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Witness Seminar

## Women and HIV in the UK

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Edited by Emily Jay Nicholls and  
Marsha Rosengarten

The witness seminar is part of a series convened by Emily Jay Nicholls and Marsha Rosengarten, Centre for Invention and Social Process (CISP), Goldsmiths, University of London.

The series forms a component of research within “Disentangling European HIV/AIDS Policies: Activism, Citizenship and Health” (EUROPACH), a collaboration between four European universities – Humboldt-Universität zu Berlin (Institute for European Ethnology), Goldsmiths, University of London (Department of Sociology), University of Basel (Department of History) and Jagiellonian University (Institute of Sociology).

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**ABBREVIATIONS**

BASHH	British Association for Sexual Health and HIV
BHIVA	British HIV Association
CD4	CD4 count is taken as an indicator of the strength of the immune system
SRHR	Sexual and Reproductive Health and Rights
ICW	International Community of Women Living with HIV
GNP+	Global Network of People Living with HIV
SWIFT	Supporting Women with HIV Information Network
PRIME	Positive tRansItions through the Menopause
THT	Terrence Higgins Trust
U=U	Undetectable = Untransmittable
UK-CAB	UK Community Advisory Board
WHO	World Health Organisation

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### **BACKGROUND TO THE WITNESS SEMINAR SERIES**

As convenors of the seminar and editors of this text, we would like to offer some background to our decision to conduct witness seminars aimed at enhancing historical understandings of the HIV/AIDS epidemic in the UK. Included in this background is an account of how they were organised and who we approached to participate.

This witness seminar, ‘Women and HIV in the UK’ was the first in the series for the UK component of ‘Disentangling European HIV/AIDS Policies: Activism, Citizenship and Health’ (EUROPACH), funded by the Humanities in the European Research Area (HERA).

Our decision to employ the mode of a ‘witness seminar’ was inspired, in part, by a meeting with the Advisory Committee that we assembled for the UK research. We had intended to use this meeting as an opportunity to present the project and our work so far to advisory committee members and to ask for advice and feedback. However, what emerged was not a simple two-way dialogue where we asked for advice and they gave it, but instead a space in which all of the members of our advisory committee drew on their experiences and expertise, bounced off one another, and told us far more than we might ever have thought to ask them.

One of us had already consulted some of the witness seminar transcripts produced by the History of Modern Biomedicine Research Group based at Queen Mary, University of London and available through the Wellcome Library. What was immediately apparent in these transcripts was their ability to capture both technical and specialist knowledge about particular health issues, but also that the issues were made readable and comprehensible to someone with little knowledge of the topic at hand. Although our witness seminars take a different format, we hope similarly that the resulting texts will shed light on some of the complexities of the history of HIV/AIDS.

Having already considered the possibility of using the method ourselves and then being part of the lively space that emerged in our advisory committee meeting, we decided to hold the witness seminars in order to provide a history or, rather, histories of the UK HIV/AIDS epidemic, reflective of different perspectives, tensions and personal experiences. The resulting text from this seminar sits alongside oral history interviews undertaken as part of the EUROPACH project and other witness seminars undertaken during the course of our research. By contrast with the personal narratives provided by our one-to-one interviews, we have sought to create a space in which people from different backgrounds and with different experiences of the epidemic could come together and tell their stories in conversation with others. As such, the personal narrative

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is still present within the witness seminar transcripts, but this is in conversation with others' experiences and has thus resulted in a mode of collective retelling.

Although we were inspired by the witness seminar transcripts we had already consulted, we decided to undertake this work in a manner attuned to our prior familiarity with the HIV epidemic and the manner in which many of those invited were well-versed in discussion about historical dimensions of the epidemic. The more conventional witness seminar design often asks participants to prepare presentations in advance. Bearing in mind our participants' experience in collaborative discussions and conscious that those we had invited would be better placed to decide on what was relevant, we did not specify any prior preparation. Nor did we ask for any style of presentation. In sum, we prioritised cultivating an open forum where a dialogue would emerge between participants who in some cases were already familiar with each other and in other cases not. Nevertheless, it was necessary to provide a starting point and for this reason we circulated a list of topics for possible discussion a couple of weeks before the meeting (see Appendix).

### **SEMINAR INFORMATION**

Some of the participants in this witness seminar were already known to us through our own engagements in HIV and our knowledge of their contribution, while others were invited on the recommendation of those we had already approached. As mentioned above, we circulated a list of proposed topics for discussion a couple of weeks before the seminar, but made clear that we would welcome diversions from this list.

The seminar *Women and HIV in the UK* was held in International Hall in London on 4<sup>th</sup> June 2018 and was scheduled to run for two hours. During the seminar, audio recordings were made, which were then transcribed and edited in order to enable a clear reading of the text. Footnotes were then added and the text was circulated to participants with an invitation to further edit, redact or expand on their contributions. All participants signed consent forms agreeing to make the final transcript available for public viewing once they had been given the opportunity to edit or redact their contributions.

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**WOMEN AND HIV IN THE UK**

*This witness seminar brought together women living with HIV, activists, clinicians and academics – with most participants inhabiting more than one of these categories – in order to discuss the history of women’s activism and experiences of living with HIV. What was particularly striking in this discussion was the way in which personal experiences and broader political issues were brought into conversation with one another, but also the ways in which the discussion was attuned to other issues pertinent to the needs and experiences of women living with HIV. That is to say, not only did participants engage with policy and programming through their own experiences, but so too did they situate HIV within a broader political context, keeping in mind the effects of, for example, poverty or migration on living with HIV.*

*In discussing the early days of activism, participants described the kinds of peer-support available for women, but also the ways in which these responses could sometimes result in a feeling of shouldering a considerable amount of labour. While stressing the enduring struggle for visibility and for a place from which to speak and make demands, participants also reflected on the weight of speaking out, especially in contexts where the support for speakers was deemed to be inadequate, or quite simply not available. Participants reflected on the necessity of including women in research and programming, and the changes which have occurred – albeit some only quite recently – in these practices, as well as the importance of ensuring that the work that is asked of women living with HIV in these endeavours is adequately acknowledged. Moreover, participants highlighted the ongoing issues facing women living with HIV and the necessity for a medical practice which responds to and accounts for pleasure, as well as future considerations with regards to care.*

*The seminar began with a brief description of the project and the purpose and process of the witness seminar. Participants were then invited to introduce themselves and describe their first engagements with HIV.*

**Emily Nicholls:** I started researching HIV as part of my masters research, which looked at the history of the HIV antibody test and how its role in the epidemic has changed, and I then went on to do my PhD in Visual Sociology where I followed the making of an archive of HIV. I asked questions about experience and expertise and, really, the incorporation of personal experiences of HIV within the archive, and its relationship with archival practice. Now I'm working on this project as the UK researcher and looking at how the history of HIV is mobilised in current policy and activism.

**Jacqui Stevenson:** I am a PhD candidate at the University of Greenwich, and my thesis is looking at women's experiences of ageing with HIV. I'm also a trustee for the Sophia Forum which is the UK's only women and HIV organisation, and I've worked for the ATHENA initiative which works on gender equality in HIV globally. I suppose my first involvement was as a volunteer at the Mildmay Mission Hospital in the patient befriending service. I then did my Masters in Human Rights and focused on HIV, and during that I met Liz Tremlett<sup>1</sup> who you will all know and then Alice Welbourn<sup>2</sup>, and became an intern for Sophia forum, so that's how I got involved.

**Shema Tariq:** I'm a consultant HIV physician at Mortimer Market Centre which is around the corner, and medical anthropologist and public health academic. I have been working in HIV since 2003 as a doctor, and for the past ten years I have been conducting research in HIV, primarily focusing on HIV and women. My PhD was on HIV and pregnancy, all my postdoctoral research has really focused on HIV and ageing in women, and I currently lead a large study called PRIME (Positive Transitions through the Menopause)<sup>3</sup> which looks at the menopause in women living with HIV, and I have a big interest in the representation of women in HIV research.

**Angelina Namiba:** My name is Angelina Namiba and my first encounter with HIV was much more personal, it was my brother's diagnosis in the early 90's, just pre- the treatment era, and going through his illness. But then also my own diagnosis and then losing friends, and then I

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<sup>1</sup> Tremlett is former chair of the UK board of the International Community of Women Living with HIV (ICW); and later became the International Coordinator of the People Living with HIV Stigma Index.

<sup>2</sup> Welbourn is the former international chair of the International Community of Women Living with HIV (ICW); a co-founder and Sophia Forum; and the Founding Director and Chair of Trustees at the Salamander Trust.

<sup>3</sup> PRIME is a three year qualitative and quantitative study based at University College London's Institute for Global Health and funded by the National Institute for Health Research (NIHR).

actually started getting involved with HIV properly when I decided to work for Positively Women. Working for Positively Women was very significant because it is one of those organisations that was started in 1987 by two women living with HIV at a time when there was nothing available for women. And so for me, working for an organisation like that is really important, after I had learnt to cope with my own diagnosis.

**Yvonne Gilleece:** I'm a consultant in HIV working in Brighton. I've been a consultant there since 2005, and I also work with Shema Tariq on the BHIVA pregnancy guidelines for women living with HIV. I'm also a chair of SWIFT (Supporting Women with HIV Information Network), which is a group of individuals, women living with HIV, medics, academics and carers of people living with HIV looking at HIV research and trying to develop that, from the start has community representation involved in the design of studies. PRIME was the first time that we (Shema and I) worked together actually, as part of SWIFT.

I first started working in HIV in '95, it was part of my general medical rotation at King's College Hospital. I wanted to be a gastroenterologist and hepatologist specifically, and I was doing my membership, did an HIV job and just thought, "What am I doing? This is what I want to do." So, I came in pre- good treatment, so I saw things before we had very good treatment, and then luckily good treatment came along, so I have been in it a very long time. I worked out the number of years I have been working in HIV and it's been 23 years, which is a very long time actually. I feel very strongly that it's very much the case that we will move things forward because of the work of medics and pharma, but also that collaboration with the community is necessary to change things, and I think that's why it's changed more than any other disease entity in medicine.

**Winnie Sseruma:** I first started being really engaged with HIV with my own diagnosis in 1988, and that's when I started to really understand what HIV was and to then go on to try and support others living with HIV. However, my work, whether that was volunteer work, whether that was paid work, that didn't really begin until I moved to the UK in 1996.

I was diagnosed in North America and I left North America to go back to Uganda, and then moved from Uganda to the UK. In 1996 when I arrived in the UK, a lot of people were dying, especially from the African communities, and there was a move to set up a policy organisation to make sure that the work that was being done on the ground was actually embedded in policy work. So I found that at that particular time, a lot of services were not set up to accommodate women and children, and the majority of women were black Africans, and the majority of

children were black Africans too. So, I engaged at that level and started to work with people who were actually trying to set up this policy organisation, which eventually became the African HIV Policy Network, and at some point I chaired it, and I will leave it there.

**Marsha Rosengarten:** I'm a Professor of Sociology at Goldsmiths, and I have worked on HIV since the late 1980's-early 1990s'. I began in Australia at the HIV Social Research Centre, UNSW and moved to the UK in 2001. My research has mostly focused on how biomedical technologies have changed the epidemic, more specifically, how gay men's sexual practices have changed, but also how medical practice changed with antiretrovirals from forms of palliative care to complex negotiations of drug technologies and their early side-effects. In 2008, I started following the development of PrEP (HIV Pre-Exposure Prophylaxis) after the controversial trials in Cambodia and Cameroon, and I have watched a shift in people's attitude from something that was a, "No-no, why would people want to take anti-HIV drugs if they are not positive?" to strong advocacy for and that WHO has endorsed.

**Jo Manchester:** I was diagnosed in 1986 after being tested without my knowledge or consent by a gynae consultant.

I was diagnosed very early on when there was nothing, there wasn't any counselling, there wasn't any support, there wasn't any information. So later I went away, I did a year overseas to West Africa as part of my degree, and that was '86 to '87, so I came back in '87, just after Positively Women had started, so I got involved, and I met Jane Shepherd. By that point I was living outside London and for me there's always been London and then the rest of the country, and that's still very much the case. So, I'd come to London to find women and talk and be amongst people who understood, and then I would go back to the wilderness where even doctors had no idea what to do with you.

So, I was a member of Positively Women, and I started doing talks, the ones with the midwives and the nurses and the prison officers and the schoolchildren and the policeman, all that kind of thing. So, I started talking about myself which was quite cathartic, but also very strange, and then I got a job as a teacher, and then I lost my job as a teacher because the staff found out about my status and wouldn't work with me anymore. So that was all a bit distressing too, and at that point I applied to go to the conference in Amsterdam<sup>4</sup> where a group of Dutch women had organised a pre-conference to bring women from all over the world together. So I was one

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<sup>4</sup> VIII International AIDS Conference, July 1992

of those women at the pre-conference, and that's when we formed the International Community of Women Living with HIV (ICW). That's when I really found my voice because then it wasn't just my voice anymore, it wasn't just about me, it was about hearing all these experiences of other women from around the world. It made me feel that actually, I am the lucky one, and it really made me realise quite how privileged I was and put everything into context. Being able to talk about issues rather than with myself was really important. So at that point I became very open and active, and I was with ICW for quite a long time. Then I left to do my Masters and paid work. Anyway, now I have two children, I live outside London again, and so I am a little bit back in the closet again, because I'm living a family home life and I am doing other kinds of work now, so I'm half in and half out. But I am going to Amsterdam<sup>5</sup> and really looking forward to reuniting with the ICW women that can get back together there. So, I am on the verge of launching myself back in.

**Jane Shepherd:** I am Jane Shepherd and I was diagnosed in 1990 in the UK in London, and the first thing I did, the day after my diagnosis, I went to Positively Women, so that's where mine and Jo's paths first crossed. I got very involved immediately, I wanted to challenge the stigma, I wanted to live openly, that was my activism. But then I went back to Zimbabwe where I was working and I found it incredibly difficult. It felt inappropriate, to be honest, being asked to set up support groups in townships, it just wasn't working out for me in particular. I went back in the closet really, and I decided that my act of resistance would be to have a career and to do the thing that I've always wanted to do, so I became a graphic designer and then, eventually, I came back to the HIV field as a graphic designer. So that was my form of advocacy, but that felt rather unsatisfactory because you are always in the background, and I just wanted to be more visible and to have more of a voice and tell my own story, be part of the bigger story.

So I started to become more active in the UK Community Advisory Board (UK-CAB), in treatment advocacy. I'm very interested in looking into the life histories of women living with HIV and looking at how we construct our narratives, how we tell our stories and how that has changed over the arc of the epidemic. So that's the point that I'm at now, prepared to give it all up to do a PhD. That would be my final fling [laughter] I would be an academic, but then I also want to be an artist, so I've still got to fit that in.

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<sup>5</sup> 22<sup>nd</sup> International AIDS Conference, July 2018

**Corinne Squire:** I'm Corinne Squire, I'm a Professor of Social Sciences at the University of East London (UEL) and I'm also part of the Centre for Narrative Research. I first became involved in HIV when a friend of mine was diagnosed in the mid-80's, somebody called Stuart Marshall who was a filmmaker, and we were working together. Few of us knew anything about HIV. Then another friend I was in the Communist Party with called Mark Ashton who was part of the film *Pride*, became diagnosed then became ill and died very quickly.

After that, I got involved with Terrence Higgins Trust (THT) as part of the community education programme, and subsequently I was working in the US, so I became involved with similar HIV NGOs there, especially the Hyacinth Foundation that worked with support groups in Trenton and Jersey City. And what was really interesting and inspiring about that was that people were from really different US backgrounds and were all working together, so it was a really strong coalitional politics. And then I was involved a little bit with ACT UP in the US in the late 80's, particularly with the ACT UP women's group which had some interesting initiatives, some of them were actually quite in conflict with the initiatives of HIV positive African American women at the time. So, out of that I edited a book about women and HIV and psychological issues, and then started to do some research when I came back to the UK, particularly because I was really interested in how people were managing to work together so positively. So I did some research, mainly with people from Positively Women and Body Positive at that time, looking at how they were using and making support for themselves. I've continued that work, sometimes with the same people. I started in '93, and there's been five interview rounds with some of the same people, and that's across the UK.

Partly because my partner is South African, I spend quite a lot of time in South Africa, so I did some similar work in South Africa in 2001. That was quite useful because there wasn't really that much at that time, so people were really speaking at that point directly to the archive. They said to me, "We want this in an archive," and they were horrified by the idea of the research ethics requirements for the erasure of data. So, we archived some of that stuff in an African Studies archive in Cape Town, and a couple of books came out of that. I've gone back a couple of times to those people too, to talk to them again about the changing picture of what's happening.

More recently, some people at UEL and myself, and a few other people, along with a lot of fairly small community organisations, particularly in London, started something called the HIV Psychosocial Network to try and bring together people's research, organisations' research, so it didn't get lost in reports and cupboards. Sometimes, when you've done a report for your

fundings, the data just goes in a cupboard and nobody remembers it. So, now we're doing an Austerity Audit around HIV services. The other HIV research I am involved with now is about resources issues around the epidemic and how those are neglected in relation to medical issues.

**Emily:** As you will have seen, I've circulated a list of proposed topics for discussion, and I think I said this already, but we're really happy for the discussion to go in whatever direction everyone in the room wants it to go into, so if there's anything that we've missed off then please do raise it. But I wondered if maybe we could start at the beginning of the list, and talk about the early activism. A few people have mentioned Positively Women already, and maybe we could begin by talking about what some of the early organisations were involved in doing, as a place to push off from?

**Jo:** Positively Women was really all about peer support when it was first founded. It was just a lifeline for women to be able to come together and talk to other women who understood what they were talking about. Often, if you went to a support group that was predominantly men, they were great and very supportive but you couldn't really talk about your issues, like your relationships or having kids, all of that. Out of that peer support, I think an activism grew very slowly. I don't have the impression that it started as an activist organisation, I think the activism grew out of an anger, actually. Because I think when you first get involved there's the stigma of HIV, which was so massive that, even though there was no reason to feel any guilt or shame, everybody did. So it was when you finally met other women then you actually could let go of that. And then, you just start feeling angry, and then I think out of anger the activism comes.

So Positively Women started getting more involved in talking. Sheila was always angry, do you remember Sheila<sup>6</sup>? She just used to rant brilliantly, and she just completely told it as she saw it, and she didn't put up with anything. Diana Princess of Wales went there and all the health secretaries and everything, well she just told them exactly what women needed, what women were getting. But on a larger scale, I guess it was then linking with the other organisations, so THT, National AIDS Trust and Body Positive coming together to create an activism I guess.

**Jane:** I was thinking also about the other organisations in the 90s. There was the Landmark, which was very much the model of support that we had, and that we've ended up with decades later. The model of: you provide meals and washing facilities, and counselling and all those things, but you weren't actually actively engaged in designing those services or having a voice

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<sup>6</sup> Sheila was a co-founder of Positively Women

in them, or in any other advocacy work. It was very much quite a passive model of support. It's interesting that Positively Women didn't go that route, I don't know why we didn't end up with laundry facilities and therapy rooms and...

**Angelina:** I guess I got involved with Positively Women in 1996. That was just three years after my diagnosis, and as I said before, I just felt that I had done my degree, I was working as an information officer for the Department of Health ironically enough, and I couldn't even tell personnel that I was HIV positive. So I moved hospitals from the Royal Free to Paddington because our office was right next to Paddington. But anyway, after I had worked there for a few years and I got into contact with Positively Women. My first encounter with them was very much about... They used to have a 'relax and restore' day for women, and in those days it was really important to have something that made women feel like women again, because there wasn't much around and a lot of women felt that because of having a diagnosis they were less of a woman, they were not worthy etc. So, they used to do these pampers days, and I remember going there as a volunteer to plait the hair of some of the women. I just thought, you know what, I really like this and I need to be doing it properly.

So when they advertised for a job I applied, and what kind of struck with me with that, is also how much things have changed. In those days, a lot of women who I had seen at Positively Women were white women, there were very few African women and it was even hard to get them in. I went in with a colleague of mine, we were employed as the first African women's support workers, because I wanted to try and get in more African women to the services, because they really weren't accessing services yet and there were a lot of them being diagnosed in hospitals. And so when I started working there, like you were saying, it was very much about the peer support, we weren't doing a lot of activism as such, it was just about surviving, I think. Making sure that women were getting what they needed and they weren't feeling isolated or stigmatised against. But one of the things I loved earlier on about Positively Women was the fact that they were trying, as you said, and I wrote that down Jane, they wanted to make sure that we were having our voices as women living with HIV heard.

One of the things was the lack of speakers who were open about their status. When we used to go into schools, and when I started off, I was just like, "Oh, absolutely no way I would ever, ever be out there speaking." And I remember we used to have a magazine, I still have all the archive copies, and that magazine used to ask us to write about our stories. I wrote a bit because I like writing, and the first article I wrote was under the name of 'Angie' so there's absolutely no way that you would recognise that it was me. And the next one I wrote was as 'Angelina'

and the next one I put my full name in, and then by I think the fifth magazine that I contributed to I was on the cover [laughter]. But it was a process, because I used to go around with one of the speakers to schools, and I remember going with her to a clinic and she did a talk, and I felt really inspired by her and I thought, you know what, we really ought to be telling more of our stories, getting our voices heard.

So then I decided to become a diplomatic activist, as opposed to a very angry one. Because it's really important, activism is so important in this field, but then we also need to make sure that the points we are trying to make are actually heard by the decision makers. So, you need the angry activist, like the ACT UP people, all those people who'd shout at and demand the things which we need, but you also need the diplomatic ones who can be heard, if you know what I mean. Because sometimes it's very difficult to engage with someone, you end up being really angry, but actually we are saying the same things. We are using what they are saying to actually make sure we have the ears of the people who do... So that's what I do now. But I think for me one of the things about Positively Women is the tenacity of the two women who started the organisation, Sheila and Jayne, and then subsequently joined by the others. For them to persevere in that climate and to reach a place where the organisation is a national one, I think is just amazing. But we must never forget that without those two women a lot of us wouldn't actually... I know I wouldn't be here or being as open as I am about my status.

**Winnie:** Just to almost tailgate on what you are saying, when I arrived in the UK in 1996, I had already been diagnosed about eight years before that, but I had lived in North America, where I had to pay for my own treatment, and had already been on monotherapy, then dual therapy, and I was like, "I have had enough," and then was in Uganda. Basically, I just wanted to disappear, and I thought there was nothing else. Coming to the UK was really just like a holiday, just to make a decision, basically, on whether I wanted to live or die. It's really interesting how that manifested itself, because I first went for a check-up and then of course my immune system was shot. I had one CD4 count<sup>7</sup>, and I was just literally on my last legs. But I told the doctors that I am here just to holiday, I can't start treatment, and it wasn't until I went to Body and Soul, and saw a lot of women, many of them were African women, many of them were from Uganda where I am from, and I just sat at the back and listened to them, and I thought, "Wow, I want to be like these women."

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<sup>7</sup> CD4 count is taken as an indicator of the strength of the immune system.

They were talking about having been really ill, and then literally resurrected with their combination therapy, and now they were taking it and I thought “Wow wow wow!” And so after that I volunteered with Body and Soul and wrote about my experiences before I arrived in the UK. But one of the organisations that I joined was the UK Coalition of People Living with HIV, and it was mainly a gay organisation, and I think there was one black woman who was working for it, she is still my friend, she is going back to Zambia, she still lives there. I used to sit in meetings and think, “What am I doing here?” Then within the UK Coalition of People Living with HIV there was another one called European Coalition of Positive People. It was a European organisation led by a guy called Colin Webb, and so we got talking because he had been in the army in Africa and all sorts of different things. So I started working for this particular organisation, and there was one particular moment that was a big moment for me. I was sent to the US with the guy that started the UK Coalition for People Living with HIV, John Campbell, he is now not with us anymore. I went with John, we did a ten day trip of the US, of ACT UP organisations, going to meetings, ACT UP from New York, Philadelphia, San Francisco, Washington DC, we just went to ACT UP meetings, and I thought, “Wow wow wow,” and for me that was really significant.

However, what I noticed in those meetings is that there were very few women, and when they spoke, I don’t think they were very well heard in those meetings, and from that trip I came back to the UK having literally been bitten by the activists, the way I thought about it, angry bug, and I said to *Positive Nation*, “I want to be on the cover!” [laughter]. And it was something that I debated very much with Graham McKerrow, who was the editor at that particular point, and he was saying, “This is going to be big, are you sure?” And I said, “Yeah, I am sure.” So, I became, I think I was the first African woman to be on the cover of *Positive Nation*, and the title was, “Don’t mess with Winnie” [laughter], and within the article I think both Graham and I were just so anxious about what the response would be, but the response was phenomenal, it was really encouraging, it was great. And from there I just have never shut up, still here.

**Jo:** I was very stuck in the 80’s when I was talking before, so I need to move forward a little bit. I am just thinking about the beginning of ICW and how it all started. So, as Jane said, when people organised things for women it was mainly to come together and for peer support. At the pre-conference, they had organised all these movement sessions and massage and things, and after a day the women were just asking, “What are we doing? We need to get active and we need to make an impact on that conference, and we need to speak.” And so the facilitators were very upset, there were a lot of tears, because we weren’t following their agenda. But we created

our own agenda, there were 57 positive women there and we spent a day where we brainstormed what women with HIV need. We had it all on flip chart paper, and we had over 120 bullet points around the room of what women need. A small group of women went off to negotiate with Jonathan Mann to get involved in some way with the conference, he was the president of the International AIDS Society at the time.

They went along and negotiated with Jonathan Mann for positive women to have a presence at the conference, and then we thought, “Okay, we’ve got 120 things, we need to boil them down.” So we spent two days, just condensing these stories and issues down into the 12 statements which became ICW’s 12 statements<sup>8</sup>, and I think it was a really incredible piece of work, because we took everybody into account, whichever country people came from they were represented there in those 12 statements. There was one, the very last one, number 12 was about the definition of AIDS, which to people in the UK was very strange, but the for the American women, you couldn’t get Medicare unless you had a diagnosis of AIDS. So women were dying much earlier than men because they weren’t getting diagnosed with AIDS. So when those American women went back to America, and really started lobbying the CDC, the definition was then changed to a CD4 count less than 200. I do believe that was really those women finding their voices and joining forces with people like ACT UP to really lobby on that issue. But apart from that one, I would say all the other 11 are still completely relevant today, and I am really proud of being part of that.

So when we came back, after the conference, I had lost my job so I was free, and Kate Thomson<sup>9</sup> had just left Positively Women. So Kate and I set up the ICW coordinating office, initially it was a network of activists. All the women that were involved were open about their status and they wanted to set up stuff in their own countries. Kate had shared what Positively Women had done in the UK, so people went back to Uganda, to Zimbabwe, to New Zealand, Australia, Mexico, Argentina, and set up mini-Positively Women, communities of women in their place. And so from that point I guess my activism grew and I became more interested in the international scene really. John Campbell invited me to join the steering group of the UK Coalition of People Living with HIV, so I was there on the steering group when it first started. I did move away from UK AIDS politics a bit, because I felt there were just so many issues that

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<sup>8</sup> The 12 Statements can be viewed on ICW’s website: <http://www.icwglobal.org/our-organization/history>

<sup>9</sup> Thomson had helped to establish Positively Women and later went on to become Head of the Critical Enablers and Civil Society Hub at The Global Fund.

were so pressing globally. At ICW we were basically trying to get positive women from all regions to attend conferences and meetings and to be speaking for themselves. But it did come out of that peer support, it was that amazing sense of actually taking control. And then at the opening ceremony of the Conference in Amsterdam, ICW women stood on the stage and Isabel from Belgium read out the 12 statements, and it caused a huge impact on the conference in 1992.

**Corinne:** I just wanted to say that I think that during that period, it was probably less remarked on than it should have been, but there were a lot of women tackling their doctors in very activist ways. I remember groups of women who would say to me, “We went and occupied our doctor’s office, and we insisted on this and this,” and that was quite powerful, for doctors’ offices to be occupied by groups of often African-origin women who would just sit there and say, “This is not acceptable, we require better treatment from you and a more respectful approach.” I think often they reported that they did get good results from this. Some of those women are still around, and I think it was very important for those key consultants, there were a few consultants who dealt with an awful lot of people at this time, to be tackled by the women.

**Shema:** I was going to say, I think that tradition still holds true now, and if you look at the history, I don’t know if you agree Yvonne, if you look at the history of the management of women living with HIV, a lot of our advances have been pushed by women living with HIV. So if we’re thinking about vaginal deliveries in the context of HIV, it was really women who were pushing to try and have vaginal deliveries, and recently with the idea of breastfeeding in the context of HIV. I guess most recently, we have been writing the pregnancy guidelines, there’s a change in language that we use when we’re talking about pregnancy and HIV. A lot of that language change has come from women. So I think that remains true now, that history of women changing the management and pushing advances forward.

**Yvonne:** I would completely agree because I think, certainly in the early era, the main safety data we had for HIV in pregnancy was based on European delivery data, which was very clear that caesarean section was safer. But women just had their babies, they had delivered normally before and they were going to deliver normally again, and they just did, and eventually, slowly but surely, women worked with their medics and the data came together, and it was proved that it could be safe. And the same thing is happening with breastfeeding, and again it’s the combination of women saying, “Actually, I really do want to breastfeed, it’s very important to me,” and medics having to understand why it is important, both nutritionally and culturally. It can be telling about HIV and individuals’ HIV status as well, just inadvertently, by not

breastfeeding. So it has taken open discussion and dialogue to make that difference, and for medics to actually get their head around the fact that they have to change so that people don't go underground and do something that they have been asked not to do even though they really feel that they need to do it, they want to do it. It's working together and just that open discussion has allowed that to move forward.

I certainly I think that Shema and I, working with SWIFT, we both felt very strongly that community representation was very important from the beginning on the steering group. With SWIFT we have four community representatives, and that's hugely important, and I think we very much want to work with community. We worked with Angelina, met Winnie before, and Shema has worked with Jane as well, and it just makes it so much better, it takes things forward. So although it's not pure activism in a way that is activism as well, just the working together is the activism of the community with clinicians to actually move things forward, and as you say it doesn't have to be angry, if you can work diplomatically well together it can succeed. It's the combination of the two. And I think that's where Shema and I both very much have the same focus and we have changed the pregnancy guidelines. We have seen women develop in SWIFT from newly diagnosed and very quiet, very unsure, to presenting internationally with support from women living with HIV and from physicians who are really research active in HIV, and that's been huge, it's just been amazing to see hasn't it? Really amazing.

**Jane:** I think also that model of community representation and of community advisory boards (CABs) has come out of early days in the epidemic, of the Denver Principles<sup>10</sup>, which women in a way have had to fight for a place in. I think, because that's been a very male domain, because it's science, it's the stuff that women traditionally have not been encouraged or supported to find a place in. So yeah, I think it's been a more recent struggle, because it's clearly a very important model, community representation, and important for women to find a space there. I don't think that's been very easy and part of the activism of women in this country is not just of having their needs listened to and acted on, it's actually jostling to get up on the platform and be given a place from which to do that.

**Angelina:** I would absolutely agree with you, and also I think as part of that, what we as community representatives have done is go from just being a tick box to actually educating ourselves actively in seeking that information and the knowledge, so that when we are sitting at the table we actually have something to contribute rather than allowing people to just say,

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<sup>10</sup> Published by PWA Coalition (1987) and available here: <http://www.actupny.org/documents/Denver.html>

“Okay, we have got a woman there.” So we have gone a bit further than that. It’s taken years, but I think back to people like the activists that paved the way, ICW led the way for the women as well, but for us in terms of now, where we are at, those of us who are involved, a lot of us want to be involved, and we want to learn, and we want to actually say something useful, and I think that’s really important. I think what’s also important, is that we activists are now reaching a certain age and we need to be passing the baton on to younger activists. But we are doing that, we are trying to build up the next cohort of activists who will take that on. So we shouldn’t stop just because we have got amazing treatment that works for us, there’s still a lot more issues that need to be dealt with that need our voice in it.

**Jo:** I went to a meeting at the World Health Organisation (WHO), the Global Programme on AIDS in 1993, and they were preparing a strategy paper on women with HIV. So they brought together women from all over the world. I was the only positive woman, and of the 30 that were there, the majority were researchers researching sex work, because they thought that the only women affected by HIV were sex workers in ‘93. They thought that heterosexual women were safe from HIV, and that you must be doing something very risky, you must be a drug user or you must be a sex worker. So it was women speaking out that changed those perceptions. When you think back to those early conferences, the women on the stages were African women, it wasn’t African men, because African men wouldn’t speak out at that time, it was African women...

**Angelina:** They are still not speaking out [laughter].

**Jo:** ...with nothing left to lose. It was the women standing up and talking about inheritance rights, about women being inherited by their deceased husband’s brothers, or being forced to have more children when they didn’t want them and their children had died of AIDS, and their families were putting pressure on them to have more. It was because of those women speaking out that UNAIDS finally realised that marriage was the greatest risk factor for women<sup>11</sup>. But it was, they really set the agenda because nothing was known about women, all through the 80’s there were lots of women around, but nobody asked us anything, nobody talked to us, they weren’t interested in us. If I turned up anywhere, everybody thought I was a volunteer. So, it was finally when women actually found their voices, and really began to shape... We have talked about the feminisation of HIV, but that’s all stuff women have been saying for years.

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<sup>11</sup> UNAIDS and WHO (2005); see also Clark (2004).

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There's nothing new in it at all, but it took such a long time for the sector to actually understand what women's issues are, what their risks are, what their vulnerabilities are.

Then I was involved for a very long time around reproductive health and rights, at a time when a lot of women were having forced abortions, forced sterilisations, forced C-sections. But it was by speaking out that things have finally begun to change.

**Yvonne:** And there were specific guidelines from the American Gynaecology Society saying that any woman with HIV should not reproduce, it was absolutely amazing, in 1991, and it was one of many countries with specific guidelines.

**Jo:** In many countries around the world, if a woman presented as pregnant she had a forced abortion.

**Yvonne:** But also, women just had babies and got on with it, and ignored the advice they were given because they knew this is wrong, and that was a form of activism as well. It was speaking out but also just deciding, "Do you know what, I am just going to do this anyway, I am going to ignore the rules that are being dictated to me, and I am going to do what I want to do," and that is what has changed, so that has happened all along.

**Angelina:** I guess I'd better pick up from there, because in the introduction I completely forgot to say what I actually do, and my passion is very much around the sexual health and reproductive rights of women living with HIV. Whenever I say that, to some people I have to qualify it by saying that I am not saying that every woman living with HIV should have a child, but I think it's incredibly important that they have the choice. I've worked with women over the years, I remember doing a workshop with women not that long ago, and it was a workshop around safer pregnancy, and she just turned round and said to me, "I didn't know we were allowed to have children." And I was thinking, "It's not a matter of being allowed, it's your choice," and so the programme I'm working on currently is around training up and skilling mentor mothers living with HIV so they can support their peers through the pregnancy journey. I think that is so important because, as I said, I have worked with women who had no choice, and then those who have had babies. One of the incredibly strong things about it is that their experience of seeing another woman who has been on that journey, and being able to share your story, and being able to know that you have choices, and being able to know that you can be supported.

Even in the days when breastfeeding was just coming into being in the UK in terms of women being supported to breastfeed, just knowing that in expressing that need you will be supported, and women have so many reasons why they want to make the choices that they do, and we can't judge them, and they need to have that information. But a lot of times that information comes from fellow women who have been through those forums, who've got the information, who can actually give them the right choices and refer them on to the right people. So I just wanted to say that it's so important, but what I also wanted to mention was, you talked about WHO and being involved in the Sexual and Reproductive Health Rights (SRHR) discussion, but that you were the only woman with HIV. For many years in terms of doing the WHO guidelines it's always been, they will write the guidelines or draft them, and then at the point where they're nearly almost publishing them, they will come and say, "We need a woman living with HIV to input," and by that point really, whatever we are going to say isn't going to change much in terms of the guidelines. But it's really good to see that process has really moved on because recently, well, 2014, WHO had a turnaround and they brought women living with HIV together to do a values and preferences survey, and Salamander Trust led on that initiative, and they managed to get together<sup>12</sup>.

What was really important about it was that the values and preferences survey was developed by and led by women living with HIV for women living with HIV about issues that affect them, and looking at the women's priorities around sexual and reproductive health. There was a global reference group of 14 women living with HIV from across the globe, all of us in our diversities. But we developed the questions and we looked at them, and one of the things we wanted to make sure was that actually women were not traumatised as part of taking part in the survey, and I think only women can understand, can even think of in terms of research, only women can think that far back in terms of it not just being about taking part and getting loads of women involved, but actually the process and what effect it's going to have on them.

So we got about 946 women living with HIV aged 15 to 74 from across the globe. We did an e-survey questionnaire, but also we also did focus groups, because not every woman accesses the internet, as we all know. But I just wanted to comment on that turnaround with WHO, so the results from that values and preferences survey actually informed the WHO Sexual and Reproductive Health Rights guideline for 2016. So they got us involved at the beginning, and used that information to write the guidelines, which was a first for them. I think hopefully they

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<sup>12</sup> See Salamander Trust (2014) for the survey report; and World Health Organisation (2017) for the WHO guideline that followed.

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are going to adopt that, but again it's because women were involved they were like, "Look don't get us in at the end, we need to actually be part of the process at the beginning." So it's just good to know that we have come that way.

**Jane:** I just have a personal reflection on when you were speaking about the trauma of doing these quite in-depth surveys, questionnaires. Those early days of telling our stories, and telling them on public platforms, it felt very liberating. I love to talk about myself, but I was often asked by groups to talk about living with HIV, I did one with children, they were teenagers, they said to me in one that I should never have sex, should I? And I said, "Well I don't see why not, you can have safe sex." And they said, "But then you are a murderer," and when I left it really impacted on how I felt about myself, it was a very difficult thing to hold and carry. There was no pre-counselling, you gave those talks, you walked away, there was nobody to speak to, because people hadn't really done that kind of stuff before, and I think women put themselves in quite dangerous situations through their own personal courage and need to tell their stories. But they weren't necessarily easy, there was not the support there should have been, and I think that we have learnt from that, but I think there was a heavy toll, I don't know if other women have that experience, it's not necessarily easy.

**Jo:** I was on television with a microphone put in my face saying, "How does it feel to be dying?" It was live TV.

**Marsha:** Something that came up for me when I was interviewing a woman, I think in around 2001, who said that it was very difficult to get involved in a relationship with a man because she would have to disclose her HIV status in order to convince him to use a condom, but that would put her at great risk of him disclosing her status to others or even his own response. What she conveyed to me was that the possibility of having an intimate relationship with somebody was off the picture for her, or posed great risk in venturing into that. I've often thought about the difficulty that women have in negotiating safe sex, which I think can be quite different to men. It's not absolutely different, but certainly different to what has taken prevalence about negotiating safe sex amongst gay men.

**Shema:** I think that's true but there's also that extra dimension that, we know all the literature about the risk of intimate partner violence either being the cause of HIV or as a consequence of sharing your HIV status. So I think there's real risks. Again, I think Yvonne is probably going to agree with this, and probably everyone around the table will agree with this, something that has been transformative over the past couple of years is U=U and getting that message across

in clinics. I think now that's a core part of my activism, because I think the majority of gay men hear that message, they have access, they talk about HIV with their friends, they are going to clubs, they are reading about it in the press, they are engaged on social media. The majority of women that I see in my clinics don't know about U=U because where are they going to access that message? That is transformative, especially for women who have been living with HIV for a long time, who have lived with the stigma, lived with the fear of passing HIV on. To be told that you are at no risk of passing HIV on to a partner radically changes someone's quality of life, and for me that's been one of the biggest moves forward in the past few years.

**Jo:** It's so important to get that information to the clinicians, because I know a woman in Cambridgeshire, and this is a major teaching hospital and she's been on treatment for years, was entering a new relationship, mentioned this to the consultant and he said, "Well, you know it's a criminal offence not to disclose your status?" And she was distraught, she phoned me in tears, and these messages aren't getting to hospitals outside London, it's really alarming.

**Jacqui:** And I think that even when the message is there, it's important to think about what it means and what you can do with it. In my PhD research workshops and interviews with women over 50 living with HIV, very few women had heard of U=U. It came up in a couple of the workshops and maybe one woman in the room had heard of it, wasn't quite sure what the second U stood for. But even when there was discussion, even when it meant something, women would still tend to arrive at the conclusion that you would still have to tell your partner, so how useful is this information? Because unless I'm going to get a PowerPoint out and explain what it all means, I didn't hear any women talk about the idea that it could mean you didn't have to tell a partner, and I don't think that's a conversation that maybe clinicians are comfortable with having, or even organisations are comfortable with having. I think a lot of the messaging around U=U is very much not designed for women, and it's not helpful, and the idea that it's the solution to stigma at a societal level I think is quite dangerous. "Now it's alright, now you never have to worry about these things," but actually that support and information that women can use it and actually do something with it, I think is really missing.

**Angelina:** It is missing and I have spoken to some clinicians, it's not Shema and Yvonne obviously [laughter], I just asked them directly, "Do you talk to your patients about U=U?" And even in a conference we have asked, "How many of you speak to your patients about it?" And one stood up and he said, "I have got some patients who I know are not adherent to their treatment." You should have seen me, I was just like [bangs fist on table] then I almost became an angry activist. So, they are making a judgement on the back of adherence of their patients,

so they are not giving them the message, and I am thinking actually this is your opportunity to explain what it means. It might just be that little trigger that your patient needs to actually take their medication properly. So, I don't think it's getting to the women, but one of the other things which is really key about U=U, is giving the full message, and making sure that as women, or as patients being given a message, is to understand that not being undetectable doesn't mean that there's something wrong with you, because there's a few people who will not become undetectable for whatever reason. So, it's very much about ensuring people get that information, what they can do with it, but making clear that there's no reason to feel bad if you are not undetectable. You can do what you need to do, but I just think, I find it really frustrating when people decide on behalf of other people. Give me the information, if I don't want to use it, fine, but I have to have it.

**Yvonne:** I completely agree, there's two things I wanted to say. So firstly, I run a women's clinic in Brighton. We're very lucky, we have women who are seen by three or four staff members, it's a long clinic appointment, but the idea is that every woman will come through the clinic and will see a health advisor, a women's worker at the Sussex Beacon, myself for medical issues, and a nurse, and we have a meeting at the start of the clinic and at the end, and very much the ethos is that we make sure that U=U is spoken about on more than one occasion in different ways to each woman who comes through the clinic, and often it is the first time that they have heard it. We talk about it in the context of a) it's a good thing, but b) it gives you that time, you don't have to talk about HIV with someone you first meet, but if you are going to have sex use a condom because you want to protect yourself against other STIs. It's about her health, her safety, it's about her rather than her being the person who is putting anybody else at risk, that is entirely removed.

I think the second thing is, it is noted amongst clinicians that there will be a differential across the UK as to how comfortable somebody is in talking about the data. Undetectable in the context of U=U in the PARTNER study is less than 200, it's not less than 40, which is the number that we use in clinic<sup>13</sup>. So there's a big amount of room for manoeuvre, but at BHIVA we want to send out a questionnaire to clinics across the UK asking about, "Do you talk about it, what does it mean to you, how do you explain it to somebody, when might you not talk about it?". As you say Angelina and Jacqui, people can be selective about who they might say it to, and we want

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<sup>13</sup> These numbers refer to the number of copies of the virus detectable in the blood. For the PARTNER study, there would need to be under 200 copies of the virus for a test to be deemed undetectable; whereas in the clinic undetectable refers to less than 40 copies of the virus.

to actually gauge what that is, why that is, and see where there is room for education on it. I do think that when people don't understand it, it's because they haven't necessarily had as much exposure to the data as they should have done, so they are not confident in saying it to patients.

I gave PrEP to a woman who had a positive partner in 2008, I was the first person in the UK to do this. We had no data to say that being undetectable was un-transmittable, and it felt very scary giving her PrEP so she could get pregnant, and so it has come from a place, from ten years ago, to now saying with absolute confidence, "You will not transmit HIV," and I can say that now in confidence, and I am used to saying it, and I say it to everybody all the time, and I think it is about medics relearning. But also, I think it's good for the community to push it because there is the U=U campaign out there, and it is that combination of getting that knowledge out to as many people as possible, again where the community and medics work together. But I think this is where medics have to be active against, or not against, but *with* other medics to push that and actually just change that whole ethos.

**Angelina:** I totally agree in terms of the community pushing it, we're going to have a study day at the national HIV nurse's conference this month, and I have actually designed a U=U t-shirt, so I am going to wear that as part of my activism, because I am co-chairing the session. I think we also need to be saying it with confidence, I thought, "I have to put on a t-shirt I have made myself," it's handmade, it's really poorly stitched, but I just wanted the message out there, whichever way we can get it out there. Because if I am wearing it, somebody will ask me, "What is this?" and I will talk about it.

**Winnie:** I want to speak to two things, and they are inter-related, and one is about the support we get as women. When I started accessing support groups it was really great. I would talk to others, I learnt a lot through these support groups, and then of course things kept evolving. I used to go to support groups, and because I looked and sounded very confident, knew what I was talking about, a lot of people would come to me to get support, to clarify things, and then I found myself not getting support, actually just giving support. It was exhausting, to a point where I just literally retreated because I wasn't getting the support that I needed, and I was supporting everybody, and I was just drained. I moved away a little bit from the national HIV sector and went into the international development sector, started travelling, started working in sub-Saharan Africa, and I learnt a lot through the work that I was doing there with women, grandmothers looking after grandchildren. And for me, one of the things that I keep doing, because I am still doing that international work even now, what I do is, whatever little bits of things I learn, I bring them back, and I have initiated this small network of women. Because I

had to decide that, okay, the support in the support groups is no longer for me, it doesn't really work for me. Now, because things have evolved a little bit for me, I need to decide what kind of support that I need and create that support, and that's what I have done. Not a lot of people now know or even say, "I have to do this for myself because this is what works for me," because things have moved on, and support groups, some of them are no longer there, and even some that are there act like they are in crisis mode, and there is just something that just doesn't work. Through this network of women that I have created, we meet up, we discuss things, a lot of different things have evolved. Because issues are complex, there's an economic dimension, there is a social dimension. And I think there are a lot of women out there looking for that kind of support, and they can't find it, and that support is really critical, and also the modes in which we communicate with people have changed, social media, a lot of that, it's really difficult to bring people in like this on a regular basis to talk about stuff, it is incredibly difficult.

On the U=U issue, I also talk about this, where I go to in different countries no one knows this. I leave women jumping up and down, "You mean this is true?!" And I say, "Yes, and you need to own it and you need to seek this information, and you need to do this." No one is talking about it, because you know what they say, they say that if you give people this information, then everything will go wrong, people will be having condomless sex, they don't want to be doing this, and that's how they justify not giving people this information. So we have a lot of work to do in terms of where we are at now, and where the movement, especially of women, and there are a lot of empowered women out there, I really, when I go to Africa and I sit down with women, I get so excited, and I really feel so... I just feel so good, because there are a lot of women getting their lives back. But my fear is that we are moving to this sort of, or not sort of, we are moving towards, and a lot of things are spoken about this gender equity issue, but we are leaving men behind, men and boys behind, even though it feels fantastic that women are coming out of their shells and moving forward. For me that is a question that's always in the back of my mind. We have children, we have young girls, we have boys, but women are getting empowered, and I talk to men and they say, "But everything is for women, all the projects are for women, it's girls here, and men get nothing," and yeah, I do agree with them to a certain point that some of the work that is being done with boys is ad hoc. But my worry is that there is this huge movement, fantastic movement of women, and there are a lot of women living with HIV in their 60's and 70's, that's fantastic, but there is a lot of work to do to bring everybody else along with us.

**Jane:** Can't they bring themselves along? [Laughter]

**Corinne:** I think that it's true in the UK situation; when we last did a round of interviews, it was the men who were reporting the most isolation and a real terror around criminalisation for instance. Maybe that fear is realistic, because that happens most for black African men in Europe, that is what has happened historically. But also in South Africa there are many initiatives for men. Nompumelelo Zungu has done some amazing work with men in Cape Town around their particular fatalism about HIV and masculinity, which is very interesting stuff, and obviously in the UK there have been all these initiatives around heterosexual men recently, how to reach them and so on. But at the same time, that amazing movement that you are talking about I think as other people have said, it doesn't always get registered as significant as it is. It's every day activism, lived activism, and it doesn't get named, and it doesn't get acknowledged.

So, I know a woman in North London who's taken part in my research, she is in her 50's, she actually has a lot of illness with HIV, she runs a network of support off two mobile phones, you cannot be with her for more than five minutes before there's all these calls coming in, she is giving support, she is visiting people, she goes to their houses, cooks for them, all this stuff. Can she make an NGO out of this? Not really, it's very difficult, and is somebody going to name her and say, "This kind of work comes from the initiatives of women like X"? It's not going to happen. Just remembering that it was Kenyan women sex workers who found that nonoxynol-9 was not a good thing, and that now that point is attributed to a particular study<sup>14</sup> but not to those women. Maybe it's just a naming thing, and in certain cases you could say that it doesn't matter in terms of people's lived realities, but I think in relation to the overall politics of the epidemic, like you are saying, it is really important to change that.

**Shema:** I think that's critical, isn't it? And that's partly the responsibility of academia to work meaningfully with women living with HIV, and make sure that you're certainly facilitating women living with HIV to gain further skills, further training, further experience, build up that capacity of women living with HIV to be researchers in their own right, and to lead on abstracts and to be authors. The number of projects I have seen where women living with HIV have been absolutely fundamentally critical to the evolution of that project and then they're erased from the final report and the final reporting, and that cannot happen anymore. That's the responsibility of the academics.

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<sup>14</sup> See Kreiss *et al* (1992)

**Yvonne:** I think Shema you have been exemplary in your PRIME study. I think that for me it's the benchmark that we need to all strive for. Your community representation from the very beginning with meaningful help to develop your questions for your study, and when you launched your study, you acknowledged that. The room had equal academics, equal community representatives who are also academics as well, because they're providing help with studies, they are helping to formulate studies. They may not have that qualification on paper but they are still academics working with you. And it was just amazing to see that come to fruition, and nowhere, as you went through, did you lose your enthusiasm and your inclusivity of all your researchers working on that project with you, no matter who they were. You were there Angelina and Jane as well, and you felt that was very much acknowledged. There was equal representation from academics who have been involved and community representatives who have been involved in the study, telling their stories and presenting the research. I had never seen that before, ever, and I think huge kudos to you for leading it, you worked with everybody but you did lead on that, and I think that really for me sets the standard as to how we should be working.

**Jane:** That study was also good because it was funded and we were funded. We got a small stipend to go to the meetings, we got travel expenses, there was money for me to do infographics, and that kind of professional input. But it is a huge issue, and it is really interesting to look at how we are recompensed, because things have changed, and there's now a very professional level of community representation, because people have been doing it for years, and they have either sacrificed a career or they have made a career or they don't have full time jobs. Kate Thomson is the prime example, she made it to a top position, I am not sure it was her career path, but that was where she ended up. But other people have worked very much at grassroots, and there's a point at which it's not sustainable as women. We live with this, we're not going to get cured or get better, this is us, we wake up with it every day, we're not going to retire from living with HIV.

**Jo:** I think I might [laughter].

**Jane:** It's something you just don't do as a nine to five. It is your being, it's inside you, and I think it's very draining because you are going to go through this for the whole of your life course. If you're in some kind of activism or involvement, and you're not getting paid for your time, you're going to endless meetings, endlessly on advisory committees or panels, or asked to speak and there's never any financial reward, I think that's an issue, personally, and I think in the early days...

**Jo:** I've been saying that for such a long time.

**Jane:** Well that's interesting because I wondered if in the beginning it was much more out of such necessity or of not knowing, there was no models for expert patients like there is now, was there?

**Jo:** We just fought to have our place at the table and be involved in studies. Countless people would come to Positively Women to do research, and so we would all ask, "Could we look at your questions?" and turn them around and say, "Okay, well that's not appropriate, why are you asking that?" They always start off question number one, "How did you get infected?" But that took experience and strength, and you would come away from that feeling... And those were the people getting paid, and those were the people with the careers and the PhDs, and you knew that you could do it much better than them but you didn't have the pathway to get through it, and also everybody around you was dying, we all just made it through.

**Winnie:** Literally. I hear you about contributing endlessly and not being financially rewarded, I know that happened to me. I used to be in so many different organisations, be on the boards of so many, chaired some organisations, and at one point I was exhausted, I was poor, I literally couldn't feed myself, pay my rent, and this is a decision I had to take on my own, and I thought, "This can't go on, I have to look after myself." I literally retreated and thought that if anybody calls me I will refer them to this person, or to this person, I am not going to say "Oh, I can't do it bye," I am going to say, "Contact this person, contact that", and then I retreated and started to look after myself, to make sure everything else was in place. But there are a lot of people who don't know how to actually do this and have ended up in really difficult positions, and it is a difficult balance to maintain, it's a really difficult balance to maintain, and it's very individual.

I also want to touch on what Marsha talked about, talked about negotiating sex, my word, that is difficult. It is not only difficult because HIV makes it so much more difficult, at a personal level made it very difficult. But I find that it's not really the main thing, for me what has happened is, it's the cultural issues. The main cultural issues where I find that either somebody knows about my HIV status and says, "Oh, we should date because we are the same," and I say, "We are the same how?" And it's "But we are the same," and I say, "We are the same how?" And they can't even say that they are HIV positive, and these are heterosexual men, they can't even articulate that, and I always have to say that we are not the same, that doesn't make us the same. So that is one aspect. Then I find that because I am incredibly vocal, I am incredibly

open, I am incredibly visible they are like, “But you are too visible, I don’t want to be out there, I don’t want to be seen with you because you are too... Everybody knows about you so they will relate this with me.” This was people telling me this, and I’m like, “Really? You are telling me this and you want me to date you?” So it is just fraught with all sorts of complexities, and again it’s individual decisions, people have to take these individual decisions about what they want to do with it. But it is difficult.

**Angelina:** It is very challenging, and like you say, a lot of women – I guess we could call it serosorting – would stay in relationships that are so bad for them, with a positive man or positive woman, depending on who you are dating, because of course in this day in age we can’t make assumptions that everybody has a heterosexual partner, and that’s another story for another day. But for a lot of the women I have worked with or come into contact with, it’s almost like that’s the only type of personal data they’re working with, and I always say to them, “But actually, the fact that that person has HIV doesn’t make him an ideal partner for you, they could be really terrible.” Why should I stay with somebody just because we share a virus? No.

We used to sit around talking about negotiating sex or finding partners, it doesn’t matter where you go, whether it’s Kenya, Uganda, Russia, wherever, the women living with HIV, a lot of them can sit in a room and talk about how challenging it is to find a partner. So we were having a discussion one time and somebody said, “Why don’t you try online dating?” And I’m like “Oh, I’m not sure about that,” and she was trying to give a lot of the women the same advice. So I said that I have never tried it, that I can’t be bothered and that I would rather meet somebody face to face, they said, “No you must do it.” She created a profile for me and everything, and she put it on, some of you will remember *Positive Singles*, they advertised on the back of *Positive Nation* initially, before internet dating became a thing, and we knew who all the men were because they were dating everybody. But anyway, so by that point they had developed one that is a dating website specifically for people living with HIV. So she put my profile on, and so I am waiting, and then I started reading other people’s profiles, I was looking at the men’s ones to meet a partner, and I looked at those profiles and what was there was, okay, “Living with HIV, have Hepatitis C,” so I am thinking, “Do I want to go out with somebody because they have an STI? Really?” [Laughs].

So anyway, I did actually go on one date because I put on... I know I am digressing, I will come back to where I am going in terms of what I do now in terms of dating, and I wanted someone between the age of 35 to 55 I think. Some gentleman got in touch and he said he was 59, and I thought “Okay, I am not ageist, and there are lots of spritely 60 something year olds out there,”

so I go on a date with him, and I think he must have been closer to 80, because he only put on a side profile picture, and I should have got the warning signals by then. So I didn't go out with him, but it was not because of the HIV, but because he lied. So now I almost, not avoid HIV positive men, but I actually just think I am more than a virus, and if somebody likes me they need to like me, because individuals are very different, and I have had very good interesting relationships. But the majority of the relationships I have had since my diagnosis in '93, I say majority, there are not that many, but in fact most of them have been with men who are not living with HIV, because I just think why should you limit yourself so much? And I try to get that across, and I know it's not easy, but it's telling people your status that makes it more difficult. But a good person is a good person whether they're living with HIV or not, if you tell them your status if they are going to accept it they are going to accept you anyway, and I say accept because people want acceptance. I would rather not have anybody than just be with somebody because they are living with HIV.

**Jane:** Which is quite interesting as well, because before U=U and this ground swell of need to get this message out there, we had the GNP+ *Positive Health, Dignity and Prevention*<sup>15</sup> which are guidelines for living your life, especially at a time when we were considered diseased and vectors of transmission, and there was this idea that you have only got to share a cup with us and you will die. So there was another way you had to live your life, and I always lived mine by those ideas, that I am not a vector of transmission, and it's a joint responsibility with partners. That they also have a responsibility to protect themselves, it's not just me, and I've had a very varied sex life, had some really awful sex, and some bad experiences, and some great sex, didn't tell everybody, always used a condom. I could write a book about it. But it wasn't one narrative is what I am saying, and it didn't all change and become fantastic the minute U=U became firmly entrenched in clinical practice.

**Shema:** I sometimes worry, although I completely understand the importance of talking about negotiating safe sex and sharing status, but in that conversation we forget about sexual pleasure and women's right to sexual pleasure, especially women living with HIV. That was certainly reflected in our data from PRIME, which is predominantly with women aged between 45 and 60, so obviously the rest of the world thinks you stop having sex when you are 40. And so I think this is a group of women whose sexual needs are overlooked because there's multiple layers of stigma, there's living with HIV, there's being an older woman, there's going through

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<sup>15</sup> Global Network of People Living with HIV & UNAIDS (2011)

the menopause, and we forget about sexual pleasure. The majority of women in PRIME, this was something surprising to me when we did the interviews, the number one thing women would volunteer when they were talking about ageing with HIV was the difficulties they were having with sex, either the loss of sex from their lives, the loss of libido, pain during sex, and how they never had anywhere to take that. Who do you speak to when you're a 55 year old woman living with HIV, you can't speak to your GP about it, you feel embarrassed speaking to them. So I worry that conversation about sex being something pleasurable, that fundamental human right is neglected in this by all of us sometimes.

**Jo:** It has been constantly neglected. When I was first diagnosed, I went back to the consultant who had done the test, and he didn't give me any information, he gave me a plain piece of paper and said to write down everybody I have ever had sex with, names and addresses, and I didn't. But I contacted my boyfriend over the past year and obviously he was convinced he had also been infected and we talked about how we'll be together forever, that kind of thing, and he was negative. We'd been together for quite a while, and so although there was no information, it was very clear that I wasn't as infectious as everybody was telling me, and so just to be able to share that with other women and have other women realise that for themselves. But you have to keep that quiet, because when you're going to all these talks you go, "Everybody has got to wear condoms, and you've got to do this and do that," but we had to get men to wear condoms to protect us, either from infection or from STIs or unwanted pregnancy whatever, but actually we weren't the risk but we were being treated as though we were the risk. And it was this constant, I can't quite explain it, but it was a very contradictory, confusing, and it really affected your ego and self-image.

**Winnie:** What you are saying about sexual pleasure is really important, and I don't think those conversations are being had at all, not here, not internationally. I remember one time, I think I was in Kenya somewhere and I was meeting with about 600 grandmothers, and I turned up first of all in jeans, and I wasn't told that I was meeting grandmothers, they told me I was meeting a few people, there were between 300 and 600, it was just like a sea of grandmothers. But being a grandmother in Africa you could be 40, you could be 50, you could be 30 something. Many of them were in their 70's and 80's, and I had to get over being in jeans because I was told I was meant to wear a dress if I was meeting grandmothers. So there are all of these dynamics about how you talk to people who, many of them who are my age but they don't know that. But I tried to get this conversation going, and I said, "How many of you have partners?" And among those there were maybe less than 30 who had partners, all of the other ones, either their partners

had died, or had gone walkabout. Literally less than 50 had partners, and the rest of the women had given up. “So what’s the point? There is no point.” So they had given up on their pleasure. Everything else, doing business, doing this, looking after their grandchildren all of that was going on, but their personal needs around sex, around being with somebody, they had just given up on it, and for me that was so sad, it was so sad.

**Jo:** In 1993, at the Berlin conference<sup>16</sup>, I don’t know if any of you remember this, but Robin Gorna had written a publication for THT for women about sex, and she really was trying to highlight the importance of pleasure, and she wrote something like “Throw away those dental dams,” because for oral sex you were supposed to use dental dams, and the THT stall at Berlin was trashed. There was a huge uproar about this, particularly from American delegates who were insisting that we should be using dental dams, and they were saying that she was being irresponsible with this messaging. But she was amazing at that, and I think she was the only person at the time who was really trying to recognise the importance of pleasure for positive women. But she was hounded, and vilified for that.

**Jacqui:** I think that refusal to understand sex for women in the context of pleasure and choice is still going on, and I think it’s really shaped UK PrEP advocacy for women. There have been such barriers to women being seen as relevant to the conversation and I think that for those of us that have been doing that advocacy, that’s been where most of our efforts had to go. And it’s incredibly disappointing and frustrating that in all of these activist spaces where you would hope that people would know a bit better, so much effort has had to go into saying, “No, actually sometimes women have sex on purpose,” [laughter] “Sometimes they like it,” and how quickly you talk about PrEP for women and people go “Oh yes, sex workers and violence.”

No, actually, and it’s been a real battle, it’s been a real sense of, “Women don’t really need it, women don’t really have risk, and if they do they don’t control their risk, so PrEP isn’t right for them,” and even if it could be right for some women, “it’s too hard, and it comes next.” And then, people have really made the case that women should wait, “Let’s sort it out for gay men first, and then we will think about women afterwards,” and I think it’s really interesting listening to reflections of the early days of activism, how much hasn’t changed. Now PrEP should be opening up this new space but we’re just repeating that same model of women having to bang down the doors to even get in.

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<sup>16</sup> IX International AIDS Conference, June 1993

**Jo:** The PrEP studies in Africa, didn't they show that it didn't work for women, what was that...?

**Jacqui:** No, it showed that if women weren't supported to adhere then it wouldn't work.

**Marsha:** The questions about why they didn't take it are very interesting but what was actually going on for those women was not really considered.

**Shema:** If women take PrEP it works brilliantly.

**Jo:** Because it was published that it's not successful in women.

**Jacqui:** And a lot of people clung to that as a useful argument.

**Marsha:** Only in terms of the immediate results of the studies that had to be closed down<sup>17</sup>. But not it's not the case that following that they argued that PrEP is not efficacious in women. The small trial in Botswana with women and the trials in Uganda and Kenya with serodiscordant heterosexual couples, including women taking PrEP, were really successful<sup>18</sup>.

**Angelina:** When the results were published they said it didn't work, and then they jumped towards saying that women weren't taking it, and the blame was being put on the women. But as you are saying, and I've asked the researchers, "Have you actually gone back and done a qualitative study with the women who were in the trial to find out why they didn't take the medication, if they didn't take it indeed?" Because we also need to look at the clinical results, they may have well been taking it but it just didn't work, but they need to find out why they didn't take it, don't just say the women didn't take it and leave it at that, and now we can't be involved in trials anymore. I think it's really important that is found out and that we are told about it properly rather than us being given that message. But in terms of PrEP, Jacqui, what you are saying is really true about how women are being left behind.

I just wish and wish the researchers and the powers that be and those who are advocating for PrEP would sit in a room where we are facilitating workshops around sexual health, or rather sex and pleasure. I have done quite a lot of them with women living with HIV, and if only they

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<sup>17</sup> In 2011, the Preexposure Prophylaxis Trial for HIV Prevention among African Women (FEM-PrEP) was closed early when it was found that many women prescribed the drug became HIV positive.

<sup>18</sup> See Thingpen *et al* (2012); Baeten *et al* (2012); Michael and Rosengarten (2013).

could be in those rooms to see and hear how women talk about their sex lives and what they want to do. When they talk about sex in general I think that we change their messages, but of course we can't get any. There are women who are diagnosed and decide that's it, that's the end, because what they think about is that it's because of the sex that they have got HIV, so they are never going to have sex, and it's fine if that's what they choose. But of course, some of them change their minds, but even if after a while they decide that they don't want to have sex it's fine, but I don't think that they should be denied that right or left with those thoughts around the fact that well "I shouldn't be having sex because this is how I got it." I wish we could find a way to get those people in that room when we are doing the workshops, it would be revolutionary.

**Corinne:** It's not as if the gay men being encouraged to take PrEP are a group that are necessarily more adherent. They are often completely caricatured as having chaotic lives, blah, blah, blah, but clearly underlying that is some sense that their sexuality is more important, more insistent, less able to be thrown away.

**Shema:** And you see this in a history of thinking around sex and people living with HIV. So certainly, I look at the disproportionate amount of research that's done on having low testosterone, and low sexual function amongst men living with HIV, and then you try and find the equivalent for women living with HIV and there's a handful of studies that look at women's sexual function. I think that absolutely reinforces this privileging of men's sex lives and need for sex culturally. Obviously that's not just within HIV, that's a wider cultural issue.

**Winnie:** But I think the PrEP issue is really worrying, because we are almost one year into the PrEP study in the UK, but I think the task of getting women onto this study is just a huge mountain to climb. From what I understand, and Jacqui you could correct me if I'm wrong, in some of the clinics, some of the spaces that were there for women, and there were very few, have been then reclaimed, because women haven't come forward to claim these spaces.

**Angelina:** How can women come forward to claim these spaces when they are not getting the message about PrEP well enough and in forums they can attend and understand? It's like anything else, if you don't have the information you can't access what is available. So of course, I think a lot more needs to be done. I don't agree with the fact that because women were not taking up the information that then they decided to open up spaces for men, they should be doing something to get the spaces taken up by women. I am digressing, but I think that in terms of clinical trials my ideal would be for there to be a cap put on participants. So, for every three

men or two men that you recruit, you have to recruit for women, do you know what I mean? It has to be a cap, 50%. It will cost the trial a lot, but if people, if researchers are being actively encouraged to ensure they actively go out there and make sure that those spaces are taken up by women I think it's very important. I may be an idealist, I don't know.

**Marsha:** I know that many of you engage with the question of HIV and menopause, and I am just wondering whether we just spend a few minutes on that. In many ways, I think it's hard to separate HIV out from the gender issues more generally. I think menopause is a bit of a mystery for medicine in some respects, a bit hit and miss about how it is experienced. I'm wondering, what is the thinking around the issues about menopause and HIV? Is it attracting much interest in HIV medicine or...? It also dovetails with the questions about a lack of attention to pleasure and so on.

**Shema:** Historically, it hasn't had any attention whatsoever, but that's partly because up until relatively recently there just haven't been large numbers of women living with HIV reaching this age. So I think we now have this amazing opportunity to engage with this experience of going through the menopause transition as a woman living with HIV. But I think we have to be honest, menopause is a hugely under-researched area, it's massively underfunded, it's neglected. I don't think people see it as important, they don't appreciate the importance it has on women's lives both biologically and socially.

My particular experience for the study is that, similarly to women without HIV, the menopause is mysterious. You start getting symptoms and you don't really know what's going on and you don't know how it's going to pan out. Many women are under prepared, as they are outside of HIV, because we don't really talk about it. But I think HIV adds a dimension, because you start getting these symptoms but you're already living with a long-term condition, so how do you know whether these symptoms are menopause, whether it's HIV, whether it's side effects from your medication? Is this different because you're living with HIV? And then if you get symptoms where do you go? You try and go and see your GP, but your GP says "Oh, this is to do with HIV, go and see your HIV doctor," so you go and see your HIV doctor and they say, "Well, we don't deal with menopause, go and see your GP." And what we found in PRIME is that women were being bounced between general practice and HIV specialists often for years, with symptoms that could be often easily managed or at least to be given information so women could be prepared and say "Right, okay, I've got these symptoms, I don't want to take any medication for it, but at least I know it will end," or "This is what I should be prepared for."

So we actually found a significant need, but one thing that was really powerful in our study was the importance of peer support, and we know that peer support works. Listening to Jo talk about the advent of peer support at the beginning of the epidemic, and we know with all of Angelina's work that peer support works in pregnancy. What we haven't done, is think about peer support across the life course, and think about peer support for women ageing with HIV. What was really amazing about the research that we did, was that in the focus groups, for many women this was the first opportunity to sit in a group and talk about their menopausal symptoms. For many women, they have just been living with these symptoms, and thinking it was just them, and suddenly it was like "Oh, everyone else feels this as well, so this is normal." So, I think for me that was the biggest take home message is the power of peer support, not just around pregnancy, but at all stages of women's lives.

**Yvonne:** I completely agree Shema, and I think your research has really shown that. Doing the women's clinic on a day to day basis I am just amazed at the number, most of the women being referred in are being referred in by other women rather than male colleagues, and when you go to look at whether a period has ever been documented in anyone's notes, it's just quite incredible. No one asks about a menstrual history, "Are your periods regular, are they not, is there anything we can do here, do you need some gynaecological help?" It just absolutely amazes me, how all of these things are just not thought about at all. It's really basic to ask about a smear, to ask about periods, to ask, "Are you in a relationship at the moment, do you know about U=U, do you feel safe?" We always ask every woman about intimate partner violence, and we showed very clearly that if you looked at our clinic versus the normal clinic, no women were being asked on a regular – or on any – basis about partner violence at all, and menopause is just absolutely key.

There are women with menopausal symptoms who have just been sitting there completely unchecked, unaddressed, and because we can offer that then finally they were being sent through to us where we could give some advice on what to prescribe. It's such an easy thing to do, it's not that difficult, but it's just "Oh, there's so much to do, we've got the annual health check, we've got to do lipids, we've got to do blood pressure," it's like, GPs do lipids and blood pressure, why don't we actually think about something that they are not doing, don't replicate it and do something different that women actually need.

**Shema:** There's this perception that you can't ask about a period unless you're a female doctor, because "Oh my God, what am I going to do with that information?" We've had to write it into UK guidelines now just to get this statistic, for the first time it's now in guidelines that you

have to ask a woman about her period every year. I can't believe we have had to be that basic, but we did.

**Corinne:** I was just wondering if they are being asked about mental health and prescribed for that?

**Yvonne:** We do ask about mental health in our clinic. I think our nurses now are very good, so we have introduced GAD-7 and PHQ-9, and again that's part of our annual health checks. They are depression and anxiety screening scores for all men and women attending the clinic, and that's something that we have introduced because we have the benefit of having an HIV specialist psychology and psychiatry service, so we can actually do something with that information. So yes, now, in the last 12 months we have that. Historically? No. Do I know what the rates are yet in our women versus our men? No. Is there good data? No. But that's something we will work towards. But it's part of what we do in the women's clinic as well. Really important.

**Winnie:** I like to embrace my menopause, because I use it as a tool to scare everyone [laughter] either scare them or get what I want. I get in a meeting and I am like, "Please open a window I am menopausal," and I just watch everybody twitch or do whatever it is. But it's just, it was difficult to figure out when I started to have the symptoms. It just took me a lot of time, and I don't remember how the penny just dropped, and I thought "Oh my God, this is menopause." But I think for me was like, "My God, I have got the menopause, I am living with HIV and I have got the menopause, and it's fantastic," [laughter] it's fabulous.

**Angelina:** Don't forget to mention there's the social support network that you have created, there's five of us in there. I wanted to mention it because three of them have gone through the menopause, and we have this forum, it's not about menopause but they discuss all their menopause issues. So that's your power of peer support. The thing is, I've got a readymade support group around the menopause on that forum because Winnie talks about it and the other two ladies talk about it, and Winnie would ask, "How is everybody today?" and someone would say, "I'm so... don't even speak to me." But actually, we all just share a lot of information and a lot of humour. So I am just already getting information on what to look out for in a very unofficial way. I already know what to do, I know what to do to make myself laugh. It's just it's there, my support group is ready.

**Winnie:** We had to create it for ourselves, it's not out there.

**Jane:** And also not to diminish that, but it's the point in your life in which it happens, and it's a point where it intersects with so many things. A big one is getting older, it's a watershed moment. If you've lived a long time with HIV and you may... I was not prepared, I am still not prepared, I am still in a constant state of panic about my old age. I actually enjoyed that lack of... of thinking, "I don't have to take responsibility for this," and with the menopause it's like, "Oh, shit!" [laughter], "I'm going to go into old age, now I've got to really pay attention to my health". You have thin bones possibly at this point. You've got to look after your parents, you become caregivers to other members of your family, your children are leaving home, there's a lot that intersects with it, and sex can be very difficult, and you may be suffering from psychological distress as a menopausal symptom. It is a lot to take on, so it's not just the menopause, it's how it all comes together.

**Angelina:** It is, but having that support network where there's people who are unofficial is so important, because these women have gone through it, they have learnt how to cope, so I can learn from them.

**Jo:** But like Shema was saying, it's so individual. My perimenopause seemed to go on forever, I had periods for 20 days, and it was just madness, and this intense dizziness that lasted for about three years that, when it finally stopped, they said, "Oh well, that could have been linked to your menopause." Really? So the peer support thing is great, but actually each individual has so many questions about their own experience, and like you say unless you're in a clinic like yours, which sounds not like clinics all over the country, I couldn't get those answers and didn't even know what questions to ask. Like you say, worries about the bones and HRT and all that business. The other thing, which Corinne was saying about mental health, when I was diagnosed I didn't have any counselling or anything and that continued because I just thought I'd worked it all out by myself, and I was absolutely fine. About three years ago, possibly beginning with the menopause, everything just crashed. I realised that actually I had mental health issues and needed something, and I went to see a psychotherapist and it was really useful.

She recommended treatment for Post Traumatic Stress Disorder (PTSD), because I told her about things that had been going on over the past 30 years. She recommended this technique called Eye Movement Desensitisation and Reprocessing (EMDR), it was amazing so powerful and so effective, and I have mentioned this to other women similar to me. We've gone through a lot of illness ourselves and multiple bereavements, all kinds of unimaginable things that at the time we just didn't have time to deal with so it was all just pushed somewhere to the back. That psychotherapy technique of EMDR is absolutely revolutionary and everybody should have

access to it. It's just amazing, and I had an email a couple of weeks ago from a friend in San Francisco who just found it for herself, I recommended it, and she said "Thank you, this is amazing." But it's a very powerful easy technique which is just so remarkable so if I could advocate one thing it would be that.

**Jacqui:** I think that's really interesting, I just think about women I talk to in my research, that piece of having other women say ways to deal with things and cope with things is really important. I think one of the things that was really striking around menopause is, I guess because menopause is not an illness, it's not a side effect, it's natural, a lot of women I talk to have this sense of, "We just have to get through it," and the idea that there were ways that it could be easier or be supported or be managed was not really available. I am always reminded of a great quote in a THT report, the first report they did on ageing, a woman says "I went to my HIV consultant, asked about menopause and he said, "I deal with gay men and African people, I don't know about menopause.""

**Winnie:** Excuse me?

**Jacqui:** It's quoted in this report. It's fascinating, there's so much in there, that boxing up of what people are, of what's relevant. And then menopause gets left out, and some of the women I talked to have said things like, "I realised I was going through menopause because I went to a support group and women who knew they had menopause were describing things and I had the same, so I must have it, and I think I've now finished," and the whole process has just been completely on their own with no support through it. They weren't necessarily complaining about that, they just thought that's what you have to do. I think there's also a lot around side effects, that women are putting up with far more than they should be or that they could be and if you don't ask the right questions, the things you were saying, if you don't ask the right questions they don't come up.

**Shema:** I think that's partly a product of the under representation of women in clinical trials. We're basing all our treatments on trials that are predominantly done in Caucasian men, and for Caucasian male bodies, not for female bodies.

**Corinne:** I think it might also be that, for a lot of women, more and more have less access to peer support than they might wish, and so a lot of side effects get attributed by them to themselves, particularly around mental health issues, so that they say, "I am this kind of person." In South Africa, you don't really find that, because everybody knows other people

living with HIV, so they know it's the medication doing this, they absolutely know that, which is quite helpful actually. I thought it was interesting that the National AIDS Trust has this account of poverty and female head of households and ageing, and what these kinds of intersections are. I think that's something that is probably quite difficult to ask about in a clinic, do you have enough food and all this kind of thing.

**Yvonne:** At Sussex Beacon a women's worker would do that.

**Corrine:** That's great, because I remember talking to a lot of women who didn't have enough, especially if you're an asylum seeker, it's £37 a week, so you are making a choice between food and transport to a support group, or you are making a choice between your food and your kid's food. That's quite a difficult thing to talk about really, it's a bit shameful in a way isn't it, in many countries? I think it's a really common thing across countries actually that people's lives with HIV, especially women's, really are just increasingly povertised and just made incredibly difficult by things like food security, transport security, housing security, especially in that hostile environment<sup>19</sup> here. We talked to quite a lot of women who were undocumented and living on friends' sofas, and in those circumstances the support groups will actually provide a meal which is quite important, as well as the peer support. But it's pretty dire that you would be relying on a meal from your support group.

**Shema:** We saw the same thing with women living with HIV wanting to formula feed their babies. They are being advised to formula feed their babies but if you are an undocumented migrant with no recourse to public funds, you can't actually afford to pay for formula and the really expensive equipment. National AIDS Trust and Body and Soul put together this amazing report which showed that women were going without food to be able to feed their children because no one in the UK will take responsibility for funding free formula despite saying that is UK policy<sup>20</sup>, and I think that's indefensible.

**Corinne:** It's a thing you would tend to associate with low or middle income countries, but this is actually in London.

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<sup>19</sup> This refers to a set of measures under the Immigration Act 2014 and Immigration Act 2016. These were intended to make it as difficult as possible for people without leave to remain to stay in the UK, in the hopes that this would incentivise people to leave voluntarily.

<sup>20</sup> National AIDS Trust (2017).

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**Jane:** And outside London.

**Emily:** I think we have gone over time already, so maybe we should let you go. I think it's been such a rich and interesting discussion today, and thank you all so much for coming. Before we close, does anyone have any final thoughts?

**Angelina:** I was just thinking it would be really good to finish the session with everybody just going round and saying for them what has changed and what needs to happen. I have just gone into facilitator mode now [laughter], I will start because I will put myself on the spot so it gives you all time to think. I just think it's really important to acknowledge the fact that there's been incredible advances in treatment and care, and it's important that women out there get the message that with access to treatment, care and support that they can lead near normal... I wouldn't call it normal, they can lead regular lives, work, have partners and relationships if that's what they want, have children or not, whatever. But I think it's also incredibly important that as we progress along this treatment path, we mustn't leave the other women behind. You articulated really well that access to this information and to this support into treatment is not equal to everybody, it depends on where you live, so it's important that we must continue to work hard to ensure that those women who are disproportionately affected actually move along with the rest of the world in the advancement.

**Yvonne:** What has changed? I felt that at the BHIVA/BASHH conference this year, it really felt like community and the medical faculties had come together, and it felt like there was a real co-working. There wasn't an antagonism between the two, it felt like we were working together more than I'd ever really experienced before, and that's hugely valuable. I think what needs to change is that it needs to get better, I think there needs to be equity of relationship between the community and the medical faculties working together, as Shema has demonstrated, to facilitate research for women. Shema has shown it works, it can work, it works really well, and that needs to be the way ahead.

**Winnie:** I am not sure what else I can add, but a lot has changed of course and we need to acknowledge that, more than ever before, we know that in order for us to get to that point where there is no HIV at all, it's not just going to be about medication. It can't be. We have to really take the social, the medical, and people's lives are very complex and we have to continue to look at that and that social support needs to be constantly part and parcel of everything that we do going forward. But it also needs to be looked at, at every stage, how it evolves in terms of the lives of the women.

**Jane:** I was going to say something that's very personal actually which was, well I might get weepy, I haven't seen Jo since, I think it was about 1996 in Harare, and she was persuading me to go on treatment, she said, "I've gone onto treatment, and it's given me my life back." And I had no access to treatment there, of course I could have gone back to England, but I was settled. And now I am looking at that moment, and seeing her today and we both survived, we both came through it, and we're both on treatment, we have lives and we have... Well she has a family, and so it feels very immediate and in the room for me, that also that we've come so far from then to now. I do feel I have a place in the advocacy field, I do have a voice. It's just a personal reflection, because I think there are probably many people who don't feel they have a voice at all. But I think there's more women living with HIV in the UK speaking out than there were, so that's a good thing. But there still needs to be more places, so that's what has to be done.

**Jo:** Like Winnie says, so much has changed but on the other hand very little has changed. When I meet women who are newly diagnosed, they are going through the same old shit that we all went through, and that's wrong. Like you say, U=U nobody knows about that, doctors don't know that, and when people are even being diagnosed they're not being given that information, not the ones that I've met recently. So, in a way everything needs to change. We have been talking for years about normalising HIV, I think we're a long way from it being normal even though it's becoming quite tedious in many ways.

Now, finally, there's a cohort of women going through menopause so we're thinking about menopause, but we need to actually be a bit ahead of that, so thinking about the needs of people with HIV living in care homes for elderly people, how are they being treated. What are care assistants like, are they going to be refusing to wash us or clean us? We need to think about the whole life cycle, from beginning to end and so it's great to be the menopausal trailblazers [laughter], but we don't want to be the care home trailblazers, we want that sorted.

**Jane:** No, we want someone else to do that.

**Jo:** And really an end to this division between people, the clinicians that really understand it, that information is not getting to places, particularly those outside London. It really is, it's a completely different country out there, you don't get support for your choices whether it's around pregnancy, birth, even today certainly there's very little sexual health, gynaecological, *nothing* about sexual pleasure.

**Corinne:** I guess what's appeared to me especially from our discussion here is that there are possibilities for being heard but they still have to be fought for; it's like democracy, it goes away if you take your eye off it, which I guess is to be expected, but it's quite sobering really. As Winnie was saying there's still quite little, I think decreasing, attention, to psychosocial and material support. That goes along with the bad side of normalisation I guess, that you get normalised to the extent that the resources could be withdrawn, and there has been a very significant withdrawal in all kinds of sectors. I think women are disproportionately suffering that.

**Jacqui:** If I think about women's place and voice inclusion in the UK, specifically in research and advocacy and speaking up and being heard in programmes and policy, I don't think we've yet reached a point where it is accepted that you should be thinking and talking about and listening to women across the board. We recently had the *Invisible No Longer* project<sup>21</sup>, which was the first of its kind, and it shouldn't have been the first. It's taken a long time to have that national focus on women, and when you talk about that and share it with people you still come up against this, "Well don't men go through this too?" It's not really the right question. You can talk about issues like poverty like immigration, and think about how women are affected without somehow implying that men aren't, and you don't only have to focus on things that only affect women if you're talking about women, and you can actually have women talk about things that affect men too. And I think in terms of what needs to change, one of the biggest barriers, and it goes back to something Jane was saying before, is that there's not enough resources, there's not enough money, there's increasingly less of it, and none of it has ever gone to women. A lot of the work that women do and have done has been unfunded and unsupported, and there's an increasing expectation that will be the case, and I don't know how that changes but I think there is this challenge of doing things because they matter and they are important, and thinking about the practicalities later. And that means that women really shoulder a huge burden of doing work that was critical and is needed but people can't volunteer forever. I don't know how that changes but I think it needs to change and it probably means some people giving up some resources.

**Shema:** I guess the biggest change for me is that we have seen HIV, certainly within the UK, become a manageable long-term condition. I think that's something that absolutely should be celebrated but while celebrating it, not to think that the job is done, because there are so many

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<sup>21</sup> Sophia Forum and Terrence Higgins Trust (2018)

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other issues. We've talked about it, the psychosocial issues, issues to do with quality of life. Similar to what Jo was saying, so thinking about women across the life course, and I guess the thing that I bang on and on about is that women don't just get pregnant and have babies, lots of other things happen to them throughout their lives, and historically in HIV there has been so much focus on pregnancy and being a mother, and of course for many women that's a fundamentally important thing, but so many other things happen for the other 50 years of our lives. We have taken our eye off the ball, that kind of stuff, so that I think is now a renewed attention, really needs to be.

**Marsha:** One of the things that I would say in response to this discussion, and this relates to that question, is that I think HIV is an extraordinary field. It has been an extraordinary field for learning and continues to be, and in relation to other areas as well. But there is still so many questions about the process, whether it's the way that RCTs are conducted, or social research is conducted and so on, about how the relationship between different ways in which such processes are affected by how HIV is understood. I think it's still an open to learning, including how to better respond. But one of the things that I was struck by was, and this relates to medicine historically, is that medicine has learnt about the body by listening to people telling about what's happening to their bodies, and that I think much of this discussion was about that in its own way too, that is, women talking about what's happening to them that has mobilised the medical response.

Thank you all very much and to Emily who has organised this seminar. She will be in touch with the transcript, and you are free to correct things, or tighten the phrasing if you feel necessary, and then it will go into the archive.

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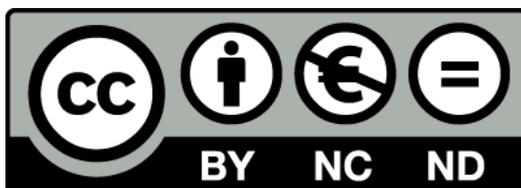
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**APPENDIX**

## PROPOSED DISCUSSION TOPICS CIRCULATED PRIOR TO SEMINAR

- Early activism
- Services and support for women living with HIV
  - Including HIV prevention, peer support, advocacy organisations
- Clinical issues
- Social issues
- The inclusion of women's voices in the HIV response
- The inclusion of women in clinical trials and advisory boards
- Women and PrEP activism
- What has changed and what needs to change?



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