

UK-CAB 65: BHIVA/BASHH feedback; Treatment as/for prevention



Undetectable viral load = Untransmittable
HIV & Women

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Number of women living with HIV in the UK

- Women are significantly affected by HIV in the UK
- In 2016, a total of 28,479 women were living with HIV and receiving care
- Women make up 31% of all people living with HIV in the UK
- Almost a quarter (24%) of new HIV diagnoses were in women

Recent research – Invisible No Longer

- High levels of poor mental health and unmet need among women living with HIV. Almost all women in workshops had mental health issues and 42% in experiences survey had a mental health diagnosis since being diagnosed with HIV .
- Nearly a third (31%) of women had avoided or delayed attending healthcare (including HIV services) in the past year due to worries about how they would be treated because of their HIV status.
- Over half (58%) of women in Experiences survey had experienced some form of violence or abuse including violence due to their HIV status.
- One in three (33%) women were satisfied with their sex life and 40% not satisfied
- Many women living with HIV in Experiences workshops had issues with intimacy, fear of sexual relations, and low libido.
- (42%) felt that HIV had affected the decisions they made on whether to have children.

Invisible No Longer-more results

- Of 53, (32%) felt their immigration process and/or immigration status had affected their ability to manage HIV.
- Nearly half (45%) of women in Experiences survey were living below the poverty line.
- Women felt HIV acts as a barrier to employment. Fears around confidentiality and telling employers that they are living with HIV. For some women HIV affected their confidence regarding their careers.
- Women who are in relationships with partners who have HIV worry about HIV transmission. They often feel invisible in the response to HIV in the UK and ignored or not taken seriously by healthcare staff.
- Average levels of knowledge of TasP and U=U among women in Prevention survey: 66% of women had heard of U=U and 63% had heard about TasP.
- Knowledge was higher among women living with HIV- 96%.

Invisible No Longer is asking for ...

- Gender parity in the UK HIV response, ensuring equitable investment, priority and attention to women in HIV prevention, research, data and services.
- Ensure that HIV research addresses specific knowledge gaps around HIV and women and supports the full participation and meaningful involvement of women.
- Prioritise reducing late diagnosis of HIV among women, better explore the use of innovative HIV testing approaches, and improve rates of HIV test offers and uptake in different settings.
- Improve data collection and disaggregation on HIV and women, ensure local level data is available, and include sexuality data for women in national reporting.
- Invest in HIV support services that meet women's needs holistically and enable women to not just live well but to thrive, including peer support and support for mental health and gender-based violence.

U=U and Women, I asked a women's program from PositivelyUK

confident
Assurance community
Equality I am equal to you
Relaxed about my situation
I can explain to family My health is now protected
Give advice Evidence against criminalization Here to stay Safe
Relief that I cant transmit HIV to my partner knowledge is power
There is a better chance to be with negative people Enjoy I am empowered
Powerful and in control of my sexual life Relaxed mind
Comfortable Educate others more information is less stigma
not disclosing my own status Pleased
I can lift my head up high
Not be blamed for transmission

U=U and Women - I also asked my network of women living with HIV some questions



What does U=U mean to you as a woman living with HIV?

- Peace of mind , Confidence to live my life, knowing I cant pass it on.
- Confidence, ready to move on, I can now be on TV etc.
- No more being tense, scared for another person's safety, in case of an accident my partner will be safe.
- Regular testing for both partners is important to stay safe
- It is important to remain undetectable to not pass the virus (how do we ensure that happens for individuals)
- A spike can happen so still use protection although in truth there is little, to no chance of transmission to someone.
- Pay attention to my body to recognize side effects or stress



U=U as a woman living with HIV

“I don’t need to panic if there is no condom available because I know I am no risk to the other person.

I am free to have more children if I could and free to breast feed them if I wanted to and expect to be supported by Health care professionals.

My life is a notch up from the normal it was, basically like any other woman”

How does U=U work in your everyday life as a woman living with HIV ?

- helps me have a chance to enjoy my relationships. Don't have to disclose now
- If I decide to tell a potential partner about my status, being able to say with confidence that I am uninfected, makes that conversation easier for me.
- Gives me confidence to reassure women who want to have babies that it is possible to have an HIV free baby.
- Very little as all my close friends are aware of my HIV status . I have not told my family because they are miles away .
- Great for young people who had given up hope of marriage due to living with HIV.
- Peace with no marital rules of where are you, who are you going with, etc. I want to enjoy my coming of age with no strings attached
- As a woman living with HIV, I make sure when having sex I use a condom to protect my self from the STD's.

U=U everyday life as a woman living with HIV

“Its become normal at least to our community. Its not something I think about everyday .

The only time I think about it is when I have to take my medication but even then, I am on auto-pilot because I am taking lots of other medication so its not like okay now I am taking my HIV Meds.

It means I can live my life happily and freely, but not completely free yet because we still have work to do around stigma ”

U=U, what do you want to see change

- More information and awareness about U=U to both women living with HIV and the public in general. Everyone to know.
- Stigma, we need outreach in different areas of London.
- Discussion everywhere including clinics as some don't talk about this to their patients.
- The public to be notified of the change of circumstances in living with HIV and for us to move on with our lives freely with caution as usual ,loving ourselves.
- Stigma and discrimination because everything from a medical and scientific point of view is going okay, not perfect but okay. What I would like to see change, is the social aspect of it.
- Support to comply with medication and to achieve a better quality of life.

U=U ,what do you want to see change

“it would be wonderful if it was socially acceptable,

but the fear factor is still there and the stereotypes haven't really changed,

a lot of people who are living with HIV still feel shame and cannot share there experiences.”

U=U, who can make the change happen ?

- We can make the change, also media and health care professionals.
- All of us stakeholders should actively be involved in making the change
- Individuals who can confidently speak about U=U to others; organizations who work with people living with HIV including Sexual Health Clinics; HIV clinicians; pharmaceuticals; the NHS...
- Maybe a more effective advertising campaign , but we all need to be a bit more out there with it.
- The only people who can really make change are ourselves by being brave and being open about our status.
- It is up to us to voice up for our freedom. How can we expect change if we don't act on it? Let's join hands and speak out .We are survivors of a great war of life.
- Knowledgeable health and social care professionals and sustainable peer support ,working in partnership

U=U, who can make the change happen ?

"I don't know who can make the change because as People living with HIV, we have tried we haven't stopped . We are still carrying on. We don't know why intolerance to HIV is high in the UK even though we are going forward scientifically so that's a bit confusing, obviously there are social dynamics.

It is all very political , politicians have work to do. It is the policy makers that need to do the work, put something in place that will educate the average person because they are the major contributing factor to this discrimination.

The stigma thing, the whole testing process, how they test people eg. who they think is at risk, they ask all kinds of questions about why a woman has volunteered to test for HIV, whether she is gay, a drug user etc. Is all that necessary?

If you are just a human being having unprotected sex or any sex at all there shouldn't be any further questions to ask .

So it's the attitudes but it's the policies that will inevitably change peoples attitudes , it's a tricky one"

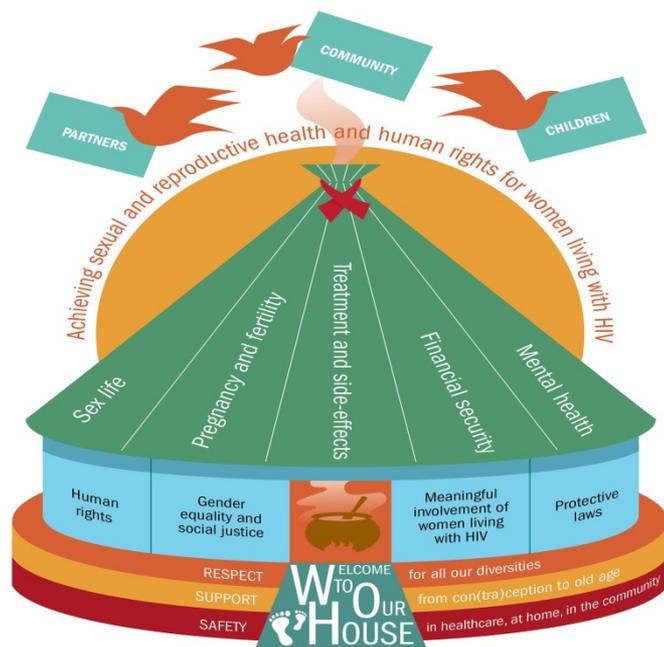
Now we have U=U, What is outstanding?

- How about unequal power dynamics? women's agency over their lives and gender based violence?
- What next for Breastfeeding?
- What next for women's sexual health and prevention?
- What next for wellbeing and quality of life? After Undetectable? 4th 90?

Intersectionality of women's lives and how to empower with U=U



U=U for women is about upholding the Sexual and Reproductive Health and Human Rights of Women living with HIV



Building a Safe House on Firm Ground: report of Global Survey on Sexual and Reproductive Health and Human Rights of women living with HIV

Acknowledgement and thanks

- PositivelyUK women's program.
- All the women living with HIV who directly contributed to the presentation.
- All the women and healthcare professionals we interact with everyday that give us the insight that informs our work and so have contributed indirectly.
- UKCAB for inviting me 😊

References

- [Ibase :http://i-base.info/htb/32308](http://i-base.info/htb/32308)
- [Sophia Forum:](#)
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- [PositivelyUK: http://positivelyuk.org/women/](http://positivelyuk.org/women/)
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- [Salamander Trust: http://salamandertrust.net/?s=building+a+safehouse](http://salamandertrust.net/?s=building+a+safehouse)