

HIV positive women and drug and alcohol use







# HIV Positive **Women** and **Drug** and **Alcohol Use**

Silent Voices, a unique participatory ICW project carried out by and for HIV positive women on the experiences of HIV positive drug/alcohol using women living in London, UK, aims to address the current lack of support and information available for HIV positive women who also use drugs and alcohol. In order to find out what services the women needed, we explored relationships, employment, motherhood, available services, and barriers to access. The project also aimed to create links among HIV positive female drug users with the help of local partner organisations, to collate information on current policies and practice, and to develop advocacy tools around reproductive health rights, access to care, treatment and support, and prevention. Using a participatory approach, focus groups and individual interviews were conducted by HIV positive women, the majority of whom are ex-injecting drug users, with HIV positive women who are (or were) also users. Full report available from www.icw.org.

## Prevalence (UK only) of HIV among injecting drug users -

During 2005, a reported 112 people were diagnosed HIV positive with a risk factor of injection drug use. By the end of December 2005 at total of 4,392 people had acquired HIV by this route. Statistics indicate that 1348 women as opposed to 3075 men probably acquired HIV through injecting drug use (UK – all years until the end of March 2006).

Source: Health Protection Agency website: http://www.hpa.org.uk.

#### Background of research participants -

The 20 HIV positive participants were from a range of ethnic and religious backgrounds. They also varied considerably in age and number of years since their HIV diagnosis. Of the 20 participants five were diagnosed after 2000 and two as far back as 1987. Nine of the 20 women have been either arrested or cautioned, and five have spent time in prison. Sixteen women had received their diagnosis in either clinics or hospitals and four were diagnosed in prison.

Diagnosis – An HIV positive diagnosis is a life-changing event, and may induce shock, a sense of helplessness, 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. When asked about the manner in which they were given their diagnosis, all the women had something bad to say, regardless of the country they were living in 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.

Responses to how their diagnosis affected the women's lives varied widely. Some women increased their drug use or started using drugs. Others drastically changed their lifestyle and started reducing their drug intake. Most of the women who have been living with HIV for many years described how they originally believed that their lives would be cut short. Now they have had to readjust their thinking about life and the future. A few women got involved in HIV or drug related activism. This generally increased their feelings of self-worth. However, for one

<sup>&</sup>lt;sup>1</sup> The number of HIV positive women and men who do or have injected drugs, or indeed who take other drugs, is likely to be higher. These statistics reflect transmission route only.







woman, being a 'public face' took its toll with a loss of privacy and the impact of being open in public on loved ones.

**Partners** – Of the 14 women who gave indepth interviews, seven were either married or in long-term relationships. Only one had an HIV positive partner, the others had partners who are HIV negative.

The women's stories illustrate their concerns about disclosing their HIV status and drug use to existing or new partners. Would existing partners leave them? Would it limit their ability to find new partners? In fact, ex and existing partners tended to display a good level of support. However, new partners were generally more wary when told and sometimes the strain meant that the new relationship ended. The fear and expectation of rejection worried the women and this increased as the relationship became more serious.

I was very frightened of rejection, of passing the virus to somebody else. Now I don't worry so much because I know if I use a condom I don't have to disclose it. But I'm always thinking that I am going to be rejected.

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 get panicky 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 do you get your money, what do you do? I am just very scared. I would say that if I meet somebody for one day, it's fine. But when you want to carry on with the relationship... I just freak and don't want to.

Nevertheless, when thinking about a longterm relationship the women believed it was important to disclose as early as possible. Interestingly, a large proportion stated that after many years of living with HIV they were less likely to disclose as readily as before. On the other hand, some women in the early stages of diagnosis felt disclosure was far too difficult and made a decision to not have sex at all. All the women felt strongly that if it was going to be a one-night stand, it was important to practise safer sex.

Family and friends – There were different examples of how, and indeed if women disclosed their HIV status and drug use to their family and friends, and of the reactions they received. Reactions varied from shock and discrimination to full, loving support.

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

For 15 years I didn't tell my parents about my drug use, or my HIV.

My sister wouldn't even come and get her Christmas presents but this was in the days of ignorance so no one knew any better. She wouldn't even come to the door and a year later her husband asked me not to kiss and cuddle the kids.

I've never had a bad response in terms of someone completely shunning me, but I have had experiences of people being freaked out and not being able to deal with it.

It is clear that disclosure is not a one-off action for women living with HIV, where a decision is made, acted on, and accepted or not by the women, their partners, and family and friends. Disclosure is an ongoing process involving new information, and circumstances, and can continue to create fear and apprehension. For HIV positive women who are also injecting drug users, revealing drug use and co-infections is an additional worry.







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It's more easy to say I am a recovering addict because it's like saying, '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, oh my God!

I've tended to disclose the Hep C first to use it as a tester.

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'. I think she finds it more difficult to tell people that I'm a drug user than the fact that I'm HIV positive.

Telling children – Disclosure of an HIV status or about drug use to your children is similarly fraught with concern about possible negative or fearful reactions, and about the impact on the children's lives. Children's acceptance 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.

I knew it was hard enough growing up in London with no services available for the kids. They worried enough about my drug use so I chose not to tell them about my HIV status until they were grown up.

Naturally, the women felt that telling their children that they were HIV positive was extremely distressing, let alone dealing with the possibility of losing a child.

I had a son, he died last year. When he reached a certain age he was telling me, why? How can you explain to him? Well he knew. I did tell him when he was 12 that he was HIV positive. But then you know its like 'mom, where did I get it from?' Ah, from me!' and it was really painful. I love you so much my son — I am sorry, I didn't want, I didn't want you to be sick, and its not only sick, it's bad. Can you imagine?

Wider community/society – 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 said that they enjoyed being in environments where they could be anonymous and feel a part of 'normal' living. Generally, the drugusing community was more accepting of a positive diagnosis than the HIV community was of drug use.

In a way it's easier for me because I'm involved in drug user's stuff. I think that drug users accept a positive diagnosis more readily than the straight community.

Being invisible or treated disdainfully because I'm a drug user, even amongst other HIV positive women, makes me feel isolated. Maybe it's because I can't be honest when everyone else is being honest—it's not easy to launch into the conversation and say you are an injecting heroin user and smoke crack at the weekends!

But not always...

In the early days we were rejected by nearly everyone, even other addicts. We had bricks through our window. Word got out we were living on this estate and kids were chanting 'they've got AIDS', and things like that.

During international HIV/AIDS events the voices of drug users are seldom heard and their concerns rarely mentioned<sup>2</sup>. This omission is particularly alarming given the close link between HIV transmission and drug use, and the rising rate of new infections among injecting drug users, especially those from Eastern Europe.

<sup>&</sup>lt;sup>2</sup> Silent Voices came into existence because the researchers had experienced discrimination within society, and more alarmingly, from their own peers. Anecdotal evidence has been gathered by ICW of discrimination by HIV positive male drug users towards HIV positive female drug users wishing to become pregnant.







I can't find any organisations that I can fit in. I know there are places for HIV positive people, 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.

At a local level the majority of women stated that even though they were able to discuss issues around their HIV status they felt that being honest about their drug use and lifestyles was very difficult even amongst their peers. At some point in their lives most had experienced varying degrees of ostracism upon disclosure. They even felt marginalised and judged by other HIV positive women.

I suppose my positive diagnosis made me very aware of discrimination against drug users including from other HIV positive 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. That was a real eye opener and it did change the way my life turned after that – I got a lot more active around drug using issues.

Professional and working lives - All but two of the women participating in the research have previously worked or still are working in various professions. These included: Spanish teacher, painter and decorator, nursery nurse, project worker, and management and key development roles within both national and international HIV organisations. 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 BAs, MAs, and one PHD. Silent Voices feels strongly that this part of our research challenges the stereotypical picture often painted by society about drug users who are seen as not able to hold down a job or contribute in any other meaningful way to society.

While some women considered themselves disabled they still felt that they could work part time. Their main anxieties around work were disclosure to employers, the fear of

losing their benefits, and the concern that their health would later decline. Maintaining confidentiality at work is not easy given the need to take time off for health related appointments, treatment and illness. The side affects of drug use may also be detected.

Because of my addiction I used a lot of my veins in my legs with methadone amps<sup>3</sup> and I consequently ruined my circulation. I had a lot of scarring and I also had very swollen up hands and feet to the extent I had to wear trainers to work. It got a bit iffy and I had to lie and I said that I had a serious health condition.

Apart from the few women working within the HIV community who felt able to disclose their status, most who are or have been in full time employment did not feel able to do so. In fact some of the women said they had been discriminated against at work after disclosure. Other concerns regarding confidentiality were related to pension schemes and health questionnaires.

I was asked to fill in a health questionnaire for pensions and there were specific questions about substance misuse and HIV and Hep [hepatitis] and I was advised not to lie by the union and I started freaking out because I had just been offered my dream job and if I filled this in truthfully would it be taken away?

**General health –** Three quarters of the participants have a dual diagnosis of HIV and hepatitis C virus (HCV). At the moment there is no cure for either HCV or HIV and this will remain an ongoing issue for the women and the National Health Service.

Silent Voices research clearly shows that more in-depth work around long-term HIV survival should be conducted. As the survival rate among HIV positive women in this country improves, they face other health

<sup>3</sup> Methadone ampoules are containers of methadone.









issues they thought they would not live long enough to experience, for example, liver dysfunction and cancers.

Only half of the participants, the majority of whom have been diagnosed for longer than ten years, were on combination therapies. Other medications taken by the women included: anti-depressants, sleeping pills, tranquilisers, dihydrocodeine<sup>4</sup>, anti-psychotics, acyclovir<sup>5</sup> and thyroxin.

All the participants have used and have benefited from complimentary therapies, such as massage and reflexology. Although the majority of women used these more in the past, many stated that they would use them more frequently if they were easily accessible.

Sex and sexuality – The women's feelings towards sex and sexuality varied greatly. Some were still too scared about disclosure, and the fear of infecting partners, to think about a sexual relationship, or to have a relationship that did not involve disclosure.

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.

Before HIV I was more sexually active – I liked sex. But now what's the point you have to be careful and watch out.

If I weren't positive I would be messing around more.

Weighing up the pros and cons proved hard for those embarking on serious or casual relationships.

It's hard, it's very hard. Disclosure is the key and some people won't understand why it's important to use a condom. Then the sexual relationship is hard and disclosure is a massive problem. Others, especially women who are long-term HIV survivors reported that they are now confident enough to have a casual relationship without disclosing, as long as they practiced safe sex. But safe sex was not without angst. For example, a number of the women felt that having to practice safe sex made it less spontaneous. One woman expressed her discomfort at condom negotiation and the possibility of it breaking, while another woman felt that condoms gave her the confidence to have healthy, quilt-free sex.

I grew to like condoms as there is no mess. And I felt as if I was in control. I wasn't prepared to let anybody have unsafe sex with me and throw it in my face as I had heard happened, so maybe in some ways HIV has made me more assertive sexually.

Those women who felt their libido had changed said it was connected to things like feeling ill, body changes due to lipodystrophy, not using speed anymore, general relationship problems or the menopause, and was not necessarily directly related to HIV.

In the early days I did feel very afraid of infecting people. Now not 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 because they affect how I feel about myself and that affects my sexuality.

Not all the women experienced a decrease in their libido. In fact one woman said hers increased.

They tell you when you go through the menopause that you lose it but I think I must have caught everybody else's then.

**Motherhood** – Nine of the study participants are mothers, three of whom have had a child since their diagnosis. Seven women have

<sup>4</sup> Codeine based pain killer.

<sup>&</sup>lt;sup>5</sup> Used to treat herpes.







one child each while two have three children. One of these children has subsequently died from an HIV-related illness and another from addiction. Two of the children have been adopted by other families. One woman was pregnant during the study.

Research has advanced regarding how HIV is transmitted from mother to child and about how to greatly minimise the risks of transmission. Having said that, from the reported experiences of the women, not all health professionals are aware of these developments, and therefore do not support the reproductive choices of HIV positive women. Women's concerns about the impact of pregnancy on both their health and the child's greatly influenced decisions around childbearing.

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 while pregnant – there are a lot of issues and it has coloured how I feel about having a child.

Sadly, women and their partners still experienced anxiety during pregnancy and post-delivery. This may have happened because of *fears* about the possible impact of HIV rather than a realisation of those fears. This may well demonstrate a lack of encouragement and specific support for HIV positive mothers from health professionals.

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.

For the women who decided to become pregnant there were different experiences within the health system. The HIV doctors were supportive and gave advice about becoming pregnant. Issues of sero-discordance and minimisation of transmission to the negative partner were

also explained to couples. However, such supportive attitudes are not generally prevalent among the other professionals involved, especially after birth.

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

The research highlights that these attitudes are the result of a lack of information among health professionals in general, and highlights the need for training at all levels of the NHS. Even when the consultants are supportive, they tend to adhere strictly to the guidelines regarding mother-to-child transmission without listening to the concerns and desires of the women in their care. Sometimes they simply ignored the latest data available regarding PMTCT.

I did have a CS (Caesarian Section). I wasn't happy because I asked the doctor if I could have the CS when the baby was due. But they wanted to do it a month before. I think my child was born with a lot of anxiety. He didn't sleep as a baby. It was awful, very, very stressful.

Many of the women who have been living with HIV for many years said that they had had no choices, and were actively discouraged from having children, because in those days the belief was that both mother and child would die. One woman who has been diagnosed for nearly 20 years was still young enough to have a child. She no longer accesses services other than her clinic and she had not been given any recent information about having children. The Silent Voices team were concerned that this was because she was still taking drugs, illustrating that judgmental attitudes around HIV positive (and negative) injecting drug users having children abound outside and inside 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 decreased over the years. This could be because they are all getting older and wiser or maybe because the majority are also co-infected with HCV and therefore need to take better care of their livers. It should be noted that the women who do not drink (with the exception of one woman who is currently pregnant) all belong to an abstinence-based drug and alcohol self-help group. Only three women felt that their drinking was problematic. Most of the women smoke.

Over half the women still use illicit drugs, although most claim to have cut down dramatically. All the women interviewed had in the past used drugs chaotically for long periods, but only a small percentage felt that their current drug use was problematic. Two women said that the only problem was the expense. One woman did not feel her drug use was a problem but felt that others might regard it differently, and another thought that although she was drug dependent it was not a problem for her.

Women were currently using hashish, marihuana, cocaine, ecstasy, speed, methadone, injectable diamorphine and physeptone, diazepam, heroin and crack. The women who have used, or are still heroin users have used for long periods.

Three quarters of the women said heroin was their 'drug of choice', the rest said cocaine. There were two exceptions: one woman reported hash as her drug of choice and another said that speedball (heroin and crack) as hers. Of the 20 women, 16 reported that their preferred method of drug use was injecting, four preferred smoking and snorting. Whatever their favoured method of use was previously, the majority of women still using illicit drugs no longer inject.

All but one woman had disclosed their drug use to a professional worker, for example, a consultant, nurses, or counsellor. However, responses from these professionals were in many cases negative.

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

When asked if they felt that continued drug use and drinking impaired their ability to adhere to their treatment regime, the women's answers were conflicting, ranging from some reporting heavy cocaine use and being able to adhere totally, to others who said that drinking particularly affected adherence. One woman recalled that when she was using heavily she was aware that she might not be able to adhere if she started treatment. She 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.

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

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 and used them according to their own needs. The services used were DDUs, crisis detox centres, rehabilitation centres and NA (Narcotic Anonymous) meetings. A number of women used their own initiative and stopped of their own accord when they felt that their use was out of control. 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 not a government service.







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

Almost all the women felt that they had not directly been given enough information on the use of illicit drugs while taking combination therapy. Although there was often literature in the waiting rooms at their local clinics, 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 I found out more by talking to people that were using than from doctors.

Five of the women had spent time in residential rehabilitation centres since diagnosis. Although in some cases they were not treated badly, they felt that ignorance and lack of experience around HIV meant there was usually no direct or comprehensive support from staff. One woman was faced with the staff-imposed decision 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 had problems with her serving the food at meal times. Some women felt that the facilities did not 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 when staff did not know how to deal with her. On her second visit they were more prepared and were very professional. She was completely happy with their level of support, confidentiality and their medical as well as psychological treatment.

**HIV services** – When the women interviewed were asked what three HIV services they considered most important the responses were: medical services that provide

treatment along with treatment information and monitoring of treatment; complimentary therapies; and peer support where information is exchanged.

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.

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

Although the participants may have shopped around until they found a service that they were comfortable with, it is worth adding that for the majority their HIV clinic was the only service where their needs were met.

There were various reasons for the women not accessing services as frequently as they might have, 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 due to a redirection of funds to ARV treatment and those that are usually only open during the day. Due to long-term HIV survival, many women are just getting on with 'normal living'. However, Silent Voices has exposed the isolation faced by HIV positive drug using women. They reported that present-day services do not support them in their specific needs, and in fact, many expressed feelings of being invisible and discriminated against, even within the HIV community. The majority felt the need for peer support and a meeting space, although many said that meetings need not be as frequent as weekly, and did not have to be formalised.

**Transforming society and services** – After we gathered our material together and analysed it, we developed a list of recommendations. It









is our hope that these will guide policy makers and service providers and lead to a transformation, so that we are treated with empathy and expertise. We hope our recommendations will also help end the misleading labels and blame which too often predominate in our interactions with others. Due to long term living with HIV many women are now just getting on with 'normal living'.

#### Recommendations

#### Post diagnosis:

- Post-test counselling is very important for those who have just been diagnosed – it helps in dealing with the profound and often debilitating issues that often accompany a positive diagnosis. Improved post-test counselling might help avoid adverse effects such as increase in drug use.
- With a positive diagnosis, information should be given regarding all available services, not just what the clinic has to offer.
- Ensuring that alternative therapies are available for everyone living with HIV regardless of drug use status. Given the range of conditions the women reported, it would place less strain on the national health system.
- Develop better pain management strategies for drug users. Pain tolerance among drug users can be very high, so relief dosage should be discussed with the patient on the basis of pain tolerance.
- Offer more support for treatment adherence and in some cases, directly observed therapy (DOT).
- Anti-retrovirals (ARV) should be offered to all, regardless of drug use status.

#### Disclosure:

 Disclosure affected all the participants in every sphere of their life. Realistic information must be made available to the population – to dispel misconceptions about HIV. This will help with the issue of disclosure and also in reducing stigma and discrimination.

- Discussions and training regarding disclosure should be offered to women living with HIV. These can be facilitated by other HIV positive women who can share their experiences of what worked and what did not.
- The media could be instrumental in dispelling misperceptions – ironically ones they have often created within the community.

#### Reproductive and sexual health:

- Improved access to information on sex and sexual health issues, and greater access to treatment for sexually related illnesses are needed.
- More support and information should be made available to HIV positive women seeking to have a child, regardless of drug use status.
- All clinical staff should undergo frequent HIV training.

#### **Drug Services:**

- Specific peer support groups for HIV positive women who are drug users should be encouraged as a way of supporting each other and exchanging information and experiences.
- More information on drug use and its impact on HIV and ARVs should be made available to all drug services clinics and staff.
- Harm reduction should be revisited as a viable treatment option for duallydiagnosed individuals. Additionally, more information about needle sterilisation should be provided
- Rather than participate only in substitution therapies, dually-diagnosed individuals should be encouraged to participate in community programmes, in order to develop life skills which will help in re-integration into their community.

#### **Service Providers:**

- Provide flexible services to cater for different needs.
- Help service users understand what the meaning of long-term HIV survival







- and the psychological impact this has on individuals.
- Help service users understand the affects of different drugs and how their impact on individuals living with HIV.

#### **Support groups:**

- Specific peer support groups should be established for HIV positive women who are drug users. This would lead to greater community participation for this specific group.
- Training and providing information to other support groups and their clients, about the specific needs of drug users who are HIV positive would reduce the discrimination that drug users feel when attending support groups.

#### Prison and other institutions:

- Mandatory HIV awareness training for all prison staff.
- Information regarding HIV has to be made more easily available to the community, and specifically to those working within public institutions so that there is a reduction in HIV discrimination.

#### **Employment:**

- In addition to legislation outlawing discrimination against people living with HIV, employers should be encouraged to support their workers by offering alternatives such as part-time jobs, job-share, and 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 want to start work or stop working due to illnesses. They should also actively assist those living with HIV 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.

#### Research:

- Further research on the health issues of those living long-term with HIV, Hepatitis C co-infection and drug use.
- More research on treatment for those also living with Hepatitis C. Especially with individuals with genotype type 1 and 4, who are less likely to respond to current treatment.
- More research on the long-term effects ARV treatment.
- Further research on the pharmacokinetic effects of substance abuse on ARV treatment.
- Finally, more research on the benefits of prescribed marihuana in alleviating the side effects of ARV medication and conditions associated with HIV, such as peripheral neuropathy.









ICW Vision Paper 6 on HIV positive women and drug and alcohol use (2007) is the latest in the ICW series of Vision Papers. They are all for HIV positive members and our supporters to use when advocating and organising around key issues and ICW's visions, aims, and objectives. They are meant as an aid to your own work and can be used creatively. ICW welcomes your feedback and evaluation of its vision papers. Please tell us how you have been able to use them. We'd love to hear

This Vision Paper on HIV positive women and drug and alcohol use is one of six ICW Vision Papers. The other five outline ICW's position on: access to care and treatment; participation and policy making; gender equity and poverty; human rights; and HIV positive young women. All Vision Papers are available in English, Spanish and French. Vision Paper 6 is also available in Russian.

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The International Community of Women Living with HIV/AIDS (ICW), a registered UK charity, is the only international network run for and by HIV positive women. ICW was founded in response to the desperate lack of support, information and services available to women living with HIV worldwide and the need for these women to have influence and input on policy development.

All HIV positive women can join ICW for free. Just contact us at:

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