to say before we finish this interview?</p> <p>Because I have been positive for a long time...it's very different what I felt when I was 18 years old – thinking I was going to die. No treatments, no support, no counselling. But now, you have more hope, and I count with my family, whereas before I was always lying. But I think sometimes: how can we make it better for ourselves? We should be allowed to be more open. If we could give more information to people, they would treat us differently. Not so much stigma. I think it's a question of time and information. You still hear a lot of comments...and I am still very scared to disclose to anyone.</p> <p>For years you think you have a deadline, that your life is very short. And the last few years, when you have realised that people do live longer, that you are here... and many things that I didn't plan to see...and I am here... and I think that has been very, very difficult. To reverse the brain. And to think: I am here and I have opportunities to do things...but, still, not quite sure to what extent...but to retrain your brain...to think, well, I am here and I am going to live who knows how long. It's been very difficult – as much as learning to live with HIV at the beginning.</p> <p>We become more human. I've become more understanding of people – you think of life in a different way. You appreciate life in a different way – but what a cost?! A very high cost.</p> <p>Sometimes you have a big need of telling all the world: I am dealing with this on top of my ordinary life. But you have to learn to keep it quiet and not to tell anyone because it's not going to be the best option. That is very hard and I am very scared thinking if I get unwell how am I going to cope? I lie to people. You learn you have to keep quiet</p>	
<p>Do you feel as if you are kept up-to-date with relevant information and if so,</p>	

what services provide this info?

No. and I think doctors don't know as much as they think they know. I think it's very different from one person to another. And also because I started feeling the lipodystrophy effects. I was very worried about my image. The doctor at Bart's – he was quite understanding and that's why he said I could go on a holiday – not knowing very well what was going to happen. But I don't think they know much about it.

Appendix 6: Answers to questionnaire

QUESTIONNAIRE FOR SILENT VOICES

INFORMATION FOR INTERVIEWEES: THIS IS AN IN-DEPTH INTERVIEW WHICH IS PART OF ICW'S SILENT VOICES PROJECT. IT IS ABOUT SERVICES PROVIDED FOR WOMEN WHO ARE HIV POSITIVE AND ARE, OR HAVE BEEN, DRUG AND ALCOHOL USERS. RE WILL BE ASKING YOU QUESTIONS ABOUT THE SERVICES YOU HAVE USED IN RELATION TO YOUR DRUG/ALCOHOL USE AND WHETHER YOU FEEL THE SERVICES PROVIDED ARE MEETING YOUR NEEDS.

THE INTERVIEW WILL TAKE ABOUT AN HOUR AND I MAY BE JOTTING DOWN A FEW NOTES AND MAYBE ASKING YOU TO ELABORATE ON SOME OF THE THINGS YOU SAY. IF YOU NEED TO TAKE A BREAK AT ANY

PLEASE FEEL FREE NOT TO ANSWER ANY QUESTION, BUT THE ANSWERS YOU PROVIDE WILL BE HELPFUL

Personal Details																																								
<p>How old are you?</p> <p>What age group? <u>If the interviewee is reluctant to share age – ask for an age range.</u></p> <table border="1"> <tr> <td>18-20</td> <td>20-25</td> <td>25-30</td> <td>30-35</td> <td>35-40</td> <td>40-45</td> <td>45-50</td> <td>50-55</td> <td>55-60</td> <td>60-65</td> <td></td> </tr> <tr> <td></td> <td></td> <td></td> <td></td> <td>x</td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> </table>										18-20	20-25	25-30	30-35	35-40	40-45	45-50	50-55	55-60	60-65						x							36								
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<p>What ethnic group do you belong to? – How would you describe your ethnic group?</p> <table border="1"> <tr> <td>White</td> <td></td> <td>Black</td> <td></td> <td>Asian</td> <td></td> </tr> <tr> <td>British</td> <td></td> <td>British</td> <td></td> <td>British</td> <td></td> </tr> <tr> <td>European</td> <td></td> <td>African</td> <td></td> <td>Pakistan</td> <td></td> </tr> <tr> <td>Irish</td> <td></td> <td>Caribbean</td> <td></td> <td>Indian</td> <td></td> </tr> <tr> <td>Other</td> <td>x</td> <td>Other</td> <td></td> <td>Other</td> <td></td> </tr> </table>										White		Black		Asian		British		British		British		European		African		Pakistan		Irish		Caribbean		Indian		Other	x	Other		Other		White other
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<p>What country were you born in?</p>										Australia																														
<p>How long have you lived in the U.K.? (Only ask this if the person was born overseas)</p>										Since 1993																														
<p>What languages are you fluent in?</p>										English																														
<p>What is your religion?</p> <table border="1"> <tr> <td>None</td> <td>Christian</td> <td>Muslim</td> <td>Jewish</td> <td>Hindu</td> <td>Buddhist</td> <td>Sikh</td> <td>Other (specify)</td> </tr> <tr> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> </table>										None	Christian	Muslim	Jewish	Hindu	Buddhist	Sikh	Other (specify)									None														
None	Christian	Muslim	Jewish	Hindu	Buddhist	Sikh	Other (specify)																																	
<p>Disability</p> <p>Sexuality</p>										Emotionally no, physically yes heterosexual																														
<p>Are you in employment? What is your occupation?</p> <p>Volunteering. I am the Editor of Black Poppy magazine which is a drug user's health and lifestyle (harm reduction) magazine for drug users. I work on this 4 days a week.</p>																																								

<p>Have you disclosed your status to your employer or anybody that you work with?</p>	<p>Yes. I am open around my HIV status and being a drug user</p>
<p>Has your HIV status affected you financially in anyway?</p> <p>Yes, mainly it's because I've got disability benefits through being HIV but I feel like it has hindered me a bit because it's very hard to get these benefits. I feel that if I go out there and get work I'll never get them back again if I need it, so I find it is stopping me from doing that actually.</p>	<p>yes</p>
<p>About Your HIV Diagnosis and other general health issues</p>	
<p>When where you diagnosed with HIV?</p>	<p>1995</p>
<p>Where were you diagnosed? Hospital, clinic, prison? other?</p>	<p>GUM Clinic St Mary's Paddington</p>
<p>Which country where you living when you received your diagnosis?</p>	<p>U.K.</p>
<p>Would you like to talk about the manner in which you were given your diagnosis?</p> <p>It was really bad. I went in initially for a Hep C test and they said come back in 3 days for your results, both me and my partner went and had our tests done at the same time. We went back 3 days later and we were in the waiting-room together and someone came in and separated us, I went upstairs and he stayed downstairs. I remember thinking, feeling just a bit uncomfortable why that was happening and then I was taken into a room where the doctor came in and was all sort of happy and jolly and opened up the paper and said it is negative and I said thank God for that. Then he said Oh, hang on a minute, I've just made a mistake. And it's positive!!! And then he said just wait there while I go and get a healthcare nurse so he disappeared for 10 minutes and I was like completely in shock and then this woman came back in with him and asked me if I wanted a hug – I remember that I really didn't want one and I actually did it for her sake – to make her feel better, I should have just said no – I left there 15 minutes later with this brown envelope with "just been diagnosed" kind of leaflets and an appointment to come back in 4 or 5 weeks or something. It all happened at about 5 o'clock on a Friday afternoon, and I believe that they don't do this anymore because people have difficulty in accessing anything over the weekend. I thought it was pretty, well, not good. My partner was still downstairs and I went down to see him and he had the same brown envelope and was diagnosed positive too.</p>	

<p>Are you co-infected with Hepatitis C</p>	<p>Yes</p>
<p>In what ways has HIV affected your life?</p> <p>That's a big question – I suppose it made me very aware of discrimination around drug users and HIV+ women as well. I really wasn't expecting to come across that in the HIV community. I was expecting open arms and all that sort of stuff, so that was a real eye opener and it did change the way my life turned after that. I got a lot more active and focused my activism a bit more around drug-using issues. And I think it bought me closer to my mum as well. I think it was just like a huge shock but you get this strength together to deal or to move through it or something, but it is quite life-changing because I do feel sometimes in some environments with people, I feel like I've been to the bloody moon and back again.</p>	
<p>Do you have other conditions/ infections that concern you? E.g. Hep A or B, T.B, cancer. MS or peripheral neuropathy</p> <p>I get seizures – it seems to be a drug-related thing and it looks like I probably should have started HIV treatments a few years ago, and I've been offered quite heavy epilepsy medication and I didn't want to be taking that alongside starting treatment – but there's meant to be some new drug coming out which is much better – so I'm now considering it, and that has coincided with perhaps starting HIV treatments soon – so I don't want to do both so I don't know.</p>	
<p>Do you want to say how you manage with having HIV and these other conditions?</p> <p>It does interfere with my decisions, obviously. If I didn't have HIV and Hep C I would probably take the tablets for epilepsy, although I seem to be managing without. I take valium now at the times when I feel like a seizure might be coming on. I mean I only have this about 3 or 4 times a year. Now I've started taking valium it seems to be working out all right but it also affects my choices around Hep C treatment as well.</p>	
<p>Are you on combination therapy?</p>	<p>No</p>
<p>When starting combination therapy did you suffer any side effects?</p>	<p>N/A</p>
<p>Are you on any other medication?- Please give details</p> <p>Valium and I take 300 mgs of injectable Diamorphine a day.</p>	
<p>Do you use alternative therapies? If so please specify which therapies you have used.</p> <p>I do vegetable juicing – I try to have a vegetable juice everyday and occasionally I will take a tincture for hormone balance for PMT and related stuff</p>	<p>yes</p>

<p>and occasionally I take milk thistle but I don't seem to have too many complications with my Hep C, thank God. I am going to be seeking more alternative therapies out.</p> <p>I was doing a bit of yoga last year, but am not doing it at the moment. Reflexology, aromatherapy and acupuncture in the past.</p> <p>Why do you use alternative therapies?</p> <p>Because they are useful.</p>	
<p>Do you pay for alternative therapies or any other therapies?</p> <p>Yes for the juicing and stuff but if I was to get massage or reflexology I'd try to get it through one of the drug clinics for free but if there was someone local who charged £20 for a treatment I wouldn't mind paying that for an hours massage.</p>	
<p>Do you have to travel far to get to your clinic or to access any therapies or services and if so, how long does the journey take?</p> <p>I use local ones if I do.</p>	No
<p>About your substance use/ Misuse</p>	
<p>Do you drink alcohol? If yes, how much do you drink and how regularly?</p> <p>Occasionally, maybe a couple of glasses of wine every 2 or 3 weeks.</p>	
<p>Do you smoke cigarettes? If yes, how much do you smoke – How regularly?</p> <p>On and off. Some days nothing but probably just about 6 a day.</p>	Yes
<p>Are you currently still using illicit (illegal) drugs? If yes, how regularly?</p>	Yes
<p>What do you use and how regularly</p> <p>At the moment I smoke dope probably a couple of times a week. I take ecstasy every 2 months or so - now one or two. I take injectable diamorphine every day that is prescribed. Thank fuck for it. I get 300 mgs a day and 50 mgs of physeptone.</p> <p>In the past my drug using was much more chaotic. I've been using for about 20 years and I've been on a script for the last 13 so it has always been methadone of some sort, whether it be juice, tablets or amps and I've never really been very settled on those so I've always used through those periods on top and obviously coke and a bit of a crack episode. I've been on this script for 3 years and feel quite stable now but before that it was different.</p>	

How long have you or did you use drugs?	20 years								
What was your drug of choice?	Heroin								
What do you use now? Diamorphine, physeptone injectables on daily basis. Ecstasy and hash.									
What was your favoured method of use? <u>Tick as appropriate or enter given answer</u> <table border="1" data-bbox="240 688 691 825"> <tr> <td>Injecting</td> <td>X</td> </tr> <tr> <td>Smoking</td> <td></td> </tr> <tr> <td>Snorting</td> <td></td> </tr> <tr> <td></td> <td></td> </tr> </table>	Injecting	X	Smoking		Snorting				Injecting
Injecting	X								
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Snorting									
Do you consider your alcohol use to be problematic? Please say how.	No								
Do you consider your drug use to be problematic? Please say how I consider the fact that I've got a drug dependence but I really don't consider it a big problem but in the past yes.	No								
What issues can occur around using drugs in relation to any other service you use or have used? Being invisible or treated disdainfully because I'm a drug user or in some places because I'm a woman. I've felt, even in places for HIV+ women, it's made me feel a bit separate. I can't put my finger on it but I've definitely felt a bit of attitude there and I'm sure that there are my own reasons for feeling a bit isolated, maybe it's because you can't be honest and everyone else is being honest and it's not so easy to launch into the conversation and say you are an injecting heroin user and smoke crack at the weekends, you know. So I feel it's fast-tracked me in other areas because I have been positive, like when I've gone to drug services. I suppose being a HIV+ drug user is right at the end of the spectrum of urgency or fast track or whatever so it's kind of been useful a bit there, I mean I got my script through my diagnosis so I don't think, well I'm sure I wouldn't have got it if I wasn't. Being a drug user has put me off going to services actually except for Body and Soul. I found them really good.									
If using drugs or drinking heavily, do you disclose this to any professional worker? E.g. consultant, nurse, counselor?	Yes I do								

<p>If so, what response have you had?</p> <p>What springs to mind immediately, it's not confusion but a kind of response that they are out of their depth a bit, or they don't know how to respond to you or what you really need or what you are talking about or what it means when you say you a positive drug-using woman or whatever so it either goes over their heads and they let it go over their heads and try to concentrate on something else or they ask kind of inane questions in which case I let it go over my head so I don't have to engage in inane conversation. i.e. a few experiences that I've had with key workers who have just been out of college, or psychiatric nurses, they are either nasty which they can be in some of these drug treatment centres. Just not very nice at all in which case they would be quite stern about asking questions or else they can be overwhelmed and come out with things that aren't appropriate. I can't think of exactly what right now but they would just come out with comments that made me feel that they just didn't know how to deal with the situation.</p>	
<p>Were you ever on treatment and still using drugs /drinking?</p>	No
<p>Were you able to adhere to your treatment regime? If not, please tell me what you thought where the causes of your failure to adhere.</p>	N/A
<p>If you faced problems with adherence, <u>where you able to discuss these with your doctor?</u></p>	N/A
<p>Do you believe you are given enough information about your combination therapy and the use of illicit drugs?</p> <p>I've sought it out myself but not been offered it.</p>	No
<p>If you have managed to abstain from alcohol and/or drugs after a period of using, how have you managed this? - What services are there available for you to get enough support?</p> <p>I spent 3 months completely off every thing and that was in a rehab when I first got here to England and I turned up really sick and everything – I got a 2 week blind methadone detox and they asked me if I wanted to go into a rehab after and I said yes. So I managed to stay off for 3 months but I think, I also think I managed to stay off drugs because I didn't know anyone here and had just arrived in London and didn't have any contacts so I just stayed in the rehab. Another time I was off for a couple of months, sort of offish, off more than on and that was just using methadone that I was cutting down myself and staying with my mum.</p>	
<p>About the Services you use</p>	
<p>What services/support networks do you use – please specify in relation to –</p> <ul style="list-style-type: none"> • HIV, • Drugs, Alcohol, 	

<p>Wharfside clinic at St Mary's – that's probably it – I've been meaning to go back to Body and Soul for ages.</p> <p>I get my script from Blackfriars Road – That's all these days.</p>	
<p>Please tell me about services you have used in the past</p> <p>HIV – There were quite a wide variety of services that I've used – mainly when I first got diagnosed and I was finding my feet with them – I suppose it was for around 3 years at that time maybe. It's been about 7 years that I haven' been to any actually, didn't realise that it was that long but it probably is and they were The Lighthouse for lunch or to get information, THT I used to help get my housing, Body and Soul for a support network – hanging out with other women and stuff. CARA I used to go to occasionally – My mum used to go there a lot – that was her place for her support.</p> <p>I went to Positively Women a few times that was a similar sort of thing to Body and Soul – support with other women. Body Positive when they were open – I think that was the first place that I went to actually and they, I thought, were one of the most discriminatory actually against women, and so were Terrence Higgins and so were the Lighthouse. All 3 stick in my head as being the main irritants.</p> <p>With drugs it was drop-ins, needle exchange drop-ins, where you could pick up works, have a cup of tea and maybe see someone about housing benefits or whatever or maybe get your aromatherapy – I used to go to one fairly regularly in Paddington – The Caravan. But not that many with the drug ones – I think with the drug clinics you find one that's comfortable for you and you kind of stick to it. Other drug ones were really related to my script, various DDU's or GP surgeries. As far as drop-ins go I kind of went to the one that was nearest to me which was Paddington really, with any regularity – I suppose there are a few others that I went to – The WDP and one on Finchley Road.</p>	
<p>How did you find out about these services?</p> <p>Through word of mouth concerning drug services – they weren't something that I saw on a leaflet and thought I'll pop in there. HIV wise it was harder in a way to get word of mouth until you are actually around people and initially I think that was through going to some sexual places or like the Lighthouse. Body Positive and the Lighthouse I think were places that I had heard about or had seen on a leaflet or had known about, so I went to those one's first and found my way to other places through there.</p>	
<p>Would you like to talk about the attitudes you have encountered from staff and other service users.</p> <p>I suppose I really felt discriminated against really as I have said in places like the Lighthouse – Terrence Higgins was difficult to begin with, but we (my mum and I) kept going back there and got a woman in the end and she was really good but I definitely felt and it was as clear as day because I wasn't expecting that attitude so it wasn't as if I went in there expecting to be discriminated against or anything but it was a real clear, because I think actually that at Body Positive when you went they used to ask you when you went in there whether</p>	

<p>you were an IV drug user at the registration or something, but it was definitely – I felt that if I was a 17 year old boy then they would have welcomed me with open arms and give me everything I needed and that was the way it was and that if you were a woman and a drug-using woman it was like you were at the end of the line sort of thing, so it was very bad and it put me off – and it was in the hospitals as well I felt I would get treated very roughly by hospital staff and very impersonally because you were a junkie. You know, I mean again I wasn't expecting that, and that made me very aware of drug user discrimination generally and you feel – your life is meant to be in their hands now, in a way and they don't want to know anything about it so it really crystallised it how dangerous that sort of discrimination is and it put me off going to hospitals. I didn't go to a hospital for 3 years after some experiences both at the Royal Free and that was at a women's HIV unit there and that was terrible and St Mary's were terrible so I didn't go back for about 3 years.</p>	
<p>What services have you used where you have felt that BOTH the HIV and drug use have been dealt with in a satisfactory manner?</p>	None
<p>Have you ever changed services (e.g. your clinic) and if so, why?</p> <p>I changed from St Mary's for The Royal Free and both of them were terrible and I was considering going to Chelsea and Westminster but wavered for a bit, 'cos I didn't fancy going anywhere particularly, so I didn't go anywhere and eventually I went back to my walk- in clinic and then I met a nice doctor there and I felt comfortable with him and then he became my doctor so I have felt comfortable going back to see him since.</p>	yes
<p>What was your reason for accessing the services that you used?</p> <p>For prescriptions and syringes and initially some housing advice and practical issues although for a while it was for a reflexology and a cup of tea.</p> <p>For HIV it was various reasons, one reason was housing, but with HIV services really that was where I was looking for a nice supportive place that you could hang out at and then if you needed to use some sort of service you could and get a cup of coffee or whatever.</p>	
<p>Did you find that your needs were met by these services?</p> <p>I think that's really difficult and hard to answer.</p>	
<p>What needs, if any, do you think still need addressing?</p> <p>I think maybe harm reduction issues because obviously there is a huge Hep. C explosion, every body is Hep. C positive and apparently people have got it within their first 2 years of using, so the needle exchanges are stuck a bit in the 1980's in the HIV sort of mind set, where they are just giving out needles and swabs and really now that won't work, they need to sterilise all the paraphernalia – the water and the tourniquets and the filters. I think it's almost negligent now in a way not to be giving out that sort of information and equipment if you're only giving out a bit of it and not the rest of it. There are so many procedures involved</p>	

<p>in hitting up you need a selection of equipment and if one of them is clean and the rest of it isn't it's just not going to work. That is definitely the future now, the future way to proceed and I think there's issues now with crack and stimulants users that there needs to be more focus with that and looking at that and what sort of harm reduction approaches can be employed there. Especially for women it brings up a lot of issues, especially around the sex Industry and that sort of work, and can be really fraught with all sorts of complex issues that really need to be focused on more in the future and I think women's issue have been generally dodged because they are hard and so big and complex issues so I think they've been glossed over and tokenistic. My partner is a drugs worker in a women's prison. They are just locking up women by the heaps at the moment and they are just going straight back out and then straight back in and going into prison for breaking ASBO orders and a lot of them have mental health problems. I mean there are stories that I hear from in that prison and some of these girls clearly shouldn't be in there. What are they doing in there?</p>	
<p>Is there anything else you want to say about the services you have used or are still using? _____ What services would you like to see available?</p> <p>I'd like to see a women's-only treatment centre that focuses not just on heroin addiction but stimulants and benzo addiction and some more avenues so you can move on from treatment or at least start contributing back to life while you are in treatment instead of ending up in a sort of methadone limbo land where you're just going in to pick up your dose everyday and going home, with maybe support and networking opportunities to get back into school or volunteering or maybe even developing your skills in the drug field and using all that knowledge that drug users pick up over the years.</p>	
<p>In relation to drug use, please tell me what 3 services you consider to be the most necessary.</p> <p>Scripting services. Drop in services and needle exchange.</p>	
<p>In relation to HIV care and support, please tell me what 3 services you consider to be the most necessary.</p> <p>A drop-in support group or evenings. Having treatment discussions where doctors can come in and discuss what new treatments are out, a bit about them and side effects etc. A central place for support around legal issues or if you encounter any sort of discrimination through work or insurances or mortgages an information resource that is able to guide you to the right places.</p>	
<p>Would you like to receive support and care around HIV in the same place that you receive support and care around drug use?</p> <p>I don't get them in the same place and I don't know if I would like to purely because I don't trust drug services to be able to do it properly and vice versa. I think the HIV services should develop that side of things because it does keep you a bit excluded in a way so I think you should expect more support and I think me and my peers don't look for support there but I think we should have more support definitely.</p>	
<p>About your family and other relationships</p>	

<p>Are you married or in a long-term relationship? - Please give details.</p> <p>I have a partner. We have been together about a year.</p>	<p>Yes</p>
<p>Do you have children? Please give details.</p>	<p>No</p>
<p>Does your partner know about your HIV status? What issues have arisen in your relationship due to your status?</p> <p>Yes – early on we had a condom come off and although he didn't show it at the time I think he had a minor panic when he got out the door and we had a talk about it on the phone and he went to his local hospital – I told him about the drugs that you can get, post-exposure things, and he had a terrible experience in there and didn't know what to do and walked in and out about 7 times and the woman there was telling him to hurry up, she had something else to do and they took bloods and said if you're going to make sure that if you make this decision you make sure you take all these tablets because they were expensive. It was incredible and in the end he ended up not doing it. But it did raise an issue and it kind of annoyed me – annoyed at his panic and I just ended up saying, look I don't have time for you to work out all the stuff around HIV – it's your fucking responsibility to find out information – I didn't want to go through the emotional hand holding, quite frankly.</p>	
<p>How do you disclose to family, friends etc?</p> <p>In a way it's easier for me because I'm involved in drug users' stuff, so I think that drug users accept a positive diagnosis much more readily than the straight community.</p> <p>If all my friends were straight I think it would be a bit different. Actually I am sure that I would tell my close friends. I don't know. It wasn't very long ago that we were having a conversation and I was at a festival with a really nice group of people and someone said that they had had cancer not long ago and she was talking about her immune drugs and she had got over it and blah blah blah and so for some reason I thought I'd drop that I'm HIV in and as soon as I said it I realised that you can't just go round saying it – it was like dropping a bomb in the conversation.</p>	
<p>Are you open about your status? If so, how does your partner, friends, family feel about this?</p> <p>I think my mum is very supportive about me being open but I think sometimes she won't disclose it to people because she wants to protect me from attitudes so I think sometimes that's an issue but I think she finds it more difficult to tell people that I'm a drug user than the fact that I'm HIV. My boyfriend told his mum and she seems to be fine about it – I don't know if he's told his friends because he doesn't live in London so we just see each other every couple of weeks and we haven't got into each others friends much so I don't know how much his friends know. I'm not really sure actually.</p>	
<p>Do you have any coping mechanisms for dealing with these issues? What support, if any, have you had around these issues?</p>	

Yes I have my mum.	
Have you found sexual relationships are different since your diagnosis? Not as different as I thought I was going to find them.	
Has your diagnosis changed the way you feel about sex?	No
Has you libido changed in any way?	No
What is your partner's HIV status?	Negative
Does your partner know about your drug use?	Yes
Did/do you and your partner use drugs together?	Sometimes, occasionally
Please tell me any concerns, if any, you may have faced with regards disclosing your drug use or HIV status to your partner.	
What response did you get? Well luckily he already knew because we met at a conference where I did a presentation and I spoke about it. Which is helpful because it's not easy to do and what I find I do is or what I've noticed I do in a couple of relationships is that I try and get it out in the conversation pretty early on. I think people have been a little bit shocked but because it's not like Russia where 60% of drug users (are positive) and it's still a small percentage here. I think it's around 2 or 3% or something small so and now it's got to the stage that so many people have got Hep C and so many people are sick from Hep C, I find that HIV, I mean I heard someone on the radio last night talking about having cancer and they were saying that HIV is fine now that you can live with it because there are treatments and if you get cancer you die and people are now letting it lose it's seriousness a bit. On the one hand it's good but it's losing it in the wrong way, its not just dissimulating it into things. I think people are just quicker in writing it off I suppose and it's getting eclipsed by Hep C.	
Have you had a baby since your diagnosis?	No
How was your pregnancy dealt with?	N/A
Did you have a natural birth?	N/A

Did you have any complications/concerns	N/A
Have you ever tried to get pregnant? Please tell me about your experience Are you presently trying to get pregnant?	N/A
How did you feel your clinic dealt with your decision to get pregnant ?	N/A
What would you like to say about your experiences whilst pregnant and having your baby?	N/A
If you have made a decision not to have a baby what influenced this decision? HIV has changed the way I think because I suppose before I was diagnosed I thought that I would get pregnant when and if I was ready and now I think I still would. If I decided that it was something I wanted to do I think I would probably still go ahead with it seeing as it is really quite safe now but it makes it into a huge issue and the thought of taking all those drugs whilst pregnant – there is a lot of issues and it has coloured how I feel about that.	
Other Issues	
Have you ever been arrested or cautioned?	yes
Have you ever been in prison?	No
If you have been in prison, or in a police station/cell, did you declare your HIV status	N/A
Personally, have you been aware of any changes in your body since your diagnosis or since starting combination therapy (e.g. menstruation, menopause) Yes I have and I'd like to find out more information. It will be interesting to see what comes out of this research in that area, because I'm sure that there are hormonal and menstrual changes that are quite significant and I've got fibroids as well so it's a bit difficult to tell but I did hear that a lowered immune system can make your hormones out of whack sort of thing.	yes
Is there anything else you would like to say before we finish this interview? I think that it would be good to have some more solid guidelines around positive drug users and issues around co-infection and illicit drug use and treatment and issues around pain relief in hospital for drug users definitely need more research into HIV and drug use. Whilst they say that drug use can make your HIV worse	

they never seem to get to the bottom of whether it's just because of lifestyles or the drugs. I guess I just think it needs a bit more information particularly around co-infection issues. There is a bit of information out there but it's still quite changeable. It would be good to see a bit stronger centre to the HIV positive drug users. Obviously there are gay men with HIV, positive women and it would be good to see a stronger core maybe where there's a collection of information or people that you know that are tuned in on those issues. Mainliners might have been the first place that I rang up when I was diagnosed because obviously they were meant to be for positive drug users and they were terrible, they really didn't know what to say and then they were supposed to get back to me and didn't and I was really shocked and mortified and it was the beginning of a long process of being mortified, but it would be good if there was a base like that – now that Mainliners are off somewhere altogether, I think they do mainly training. It's a shame that the Griffin place shut down. That was a good place. It would be good to be able to have respite there.

Do you feel as if you are kept up-to-date with relevant information and if so, what services provide this info?

I feel that I keep myself up to date. I suppose I can't really say whether services do as I'm not accessing them.

Appendix 7: Answers to questionnaire

QUESTIONNAIRE FOR SILENT VOICES

INFORMATION FOR INTERVIEWEES: THIS IS AN IN-DEPTH INTERVIEW WHICH IS PART OF ICW'S SILENT VOICES PROJECT. IT IS ABOUT SERVICES PROVIDED FOR WOMEN WHO ARE HIV POSITIVE AND ARE, OR HAVE BEEN, DRUG AND ALCOHOL USERS. RE WILL BE ASKING YOU QUESTIONS ABOUT THE SERVICES YOU HAVE USED IN RELATION TO YOUR DRUG/ALCOHOL USE AND WHETHER YOU FEEL THE SERVICES PROVIDED ARE MEETING YOUR NEEDS.

THE INTERVIEW WILL TAKE ABOUT AN HOUR AND I MAY BE JOTTING DOWN A FEW NOTES AND MAYBE ASKING YOU TO ELABORATE ON SOME OF THE THINGS YOU SAY. IF YOU NEED TO TAKE A BREAK AT ANY TIME PLEASE LET ME KNOW.

PLEASE FEEL FREE NOT TO ANSWER ANY QUESTION, BUT THE ANSWERS YOU PROVIDE WILL BE HELPFUL

Personal Details																																								
<p>How old are you?</p> <p>What Age group? <u>If the interviewee is reluctant to share age – ask for an age range.</u></p> <table border="1"> <tr> <td>18-20</td> <td>20-25</td> <td>25-30</td> <td>30-35</td> <td>35-40</td> <td>40-45</td> <td>45-50</td> <td>50-55</td> <td>55-60</td> <td>60-65</td> </tr> <tr> <td></td> <td></td> <td></td> <td></td> <td></td> <td>x</td> <td></td> <td></td> <td></td> <td></td> </tr> </table>										18-20	20-25	25-30	30-35	35-40	40-45	45-50	50-55	55-60	60-65						x					44										
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<p>What country were you born in?</p>										U.K.																														
<p>How long have you lived in the U.K? (Only ask this if the person was born overseas)</p>																																								
<p>What languages are you fluent in?</p>										English																														
<p>What is your religion?</p> <table border="1"> <tr> <td>None</td> <td>Christian</td> <td>Muslim</td> <td>Jewish</td> <td>Hindu</td> <td>Buddhist</td> <td>Sikh</td> <td>Other (specify)</td> </tr> <tr> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> </table>										None	Christian	Muslim	Jewish	Hindu	Buddhist	Sikh	Other (specify)									None														
None	Christian	Muslim	Jewish	Hindu	Buddhist	Sikh	Other (specify)																																	
<p>Are you in employment? What is your occupation?</p>										Yes. I work for UNAIDS.																														
<p>Have you disclosed your status to your employer or anybody that you work with?</p>										Yes																														
<p>Has your HIV status affected you financially in anyway?</p> <p>Yes. After a few years of being diagnosed I got sick and left work – but then I got better and gradually got back into work. I'm earning well now but If I</p>										yes																														

hadn't stopped working for all those years I'd probably be in a better financial situation, so I've got nothing like a pension fund and all those long-term financial arrangements.	
About Your HIV Diagnosis and other general health issues	
When were you diagnosed with HIV?	Early 1987
Where were you diagnosed? hospital, clinic, prison? other?	GUM Clinic
Which country were you living when you received your diagnosis?	U.K.
<p>Would you like to talk about the manner in which you were given your diagnosis?</p> <p>I had been to my GP and he told me that I had shingles then I asked him if he thought I should get tested cos I knew that shingles could have been a symptom and he thought it was quite a good idea given my drug history, so he wrote a letter for the clinic and I went to the clinic and I was told basically that I was wasting NHS time and resources and all that. He seemed to think that I wouldn't be positive as I wasn't using at the time (well certainly not injecting then anymore) but I had the test and went back for the results and told that I was negative and then about a week later I got a letter delivered by hand through my door from my GP, saying that I needed to make an appointment as there was something he wanted to discuss with me. That was on a Friday night and the Monday also happened to be a bank holiday, so of course I spent all that long weekend thinking the worst but at the same time telling myself that I was being paranoid. I went back to see the doctor the following Wednesday and the first thing he said to me was promise me you won't get pregnant and I said why and he said well, you've got the HIV virus and if you get pregnant you will die and your baby will die. So I said right, what happens now? Are you supposed to give me an all-round physical examination and check out my health and he said no, there is nothing we can do. Come back when you get sick and there won't be much that we can do anyway. So that was it and then he said that I had to tell any partners that I had had to get tested.</p>	
Are you co-infected with Hepatitis C?	Yes
<p>In what ways has HIV affected your life?</p> <p>It was easier to see how it affected my life when it came into my life because there were certain roads that I was taking that then changed.</p> <p>When I was diagnosed I was about to embark on a degree course and I continued along that path for a while but because I got so caught up in HIV stuff that I stopped that, so who knows what I would have done if I had gone on to finish that degree. I did do another one later, but I just got caught up in organising around HIV, and that took me down a particular</p>	

<p>path and it's a path that I got a lot out of in terms of professionally, personally and in terms of the people that I met. I don't think that I would have met such a wonderful group of people if I hadn't been diagnosed (I probably wouldn't have met you even though we had all these people in common from the past). So that has been a real gift and it has broadened my horizons and given me insights into other worlds and other cultures and all kinds of stuff.</p> <p>It's really hard to say – I didn't really have a plan before HIV, I sort of by that time had gradually got my life on course, it was going somewhere but I didn't know which way it was going to go but I think that whatever I had gone for I would have probably gone for it in a pretty full on way like I did with HIV but I think that's just to do with my personality.</p>	
<p>Do you have other conditions/ infections that concern you? E.g. Hep A or B, T.B, cancer. MS or peripheral neuropathy</p> <p>In the past I have had Hep A and B. Within the last 2 years I have developed peripheral neuropathy due to medication.</p>	
<p>Do you want to say how you manage with having HIV and these other conditions?</p> <p>When the neuropathy gets bad basically I take some pills which consist of amino acids and they seem to be quite good. I don't take them all the time, just when it gets bad. It's manageable and not as bad as it used to be. As far as the HIV is concerned, for years I have managed it by trying to take good care of myself by taking vitamins and stuff but I have to say at the same time that I was doing that I was taking a lot of coke as well – so you know it was a bit kind of arse backwards! I now try and eat a good diet and used to take a lot of exercise but my work schedule these days has affected that and I'm lucky if I get to the gym twice a week.</p>	
<p>Are you on combination therapy?</p>	<p>Yes</p>
<p>When starting combination therapy did you suffer any side effects?</p> <p>Not on my first combination. But since then I've been on various different treatments some of which I have had really bad side effects. My first combination was D4T and 3TC and it was a high dosage of D4T and I was of a low body weight and it caused my facial atrophy. Another combination after that was a combination of Indinavir and Efavirenz and DDI and Ritonavir and really for 6 months I felt just so bad on that - I could hardly get out of bed, my hair started falling out, it went really thin. I'd wake up in the morning with my pillow just covered in clumps of my hair. So I changed again after that. I just couldn't tolerate it anymore and the next batch were a better combination for me.</p> <p>Then I went off the PI's eventually and just was on Efavirenz and something else with the Efavirenz. I did have slight side effects but I was kind of expecting different side effects because I had heard that you got really vivid dreams and all that kind of stuff and a lot of women I knew were hearing</p>	

<p>voices and the African women thought it was God talking to them etc. But I think, and I talked to a lot of other people that had taken acid (LSD) and had used a lot of drugs and I don't think any of us had any significant side effects. The most I had was low level anxiety, like I had taken too much speed and I always knew it was the treatments causing it but I couldn't make it go away so I'd get really caught up in a little thing or a tiny, tiny thought.</p> <p>After I stopped those 2 years ago – It was like a revelation, it was great and now I have a nice combination that suits me.</p>	
<p>Are you on any other medication?- Please give details</p>	<p>No</p>
<p>Do you use alternative therapies? If so please specify which therapies you have used.</p> <p>I used to all the time and now I get in a lot of trouble with my partner as he feels I should and I know that I should but my work seems to get in the way. As my boss says, I have an addictive personality and that I have just exchanged drugs for work really.</p> <p>In the past I used a lot of massage for pain and general well-being, a lot of acupuncture which I found really useful. I used homeopathy but to be honest it never did a thing for me. Also shiatsu as my partner is trained in that.</p> <p>Why do you use alternative therapies?</p> <p>Because they helped with controlling symptoms, especially before I was on medication, things like diarrhoea and fatigue. It really helped to sustain me generally.</p>	
<p>Do you pay for alternative therapies or any other therapies?</p> <p>Mainly not in the past. More recently I have paid as I have been able to afford it.</p>	
<p>Do you have to travel far to get to your clinic or to access any therapies or services and if so, how long does the journey take?</p>	<p>No. I mainly used local services</p>
<p>About your substance use/ Misuse</p>	
<p>Do you drink alcohol? If yes, how much do you drink? How regularly?</p>	<p>Yes but only about 2 glasses of wine a week</p>
<p>Do you smoke cigarettes? If yes, how much do you smoke? How regularly?</p>	<p>Hardly, one or two a month.</p>

<p>Are you currently still using illicit (illegal) drugs? If yes, how regularly?</p>	<p>Very rarely</p>										
<p>What do you use and how regularly?</p> <p>For the last 2 years I've hardly used drugs at all, partly because my work is just so demanding and I'm getting older and I just find, it's not so much that I don't want to, I'd like to sometimes, I guess that now working in Geneva I don't know where to get them. Well I do but I don't want to go out on the streets and get them through someone I don't know well and also if I stayed up taking coke all night I'd spend 3 days recovering and I haven't got the time to do that and I don't really have that real urge anymore. I think in a way I've outgrown them. I do get that little craving now and again but it's not that kind of craving that I would act on as in the past.</p> <p>Before I went to Geneva to work (a few years ago) I was using quite a lot, not as compared to the past but every couple of weeks at least, then it went down to just a few times a year and now it just really is very, very recreational. It helps because my partner doesn't use and if I do he doesn't speak to me for 2 weeks.</p>											
<p>How long have you or did you use drugs?</p> <p>I started using drugs when I was 13, but I didn't get a habit until I was about 16, so before that I was using mainly amphetamines and acid and then when I was about 16 I started using opiates and Diconal and I used those until I was about 24 in that way and then I stopped injecting and using smack for quite a while and just using coke and barbs and then just was using recreationally for a while before I was diagnosed and through my diagnosis. I then I got in touch with other positive women who were still using which then got me back into using again a bit with them (smack) but not that often and since those days I have occasionally fixed smack but found I got really sick and it would give me a headache, it's almost like I'm allergic to it. But from around the time that I was diagnosed right up until a few years ago I was using a lot of coke and crack.</p>											
<p>What was your drug of choice?</p>	<p>Coke</p>										
<p>What do you use now?</p>	<p>If I do, it would be coke</p>										
<p>What was your favoured method of use? <u>Tick as appropriate or enter given answer</u></p> <table border="1" data-bbox="240 1730 691 1898"> <tr> <td data-bbox="240 1730 464 1766"> <p>Injecting</p> </td> <td data-bbox="464 1730 691 1766"></td> </tr> <tr> <td data-bbox="240 1766 464 1801"> <p>Smoking</p> </td> <td data-bbox="464 1766 691 1801"></td> </tr> <tr> <td data-bbox="240 1801 464 1837"> <p>Snorting</p> </td> <td data-bbox="464 1801 691 1837"></td> </tr> <tr> <td data-bbox="240 1837 464 1873"></td> <td data-bbox="464 1837 691 1873"></td> </tr> <tr> <td data-bbox="240 1873 464 1906"></td> <td data-bbox="464 1873 691 1906"></td> </tr> </table>	<p>Injecting</p>		<p>Smoking</p>		<p>Snorting</p>						
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<p>If and when I take coke now I snort it because I don't want to go there with injecting but I do love injecting it with smack . Crack I used to smoke but it's the most addictive thing I've done but I loved it (I still dream of it sometimes). I used to smoke a lot of smack as well as injecting because I spent about a year and a half living in India and a lot of the time that I was there it was quite hard to get hold of works, it was just too difficult and the smack was so cheap so I used to smoke it either in cigarettes and chase it too and I really like the taste of it.</p> <p>When I first started fixing I was just addicted to fixing - I would just fix anything – I think for a long time I was just fascinated with needles. The last few years I've hardly fixed at all.</p>	
<p>Do you consider your alcohol use to be problematic? _Please say how.</p> <p>No, not now but in the past it has been. And also in the past times when I haven't considered it problematic but my partner has and in retrospect he might have been right!</p>	No
<p>What issues can occur around using drugs in relation to other services you use or have used?</p> <p>Within medical services you always got treated very differently I suppose. They never trusted you. They always treated you like a bit of shit on the bottom of their shoe pretty much.</p> <p>When I was first involved with setting up Positively Women we were all ex-users or whatever in those early days so that's why it took us a bit of time really to get accepted by the professionals and by other groups of people with HIV. Social workers actually refused to refer people to us. We got women coming along who had wanted to come for about 6 months but the social workers had been stopping them by saying you can't because they are all drug users. We had lots of experiences like that so it took a long time to get that recognition and respect but we did although sometimes obviously there were a few public displays of addiction that weren't particularly helpful. So in terms of services it was never really an issue for me.</p>	
<p>If using drugs or drinking heavily, do you disclose this to any professional worker? E.g. consultant, nurse, counselor?</p> <p>I remember when I went on Ritonavir asking my consultant because I was worried, because I had heard of people overdosing on ecstasy and she said that the best thing to do was to take really small bits at a time, like break your ecstasy tablet into 8 pieces and only takes an eighth at a time - and there were other doctors that I used to take lines of coke with in the consulting room. And I used to be quite up front about why I needed sleeping tablets.</p> <p>It was interesting because I had a kind of professional relationship with them as well because of working in the field and that made it kind of easier</p>	

<p>for me to be able to be honest about some of that stuff because I was already respected as a professional. If you talk to a lot of young professional doctors, I mean I have socialised with a lot of them from different walks of life and a lot of them are all doing drugs anyway. At that time I wasn't an out and out junkie anyway. I was working and keeping a job down and being nice and middle class.</p>	
<p>If so, what response have you had? If not, why not and would you like to be more open?</p> <p>I haven't really seen a GP since I was diagnosed as I had a bad experience with one a couple of years in, but I've always been pretty up front when needs be. But obviously I am not going to walk in, if I have an appointment with a consultant around something totally unrelated, I'm not going to say by the way I had some coke this weekend.</p>	
<p>Were you ever on treatment and still using drugs /drinking?</p>	<p>yes</p>
<p>Were you able to adhere to your treatment regime? If not, please tell me what you thought were the causes of your failure to adhere.</p> <p>Totally – I always think it is so funny when they say drug users can't adhere because part of being a drug user is having to adhere especially when you've got a smack habit or something. Even when I was on really complex regimes, with or without getting wrecked on top of that, I've always taken my medication. Apart from the time I lost my bag. I left it in a taxi somewhere due to being so out of it but even then I had some extra ones at home anyway.</p>	
<p>Do you believe you are given enough information about your combination therapy and the use of illicit drugs?</p> <p>Not without asking.</p>	
<p>If you have managed to abstain from alcohol and/or drugs after a period of using, how have you managed this? What services are available for you to get enough support?</p> <p>I have never used drug services. Since I have been diagnosed I haven't had a physical smack habit, the nearest I got to that was my need to smoke crack. I think my survival instinct or self-preservation kicks in. I always know that when I'm really standing on the edge and looking over, it's time to pull back.</p>	
<p>About the Services you use</p>	
<p>What services/support networks do you use – please specify in relation to –</p> <ul style="list-style-type: none"> • HIV, • Drugs, Alcohol, 	

<p>I use the clinic.</p>	
<p>Please tell me about services you have used in the past.</p> <p>Medical services, it's just the clinic. Counseling / physiologist on rare occasions through the clinic Social worker on 1 or 2 occasions through the clinic. AIDS services set up by my local borough that provided social workers Terrence Higgins Trust for housing and used them hugely in early days and they were by far the most helpful and influential in terms of sorting me out with legal advice and benefits advice For complimentary therapies: Immune Development Trust, Helios Centre, The Lighthouse and PW. Didn't really use support services as was busy setting them up.</p>	
<p>How did you find out about these services?</p> <p>Through setting up PW services. Every one knew everyone then so it was word of mouth. We were always working with Directors of other organisations.</p>	
<p>Would you like to talk about the attitudes you have encountered from staff and other service users?</p> <p>It was quite weird for me because the boundaries were really blurred, especially one time I decided that I really needed to go and see a physiologist. It was one of those years when my friends and colleagues were dying one after the other and I reached a place where I just couldn't stop crying for about 3 days and I knew what it was about but decided I needed to talk about it and it was a woman that I knew really well professionally and had been in a meeting with her just the day before my appointment with her so it was really weird having to hide and compartmentalise all that stuff.</p> <p>Another time I was at the hospital and it was late on a Friday afternoon and I knew the doctor that I was seeing both socially and professionally (my usual doctor was not there that day) and he just picked up my notes and said you think you've got problems? I've got problems too and proceeded to throw my notes across the room. I was really upset and left and didn't feel safe anymore and I knew that I needed to go back but I just didn't want to and then I got a call from my usual doctor saying she had just come back from holiday and said that she needed to talk to me because the first thing that Dr X said to me when I got back was he was waiting to see me because he was so freaked out. He felt really bad about what he had done to me. But I realised that if I had been a different patient that he didn't have that relationship with he wouldn't have done that. So I faced quite a lot of that, those really, really blurred, blurred, blurred boundaries which sometimes you don't actually want those blurred boundaries. Sometimes you want a professional doctor-patient relationship even if it's nice to say there's no hierarchy. Sometimes you just want to be taken care of and it's actually quite unsettling. That kind of thing has happened to me a lot and I've felt that I can't access services because I know the people working there too closely. On the one hand through that it's been easy for me to fast</p>	

<p>track waiting lists and queues and have had specialised treatment sometimes – there are pros and cons but it's a very different experience.</p>	
<p>What services have you used where you have felt that BOTH the HIV and drug use have been dealt with in a satisfactory manner?</p>	
<p>Have you ever changed services (e.g. your clinic) and if so, why?</p> <p>I changed my clinic once. I had a couple of friends that had moved there and I really liked the doctor that I was going to be with. The main reason was that my original clinic was very gay men focused and this other clinic had a women's clinic and the doctor was very woman focused. It was a nicer environment, it was very pleasant and easier to get there but no particular big issues that made me change.</p>	
<p>What was your reason for accessing the services that you used?</p>	
<p>Did you find that your needs were met by these services?</p> <p>Yes, at my clinic, except for the last couple of weeks. The clinic seemed to be in total chaos which was quite a shock but I think that's to do with more people with Hep C, the budget and they are overloaded and under-funded and the cracks are really beginning to show. It's quite scary to see this but up until now I feel that I have received a high quality of care.</p>	<p>yes</p>
<p>What needs, if any, do you think still need addressing?</p> <p>I think that the next thing I need to do is to see my doctor and talk to her about my recent experiences at the clinic and also talk to IBASE about it.</p>	
<p>Is there anything else you want to say about the services you have used or are still using? What services would you like to see available?</p> <p>In an ideal world I would like to see services available where people could get everything HIV related and vaguely related done at the same place so you didn't have to go off to the GUM clinic to get those bits dealt with etc. If I were to need services related to my drug use, I would like to see these services in the same place too. I would like to see things more integrated and when this has been like that, for instance having a well- woman clinic integrated, I liked it that way.</p>	
<p>In relation to drug use, please tell me what 3 services you consider to be the most necessary</p> <p>Needle exchange is a life- saving service. Maybe if they had been in place when I was using needles it would have been far less likely that I would have contracted HIV.</p>	

<p>Services where people can go and talk, get counseled about their drug use and get counseled about their options and HAVE options rather than just being told that this is the only thing we can do for you – we can just prescribe you methadone – end of story. I would like to see options, not all junkies are the same, not everyone has the same needs.</p> <p>I really wonder about what best services people can use who are using crack because my experience of crack I don't quite know what the answer is. There doesn't seem to be a substitution and it's just such a psychological thing. I could see a point where diamorphine should be more available but what about crack?</p>	
<p>In relation to HIV care and support, please tell me what 3 services you consider to be the most necessary.</p> <p>Medical services that provide treatment, along with treatment information and monitoring of treatment.</p> <p>Peer support is really key, I don't think that I would be here if it wasn't for the support of my peers, that is really what has sustained me.</p> <p>As far as being newly diagnosed, information is just so important.</p> <p>Also complimentary therapies are important and invaluable for me originally but now that I have my health back it's more like just the icing on the cake. But still feel they are important for people that don't have much physical contact with other people and you are isolated and not having sex. It's nice to have that touch and closeness.</p>	
<p>Would you like to receive support and care around HIV in the same place that you receive support and care around drug use?</p> <p>Yes if I needed it</p>	
<p>About your family and other relationships</p>	
<p>Are you married or in a long-term relationship? - Please give details</p>	<p>Long term relationship, about to get married.</p>
<p>Do you have children? Please give details</p>	<p>No</p>
<p>Does your partner know about your HIV status? What issues have arisen in your relationship due to your status?</p> <p>Oh God, where do I begin? There are issues around sex and safer sex, not having sex because I'm ill or too tired or his fear (I could go on for hours). Also around when we first got together I really didn't think that I would be here for long, in our first year he experienced a huge proportion of my close</p>	

<p>friends dying and I didn't realistically think that I had a very long future and then after 1996 all that changed and it took a long while to get my head around it, it's been a head fuck for both of us really and have had to re-evaluate things and even though it's been nice to be doing, in a way it hasn't been easy and then there were of course issues around having children.</p>	
<p>How do you disclose to family, friends etc?</p> <p>It's such a long time ago now that I disclosed to my family. I tended to blurt it out quite a lot in the early days. I think it's hard to have a meaningful relationship with someone if they don't know, because for me in the past it was such a big part, it felt overwhelming. Now it's just part of my work and other than that it's pretty much in the background. When I was at the hairdressers today I talked about it as something came up in conversation.</p>	
<p>Are you open about your status?_ If so, how does your partner, friends, family feel about this?</p> <p>My partner has always been very open about my status, his mum is fine. His dad doesn't say too much about anything really. I remember one time years ago when his father rang up and said to him I've just seen Kate on TV walking through Soho carrying condoms and talking about sex. I think that they are fine about it but they have to be really.</p>	
<p>Do you have any coping mechanisms for dealing with these issues? What support, if any, have you had around these issues?</p> <p>Probably didn't cope very well around issues with my partner and a lot of those times I was using coke so was one of the coping mechanisms that wasn't effective for us as a couple, It stopped us talking about things although it was effective for me. Now I just eat chocolate, lots of it, about a hundred grams a day at least!</p>	
<p>Have you found sexual relationships are different since your diagnosis?</p> <p>Different yes, because HIV is always there and you can't away from that.</p>	
<p>Has your diagnosis changed the way you feel about sex?</p> <p>I think it did in the early days because I did feel very afraid of infecting people. Now it doesn't so much because I don't feel as infectious but I think it affects me when I'm not well and also with body changes as they affect how I feel about myself so that affects my sexuality.</p>	
<p>Has you libido changed in any way?</p>	

When I am ill and when I feel bad about myself, but even before I was diagnosed it used to go in cycles anyway.	
What is your Partner's HIV status?	HIV Negative
Does your partner know about your drug use?	Yes
Did/do you and your partner use drugs together? No I wish I could – I'd probably take more if he did.	No
Please tell me any concerns, if any, you may have faced with regards to disclosing your drug use or HIV status to your partner. The funny thing when I met him he was so naive – the first or second night that I went out with him, we went out to a club with a bunch of friends and I did an E and about half a gram of coke and he didn't even realise. He was so sweet. He knew about my HIV status before, he had heard a lot about me and I just assumed that he realised I was doing drugs but I think he knew by the following day and he always said he was absolutely fine about it but then it transpired that he was just saying that and wasn't really.	
What response did you get? See above	
Have you had a baby since your diagnosis?	No
Have you ever tried to get pregnant? Please tell me about your experience Are you presently trying to get pregnant?	no
If you have made a decision not to have a baby what influenced this decision? I think I made a decision to not have a baby way before I was diagnosed with HIV, so my status didn't really affect that. But now at the grand old age of 44 and my partner is 40, he would quite like to have babies but it's too late for me so he has mentioned the options of adoption and we have talked about that but I have said basically it is up to him to follow up on that. I definitely doubt, due to my HIV status and past drug use, that I would be able to adopt in this country.	
Other Issues	

Have you ever been arrested or cautioned?	Yes
Have you ever been in prison?	No
If you have been in prison, or in a police station/cell, did you declare your HIV status	No
<p>Personally, have you been aware of any changes in your body since your diagnosis or since starting combination therapy (e.g. menstruation, menopause)</p> <p>Menstruation- not really. Body changes have been huge – huge weight loss but it is 20 years down the line and we all have body changes then, sometimes difficult to tell whether it is HIV related, Hep C or just related to getting older. How do you disentangle all that?</p>	
<p>Is there anything else you would like to say before we finish this interview?</p>	
<p>Do you feel as if you are kept up-to-date with relevant information and if so, what services provide this info?</p> <p>I feel like I am bombarded by information these days. There is so much out there. When we were first diagnosed I remember that there was no information on women and HIV and having to really search for any information. I feel that these days I know where to get the information myself.</p>	

Abbreviations and Glossary of Terms

Acid: see LSD

ADDACTION: a U.K. based drug and alcohol treatment charity.

Adherence: Multiple studies have demonstrated that HIV treatment regimens (especially those combining multiple drugs) work most effectively when taken at the prescribed time and quantity. Furthermore, if the levels of medications in the body aren't kept high, the HIV virus has a chance to reproduce. 7745 7257 Fax: 020 7745 7259 E-

Amps: ampoules

ART – Antiretroviral treatment

ASBO-Anti Social Behaviour Orders

Barbs: Barbiturates - are synthetic drugs which used to be regularly prescribed for anxiety, depression and insomnia. Barbiturates used to be a regular feature of the UK drugs scene, but because there is very little prescribing and no illicitly made varieties around, fortunately little is seen of them these days.

Bart's hospital – Saint Bartholomew Hospital, London

Benzo: Benzodiazepines - Benzodiazepines are among the best-known and most widely prescribed drugs in the world. They are commonly used for control of symptoms due to **stress** and as a sleeping tablet for insomnia. For the regular treatment of anxiety benzodiazepines are given in short periods to promote mental and physical relaxation. By interfering with the chemical activity in the brain and nervous system, they reduce the communication between nerve cells. This leads to less brain activity, which varies proportionally with the dose ingested.

Blackfriars Road: Assessment and shared care offered with clients' GPs, needle exchange, referral to specialist

blind methadone detox: Methadone clinics also actually have what they call a "blind detox" where the patient doesn't know when their dose is being lowered

Body and Soul – a London based organization for positive people, especially families and

Body Positive: Body Positive London, one of the UK's first AIDS organisations. 'Body Positive closure highlights lack of London HIV strategy'; BMJ (2000), 'Analysis of ...

www.avert.org/ukaids.htm

CARA : The UK's leading charity focusing on the spiritual and pastoral support needs of people living with or affected by HIV.

CD4 Count (T4 count, T-helper cells) blood test which measures the immune system's strength after a diagnosis of an HIV infection.

City Roads: 354-358 City Road, London EC1V 2PY A short term centre for drug users in chaos. Offering detox, medical and social work support. Phone referral only. ... www.disabilityuk.com/masterpages/hiv/hividx.htm

Combination: Combination of different drugs used together to fight HIV. (combination Therapy). Drugs that might be used in combination include Kaletra, Tenofovir, D4T, 3TC. Efavirenz, AZT, Ritonavir,

CS: Caesarian section/Section:

Cut: "cut with adulterants". Adulterants are various substances which are mixed into drugs as fillers by dealers, thus increasing the amount that they can sell.

DDU – Drug Dependency Unit

DF's or DF118: dihydrocodeine (DF118). An opiate based pain killer

Diconal: is the brand name of dipipanone, a pain killer. It is a pink tablet which is sometimes prepared for injection by chronic users of heroin and similar drugs. This is very dangerous because it contains silicon which damages the veins if injected. Many people who have injected it have got abscesses and some have had to have limbs amputated.

DLA: Disability Living Allowance

Discordant: A couple may be discordant for a sexually transmitted infection, with one partner having it and the other not

Dope - Hash

Druggie relationship: a couple where both partners are drug users

Dual Diagnosis: dual diagnosis normally refers to the co-existence of someone's mental health problems and substance misuse. In HIV positive people can also refer to being infected with HIV and HCV, or HIV and TB, or any other combination.

E: an abbreviated form for ecstasy. Street names for MDMA include **Ecstasy**, Adam, XTC, hug, beans, and love drug.

Esophageal varices: dilated blood vessels within the wall of the esophagus.

Freebasing: refers to the process of freeing the active ingredients of a drug from its adulterants with which, in the slang term, it has been "cut".

Fibroscan: Transient elastography (FibroScan®) is a new non-invasive rapid and reproducible method, allowing evaluating liver fibrosis by measurement of liver stiffness.

Fix: term used for injecting

Freedom pass: free biannual travel card offered to disabled people.

Gear; common term to describe drugs, mainly heroin

Griffin Project – a respite place available only to positive drug users. Now closed

GUM Clinics: Genito Urinary Medicine Clinic

HCV – Hepatitis C Virus

Helios: A centre for alternative healthcare and stress management. Offers comprehensive and integrated complementary healthcare for people with HIV and AIDS.

Hitting up - Injecting

HMP Styal: Styal was built as a children's home in 1898 and was used to house Hungarian refugees in the 1950s. It opened as a women's prison in 1962.

i-Care: Islington Care

i-Base: HIV treatment information for HIV-positive people and healthcare professionals.
www.i-base.org.uk

IDT: Complementary Health Trust PO Box 32879 London N1 3QX UK Design by Kremlin updated on 23 July 2005. The Immune Development Trust became the Complementary www.comphealth.org.uk/

injectable diamorphine: alternative treatment for heroin addiction.

IV: Intravenously

IUD: Intra Uterine Device

Juice: generally referring to methadone, methadone amps. Has also being used in reference to steroids.

Interferon: a protein produced by cells. Interferon helps regulate the body's immune system, boosting activity when a threat, such as a virus, is found. Scientists have learned that interferon helps fight against cancer, so it is used to treat some types of cancer.

KCH – Kings College Hospital – South London – Caldecott clinic – HIV section

Lipodystrophy: A disorder of adipose (fatty) tissue characterized by a selective loss of body fat.

LSD: LSD or Lysergic Acid Diethylamide is a hallucinogenic drug originally derived from ergot, a fungus found growing wild on rye and other grasses. It's commonly called acid.



Milk Thistle: Milk Thistle protects and regenerates the liver in most liver diseases such as Cirrhosis (hardening of the Liver), Jaundice and Hepatitis, (inflammation of the Liver), and Cholangitis (inflammation of bile ducts resulting in decreased bile flow).

NAM - Publications/**National AIDS Manual** (UK) <http://www.aidsmap.com/>. NAM is a community-based information provider based in the UK.

www.ohn.gov.uk/gateway/health_focus/topics/hiv.htm

Peripheral Neuropathy: A condition caused by damage to the nerves in the peripheral nervous system. Peripheral neuropathy can sometimes be caused by HIV but is most commonly a side effect of drugs.

Pharmacokinetics is the study of what the body does to a drug. Pharmacodynamics is the study of what a drug does to the body.

Physeptone: A variation of methadone. Methadone is more commonly used in the treatment of drug addiction to other opioids such as heroin. It is prescribed as a substitute for such drugs. By acting on the same opioid receptors as heroin, methadone prevents the physical symptoms of withdrawal that occur when heroin is stopped. This prevents the onset of physical cravings.

PI's : Protease Inhibitor – Antiretroviral use for the treatment of HIV/AIDS

Piping: term used when talking about smoking crack cocaine

PMTCT –Prevention of Mother to Child Transmission

Positive Nation (PN) - PN is Europe's only generic monthly magazine by, for and about people living with and affected by HIV, Aids and related conditions.

Pox clinic: any sexual health clinic

PW – Positively Women – a London based organization that provides services and support for

Recovering addict: in the process of recovery

Recovery: Recovery from addiction can be a long-term process and frequently requires multiple episodes of treatment

- **In recovery:** in the process of recovery
- **Recovering addict:** in the process of recovery
- **In the rooms:** refers to 12 steps meetings and recovery
- **12 steps program:** This 12step.org website is about 12 Step programs, which have been widely used in programs of recovery from addictive or dysfunctional behaviors. The first 12 step program began with **Alcoholics Anonymous (A.A.)** in the 1930s. The 12 Step approach has gone on to be the most widely used and successful approach in dealing with not only alcoholism, but drug abuse and also various other addictive or dysfunctional behaviors. This web site has no official affiliation with A.A. or any other 12 Step group. We strive only to act as another source for information and tools concerning 12 Step programs.

Riverhouse: Riverhouse is a drop-in centre which offers a wide range of services for HIV positive individuals: 020 8576 5875 ...

www.roehamptonclinic.com/hiv_services_main.htm

ROMA – where drug users could go and stay in order to stabilise on their script. Now closed.

Script – short for prescription – normally associated with Methadone

Seroconverting: The term "seroconversion" refers to development of antibodies to HIV reflecting acquisition of infection.

Sero-discordance: Being a couple in which one partner has tested positive for **HIV** and the other has not

Sharp bins: safe individual yellow containers for the disposal of used works

Shepperdess Walk: service has closed but used to provide services for HIV+ people and also for drug users.

Smack: common term for heroin

Speed: common name for amphetamine

Speedball: - heroin and cocaine; amphetamine mixed together

Spliff: another name for a cannabis joint. Also, to smoke i.e. you spliff in the mornings

Stella: a brand of lager (beer). Often bought in cans.

Straight: not stoned, i.e. not under the influence of drugs

Subutex: common brand name for BUPRENORPHINE This medication is used to treat narcotic (opioid) dependence. It works by preventing withdrawal symptoms, since it is actually a type of narcotic (opioid) itself. It should be used as part of a complete narcotic dependence treatment plan.

Superinfection:

- In **virology**, **superinfection** describes the process by which a **cell** that has previously been infected by one **virus** gets **coinfected** with another virus at a later point in time.
- In **medicine**, **superinfection** is an infection following a previous infection, especially when caused by microorganisms that are resistant or have become resistant to the antibiotics used earlier. **TB:** Tuberculosis

T-Cells: T cells are lymphocytes which develop in the thymus. There are two subpopulations of T cells (CD8+ or CD4+) that develop and their development in the thymus can be traced by surface markers.

The Caravan: Needle exchange project at St Mary's Hospital, Paddington, London.

The Junction: The Junction provides a drop-in centre for people who are affected by HIV/AIDS, their carers, friends and families. Services provided at the centre include therapies, computer training, lunch and social events.

The virus: familiar form when talking about being HIV positive – having the virus.

THT – Terrence Higgins Trust: For more than 20 years, **Terrence Higgins Trust** has campaigned for greater public understanding of the personal, social and medical impact of HIV and AIDS. ...

www.advocacyonline.net/tht/

To score – going out to obtain illegal drugs

Treatment: detoxification centres and rehabilitation centres used to come off drugs

Use-up: term used to describe using drugs, maybe a binge

Viral load: The amount of HIV in the circulating blood. Monitoring a person's viral load is important because of the apparent correlation between the amount of virus in the blood and disease severity

WDP Individual and group work programmes, drug education, drop in centre and help-line. Based in London.

www.wdp-drugs.org.uk

Works (pick up): collecting clean needles, swaps, sterile water and relevant paraphernalia

Works (pick up): collecting clean needles, swaps, sterile water and relevant paraphernalia

Useful contacts

- **ADDACTION:** a U.K. based drug and alcohol treatment charity. Includes drug information, parent section, publications and links
Address: Suite 171416 - 19 Southampton Place London WC1A 2AJ
Tel: 020 7745 7257 **Fax:** 020 7745 7259 **Email:** mail@caralife.com
- **Black Poppy Magazine:** Black Poppy is an is a non profit making, user run organisation that creates and produces the drug user's health and lifestyle magazine
- **Blackfriars Road:** Assessment and shared care offered with clients' GPs, needle exchange, referral to specialist ... 151 Blackfriars Road, London, SE1 8EL Phone: 020 7620 1888 .
- **CARA :** the UK's leading charity focusing on the spiritual and pastoral support needs of people living with or affected by HIV.
- **City Roads:** 354-358 City Road, London EC1V 2PY A short term centre for drug users in chaos. Offering detox, medical and social work support. Phone referral only. ... www.disabilityuk.com/masterpages/hiv/hividx.htm
- **Drug and Alcohol Team**
- **Helios Centre** 116 Judd Street, WC1H 9NS www.helioshealth.org.uk
Tel:020 7713 7120 Email: contact@HeliosHealth.org.uk A centre for alternative healthcare and stress management. Offers comprehensive and integrated complementary healthcare for people with HIV and AIDS. There is a programme for older people of complementary healthcare and psychotherapy. A specialist clinic offers integration therapy for dyspraxic children and children with learning difficulties, dyslexia or behavioural problems. Also clinic for adults with phobias or co-ordination problems. Runs yoga and qi gong classes. Phone for details of treatments and charges. Workshop for gay men, 1st Sunday of each month, 10am-6pm.
- **Homerton Hospital** –North east London www.homerton.nhs.uk/
- **i-Base:** HIV treatment information for HIV-positive people and healthcare professionals. www.i-base.org.uk
- **ICW** – International Community of Women Living with HIV/AIDS
- **IDT - Complementary Health Trust** PO Box 32879 London N1 3QX UK Design by Kremlin updated on 23 July 2005. The **Immune Development Trust** became the Complementary Health Trust... www.comphealth.org.uk/
- **LEAN:** London East AIDS Network: Advice, advocacy and home support services for people affected by HIV in East London. 0181 519 9545; 35 Romford Road, London E15 4LY.
- **Lighthouse** is a charity providing services to people with HIV and AIDS. Some services are only open to people living in particular areas and other services ... www.patient.co.uk/showdoc/26739518/
- **LDNA London Drug and Alcohol Network:** Unit 8b New North House Canonbury Yard, 202-208 New North Road, London N1 7BJ, Tel: 020 7704 0004 Fax: 020 7359 1317, Email: info@ldan.org.uk Website: www.ldan.org.uk
- **Mainliners SMART** Service offers these services: Assessment, counselling, support, and information for people with drug related problems. www.multikulti.org.uk/agencies/spanish/london/19353/
- **NAM:** NAM Publications. National AIDS Manual (UK) <http://www.aidsmap.com/>. NAM is a community-based information provider based in the UK whose sole aim is to ... www.ohn.gov.uk/gateway/health_focus/topics/hiv.htm
- **Positive East** is a voluntary organisation providing a range of services to people affected by HIV/AIDS in East London. Advice services ... www.lbwf.gov.uk/index/care/adults-and-older-people/hiv-aids.htm
- **Positive Nation** Positive Nation is Europe's only generic monthly magazine by, for and about people living with and affected by HIV, Aids and related conditions.

- **RIVERHOUSE.** Riverhouse is a drop-in centre which offers a wide range of services for HIV positive individuals: 020 8576 5875 ...
www.roehamptonclinic.com/hiv_services_main.htm
 - **Royal Free Hospital**
 - **Streatham Women Clinic:** Working Women Streatham Hill Primary Healthcare, 41a-c Streatham Hill, SW2. Telephone: 0181-674 7178. Offer an outreach service to sex workers on the street and in flats and saunas. They carry free supplies of condoms and sterile works and cover the boroughs of Lambeth, Southwark, Lewisham and Croydon.
 - **The Junction** 207a Anerley Road London SE20 8ER Tel: 020 8776 5588 Fax: 020 8316 2008 Catchment's Bromley and surrounding areas Services: The Junction provides a drop-in centre for people who are affected by HIV/AIDS, their carers, friends and families. Services provided at the centre include therapies, computer training, lunch and social events.
 - **The Kobler Centre: specialist HIV clinic.** Kobler Centre St Stephen's Centre, Chelsea and Westminster Hospital, 369 Fulham Rd, London, SW10 9TH Tel: 0208 846 6135
 - **The Landmark**
 - **Mortimer Market** – Bloomsbury Clinic
 - **THT – Terrence Higgins Trust** For more than 20 years, THT has campaigned for greater public understanding of the personal, social and medical impact of HIV and AIDS.
www.advocacyonline.net/tht/
 - **UKC – UK Coalition:** A national patient group, informing, campaigning, researching and advocating for people with HIV. Includes links to further resources.
www.ukcoalition.org/
 - **Westminster Drug Project:** Individual and group work programmes, drug education, drop in centre and help-line. Based in London. www.wdp-drugs.org.uk
 - **Whittington Hospital** – North London en.wikipedia.org/wiki/Whittington_hospital
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