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# EUROPACH

Witness Seminar

Antiretroviral Drugs up  
to and Including the  
Proposition of TasP and  
PrEP 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**

AmfAR	The Foundation for AIDS Research
ATU	AIDS Treatment Update (Nam publication, later HIV Treatment Update)
AZT	Zidovudine
CD4	CD4 count is taken as an indicator of the strength of the immune system
DDI	Didanosine (trade name: Videx)
DoH	Department of Health
EMA	European Medicines Agency
GMFA	GMFA - The Gay Mens Health Charity (previously Gay Men Fighting AIDS)
IAPAC	International Association of Providers of AIDS Care
IAS	International AIDS Society
KS	Kaposi's Sarcoma
MRC	Medical Research Council
MSM	Men who have sex with men
NAM	HIV organisation providing information and resources online at <a href="http://aidsmap.com">aidsmap.com</a> (previously National AIDS Manual)
NAT	National AIDS Trust
PI	Protease Inhibitor
PPI	Public Patient Involvement
PrEP	Pre-exposure Prophylaxis
RCT	Randomised Control Trial
TasP	Treatment as Prevention
TDM	Therapeutic Drug Monitoring
THT	Terrence Higgins Trust

U=U	Undetectable = Untransmittable (a community-based campaign to ensure the individual prevention benefit of treatment is recognised and understood at all levels of society)
UNAIDS	The Joint United Nations Programme on HIV/AIDS
Viral Load	A measure of the amount of HIV detectable in a sample of blood
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, ‘Antiretroviral Drugs up to and Including Treatment as Prevention (TasP) and Pre-Exposure Prophylaxis (PrEP) 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

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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 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 *Antiretroviral Drugs up to and Including the Proposition of TasP and PrEP in the UK* was held in a meeting room in International Hall in London on 23<sup>rd</sup> November 2017 and was scheduled to run for two hours but ran over for an extra half an hour. Some participants left during the last half hour. 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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**ANTIRETROVIRAL DRUGS UP TO AND INCLUDING THE PROPOSITION OF TASP  
AND PREP IN THE UK**

*Although we circulated a list of chronologically organised proposed topics a couple of weeks before this witness seminar, the meeting did not result in a chronological account. What emerged instead was a more topological pattern of engagement, whereby some of the early issues were connected with those of a more recent nature and, in turn, reconnected to develop a richer perspective on the earlier time. Antiretroviral medications were discussed not only in terms of their development or the ways in which they changed what it meant to be diagnosed with HIV. Rather, the discussion included some of the antagonisms, difficulties and broader changes which have accompanied the current drug prevention and treatment, while not forgetting the difficulties endured with early drug therapies including monotherapies. And often issues relating to but not necessarily limited to the history of antiretroviral medications were discussed.*

*Indeed, the transcript of the seminar brings into view issues of care where, for example, activists offered to protest about a lack of space for a clinician; how modes of caring for patients changed in the context of effective treatments; and how notions of certainty and uncertainty had to be navigated with the introduction of effective treatments. References were made to other health issues; how HIV changed certain styles of medical practice and new forms of patient involvement; how the recent discourse around the issue of PrEP might be likened to the discussions surrounding the introduction of the contraceptive pill in the 1960's. HIV activism was discussed in terms of and in reference to the women's liberation movement and broader LGBT politics. Notions of responsibility; the necessity of understanding the difference between thinking of treatments in relation to individual needs, and, in contrast, to public health policy. These are just some of the issues raised in the course of our discussion and, as such, provide a complex account wherein antiretroviral medications can be seen as being implicated in various sets of relationships and alluding to many more histories of the epidemic that extend beyond a focus on the infection of HIV.*

*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.*

**Graham Hart:** I'm a professor of sexual health and HIV research at University College London. I'm also Dean of the faculty of Population Health Sciences. I'm almost certainly Dean because I had a huge academic success because of AIDS, so I think that's quite an important thing to say, that people's careers and lives intertwine and I think that's important to register really pretty early on. I started in 1986 at Middlesex Hospital Medical School as a lecturer, sitting in a clinic in James Pringle House which was on Charlotte Street where I met colleagues. Jane [Anderson] was there very early on. So that's where I come from.

**Jane Anderson:** I'm a doctor. I qualified in 1984 and my first job at St Mary's Hospital was on the AIDS ward, and my clinical career has really been in parallel with the epidemic and I spent time at James Pringle House in 1988 to 1990 so we overlapped. And again, I've had an extraordinary set of experiences during my career which have gone from no treatment to some treatment to good treatment, to where we are today. I've worked only in London, I haven't had any experience outside a big city, I haven't had experience outside the UK, so I've got a very particular experience. The majority of my experience has been in East London, so seeing how the epidemic has affected really quite a diverse population. I've also been involved in the NGO sector, and I'm currently chair of the National AIDS Trust, and I've got a variety of other charitable NGO trust roles.

**Jane Bruton:** I'm a nurse. I retired four years ago but I'm still working now in Imperial College in London as a researcher. But I trained in nursing from '78 to '81, I worked in neuro medicine until I moved to Leicester and worked in general medicine. I've always been political, I was a political student and I was involved in the 70's at a very political time, and particularly around gay liberation and women's liberation etc. So when HIV, well, when AIDS first raised its head, then I wanted to work in it because I thought, you heard all these stories about how badly people had been treated, and a job came up in the infectious diseases ward in Leicester, which is where I was working at the time.

So I've had a little bit of experience working outside of London, where we had very few patients, but I cut my teeth on that. Then for personal reasons we moved to London and I got a job initially at Chelsea and Westminster as a health advisor, and then the job that I really wanted which was a ward sister on Broderip ward at Middlesex Hospital which was the first ward that opened specifically as an HIV ward. That came up and I got that job, and I was there like Jane Anderson through that period. I was there for ten years. When the ward closed, because obviously with treatments we then saw all the major hospitals reducing from two wards to one, we moved to University College Hospital and linked up with tropical medicine. That move was

very difficult for me personally and professionally, and so I then went to Chelsea and Westminster for 14 years and worked as, well my job changed several times but mainly as a nursing development advisor, a senior nurse responsible for sexual health and HIV, so working on the ward in the outpatient clinic. And I guess a lot of my involvement in HIV has been about trying to develop a holistic approach to care. From a nursing point of view we'd learnt so much in theory about what nursing should be, but I'd never really seen it in practice, except a couple of instances in Leicester where I was very fortunate to work with very progressive nurses, and so HIV just lent itself to us being able to really do what we thought nursing should be. And so that's been really my career about trying to develop nurses, develop the role, and ensure that patients are treated as human beings and not patients in the context of a very difficult time. That's me, and I'm a trustee of Positively UK, I've done lots of work with patient involvement at Chelsea, and I do a lot of teaching in Eastern Europe. I also did go to Uganda for three months when I did my masters in medical anthropology, particularly because of the African... at the Middlesex I felt disarmed really about how should we approach people who are coming from a very different culture, so medical anthropology really helped me to develop those skills really. So yes, I think that's it.

**Emily Jay Nicholls:** I'm the postdoctoral researcher for the UK component of this project. My PhD research had me following the making of an archive of the UK HIV/AIDS epidemic, and now I'm here working on EUROPACH.

**Simon Collins:** I currently work at a project called HIV i-Base and my job involves tracking treatment and treatment advances, and trying to understand some of the science that's going on, and try and report that in different ways. I do that in a technical bulletin for doctors that I've been editing for about 15 years. More importantly I translate it into non-technical, I say exactly the same information but in a very non-technical way, so that there are various patient resources I guess, and then i-Base also runs a direct service where people can ask about their treatment, you can email, you can ask questions online, you can phone up, and we'll take you through different options. And all that has been from a background of peer advocacy, of involving HIV positive people directly in taking an active role in choices, and options of choices that have the biggest impact on their life. Historically this comes from a situation where medicine is a specialisation that you're not really supposed to get too involved in, and clearly I think the opposite. All those boundaries and all that jargon, and all that background can get in the way of people just understanding an option between the blue pill and the red pill, or what that is, or if you need the pill at all.

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And then my personal history is, I was born in 1961, so my 20's, in my late teenage and 20's years I was exploring and finding out that there was a world out there that was different to the world I'd grown up in politically and socially, definitely. So it was a great time of finding other people that were gay, finding gay life. Really important, I similarly became politically really active, got that shock that the world could work in a different way to the way you had expected it to work, and then just the solidarity that you get from working with other people. So politically I was active through all those horrendous Thatcher years which was just this dismantling of our country, dismantling the idea of society, and that period was incredibly fertile for just having coalitions and overlapping with people with all sorts of different issues, whether it was anti-apartheid issues, or whether it was housing advice or whether it was lesbian and gay issues and visibility, or women's rights, all these things were tremendously vibrant. And without much effort you suddenly found yourself in a complete network of people who had another set of experiences, all sorts of different experiences.

So I was quite involved politically there, bunch of left wing friends really involved in a little bit the minors' strike and the print workers strike, and the lesbian and gay support groups for the seamen, things like that, and then Section 28, all that stuff that was going on there. We had marches on the local authority approaches to everything, to selling council houses, these are crazy things, so that the pockets of resistance tended to be urban left wing boroughs, and they were very dynamic. If you tell people now that Haringey Council had 3,000 people demonstrating outside the council meeting for lesbian and gay rights, and that councillors were throwing things across the room, and papers and cushions, and that's been kept off... someone told me the other day they've got this on film. And so it was a very strange activity, and I was interested in doing that. And during that I remember HIV first being reported in Capital Gay, and it was sort of, it was really another world, but it was at the level that it was single figures, 'now there's four cases'. I remember that, an inch, on the front page, I think – I hope – it was on the front page, or maybe it was inside, but I remember it going back that early, and then I found myself just socially in a group, and the UK is different to America where everybody was positive years before anybody knew anything. UK was very different, but I found myself in a social group where my friends were quite badly affected, assumed everyone was positive, that sort of network.

And then bizarrely I dropped back from the political stuff, and my life became more around social setup and what you did on a day to day basis, and I always believed there would be treatment, I didn't know about the vaccine, I have no scientific background by the way, I went

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to art college, and my work involved in setting up a community art project where people had free printing, so I was doing all that sort of stuff, but I always believed there would be treatment. My partner back then always believed there would be treatment, and so life became a strategy to get from where you were at the time to still be around when the treatment came, and that almost didn't happen. I was caught by 1996, my CD4 count was zero or had been zero for a while, or single figures, and so I was just caught by combination therapy with absolutely no expectation it would work. Really I had done DDI monotherapy and AZT monotherapy, I just stopped them because they didn't make any effect on my CD4 count, and so I had that awareness. And at the same time there was a group of people in London who had been through the same experience, and there was an organisation called AIDS Treatment Project, and this random group of people who knew treatment worked were in this strange situation of saying things that the doctors didn't agree with, and certainly the charities didn't agree with. THT missed the boat and missed the boat on treatment, and all this sort of stuff, and so that projected me more into being active and interested in treatment. And since then I've developed projects along those lines, and met some amazing people and done some things that just weren't part of my life's plan.

**Matthew Hodson:** I was 15 and decided it was about time I had gay sex, so I went to Heaven and I picked up this man who was 32 years old from New York, he was a photographer, and we went back to his hotel and we had the gay sex, and that was very nice, and then the following week I switched on the television, there was this documentary about this new virus which was affecting gay men particularly in New York, and people were dying, and I thought, "Well, that wasn't a very good start to my gay sex life." So yeah, so that was a bit of a panic. I went to university in '86, the iceberg and tombstone campaign came out shortly after that, and I was obviously... I felt I was more involved actually in the gay liberation stuff, I mean, Section 28 was obviously a big part of those university years, and the activism that I was involved in.

I came back to London, I joined OutRage! in fact I was a founder member of OutRage!. I did kiss ins and things like that and by the mid-90s I had been working at Gay Times and I realised when they came to World AIDS Day and they talked about the number of people who had died with HIV or people who were diagnosed with HIV, and I realised that I knew 4% of the UK total, and I thought, "That's pretty heavy." I started dating this guy who was the second biggest love of my life, and he was also American, and I knew right from the start that he was living with HIV, and I had to wait about a month and a half before he told me, and I was like, "Come on, just tell me I'll be fine about it, it will be fine." But it was very difficult for him, and of

course this was at the time when there were no treatments, no effective treatment, so we got engaged and my perception as I was in my 20's was that I was going to marry this person and then he was going to die, and then I was going to be a widower at a very young age, and that was the deal that I accepted because I was in love.

Of course, he rather annoyed me by then not dying, and in fact leaving me for someone else. So that was frustrating, I had picked out my outfit and everything, and that sent me spiralling off into a very dark place. And so when I was eventually diagnosed in 1998 I wasn't actually sure how I had become infected because on the one hand I could have been infected by having condom sex for three years with this American guy, but who would have had a high viral load because this was in the pre-treatment era, or I could have been infected from some random hook up in that dark period of my life. I certainly wasn't seeking the virus, but I was so depressed that to be honest I don't know if I necessarily took the precautions that I should have taken the whole time, sometimes I did, sometimes I didn't. That diagnosis changed the way I thought about my life, I had been working as an actor and I decided that was just too stressful an existence to combine with an HIV positive diagnosis. So I left that, I was working at the Museum of London, and then a job came up at GMFA, it was just an admin assistant role, it was providing admin support to the positive campaign group, and to the research group, it was booking rooms and taking minutes and stuff like that. I went there and I was really impressed by GMFA because in an early meeting I remember going to they said... they had some question which we were challenged by and the then CEO said, "Well what's the best thing for gay men? And whatever the best thing for gay men is that's what we do." And I thought that's absolutely the right attitude, and I thought it was a really great place to work.

So then by a process of a kind hearts and coronets process I rose to the top as CEO, top position at GMFA, and then last year I was asked to become executive director of NAM, providers of Aidsmap. I think I've always been passionate about information, I think that's been throughout my whole life, about information and communication. So to be given the opportunity to be involved in disseminating information, whether that's for gay men and NAM for international audiences, and I'm really keen to use whatever power we have to really look at issues for trans people who have been so neglected in provision of information, provision of services. Also keen to ensure that no one is left behind when... you look at late diagnosis, particularly amongst African communities, perhaps particularly amongst African men. So it's been a real passion for me and something that I've been really excited to be involved in.

**Deborah Gold:** I'm the chief executive of National AIDS Trust, and I'm professionally fairly new to working in HIV, it's just coming up to the end of three years working in NAT, but my personal background with HIV is that I became very politically active as a student, leftie activist from the age of 16 in my student union in my further education college, and so that meant that I had the most lovely coming out ever when I was 17 at the national conference in the LGBT party, and what that meant was that I had a whole group of university age, mainly gay men, that looked out for me through my early teens and university, and that was in the very early 1990's, so I missed being involved in all of the Section 28 stuff, but it was a part of your everyday life and very politicising.

So I became very involved in women's rights politics and LGBT politics all the way through university, and I also became very close friends with somebody who is still my best mate who had himself been very active in ACT UP in the early years and stuff. So I feel like that was woven in a little bit alongside an experience I imagine everyone has had in this room many more times than me, but I was fairly young and a friend died, and we had that very intense period of living in a hospital for four days watching that happen in the summer holiday between my first and second year at university. So it's been something that's been there through all of my politics, and then work wise I've worked in the LGBT sector from almost immediately from when I graduated on and off in different places, and so I've seen HIV alongside homelessness and how it affects things, at Stonewall Housing and alongside hate crime when I worked at Gallup, and so actually eventually working specifically in HIV and NAT has been a bit like coming home to something that's been there all the way through my politics and career.

**Edwin J. Bernard:** In my current work I'm the global coordinator of the HIV Justice Network which is a global network of activists who want to make sure that people living with HIV are treated equally under the criminal law, usually in the context of non-disclosure, exposure, transmission in the context of sexual transmission. But that's only been something I have been doing for the last five years. But my personal history, I've been living with HIV for 34 years, diagnosed 29 years ago, and I was born in '62 so acquired HIV in '83, my second year at university. I was studying film and literature, and at the time it was misdiagnosed as syphilis and glandular fever, one after the other, and it's only in retrospect I realised the seroconversion illness symptoms when I was actually working at NAM in the 2000's editing the treatments training manual and realising the list of symptoms of seroconversion were actually very similar to the symptoms I had back in 1983, so a retrospective realisation of when I acquired HIV.

But I guess in those 34 years you could basically say the first half was really a very personal battle with HIV. My work, I was mostly an entertainment journalist, a music journalist, and then TV and then film, including Hollywood, went to live in LA in the 90's. But my earliest writing about HIV was actually in the context of pop music, so I remember the very first World AIDS Day which wasn't in December, it was I think in April in 1986, I wrote a cover story for Record Mirror that had Jimmy Somerville on the cover asking why the pop world hadn't yet engaged in fighting AIDS, of course they did, some of them did very soon after. And then my other I guess cultural claim to fame was the very first music, well it actually wasn't the first music AIDS fund raiser, that was Dionne Warwick's *That's What Friends Are For*, who I interviewed, but it was Red Hot and Blue which was the Cole Porter tribute, and I volunteered my time as the person to write all the press and publicity notes for that. It was through Chrysalis Records and I spent some time with a number of the artists including Jimmy, and it was quite a few of them, Jody Watley, there was a few of them I went to America, interviewed her and wrote about that, and that was how I became aware of the cultural parts of responses, because Red Hot and Blue wasn't just about music, there was actually an amazing TV special that had a lot of the arts, like Jenny Holzer, an amazing American artist response to HIV.

So I came into the cultural part. Then I moved in '91 to LA to become a Hollywood journalist, but also because I wanted to move to the light as it were. It was a very dark time living with HIV in the UK, not only were there no treatments, everybody was dying, and there was not a lot of hope, and so I made – it felt like a very selfish decision – I left my... I was with a partner, we had a house, I left all of that behind and went to live in LA. And I also wanted to go to where there was this idea of hope, and a lot of it was charlatanism I would say now, but at the time Louise Hay and her hay rides, the recently deceased Louise Hay, I went to those hay rides, and it was a quasi-religious experience being there and seeing people who were really on their last legs. So many people with visible KS and extremely thin, feeling like they had some kind of hope, including a number of my friends, some of whom believed in that and some of whom just thought it was bullshit and they all died anyway, and somehow I survived. Then also culturally, I was there when Philadelphia was released, I was there at the junket, I was writing about that, but it was interesting I never felt I could disclose that I had HIV in that world, but it was an interesting thing to write about HIV from a cultural perspective.

Then I nearly died, moved to Vancouver, was there for the AIDS conference in 96, but had already become resistant to all the Protease Inhibitors, so it was an amazing experience to be there, but not actually... knowing I wasn't benefitting myself. Took until 2001 to become

undetectable, and that's when I became... when I moved my journalism from entertainment to HIV. Left a relationship, very... the opposite of Matthew's experience, so I left the partner that expected me to die, and he was in Vancouver, I moved back to the UK, got a job at NAM, became editor of AIDS Treatment Update (ATU), I don't quite know how that happened. It was a bit kind hearts and coronets as well there. And even then I was a journalist, I didn't think of myself as an activist at all, and it was only really when we had the first prosecution for reckless transmission in 2003, and that was the first month I had become editor of ATU, and I realised there's more about living with HIV than just surviving or taking treatments, of course it's really important, there's this whole other stuff going on. And then I became much more of an activist particularly around this issue of responsibility for prevention and transmission, and that led to my work now.

**Marsha Rosengarten:** I never really know what bits to select in these things. So anyway I'll try to say what I think might be most relevant to this meeting. I'm Marsha Rosengarten, and in fact my initial introduction to working in the HIV field was in Australia, and really my knowledge of the history of the epidemic is very Australian centric, and I think the sort of political context in Australia was very different to what it was here. The beginning of the epidemic was in a way a rare moment in Australian politics, there was a lot of support and I think that has affected how HIV as a policy consideration is now situated in Australia and the way medical care happens and so on. But I worked initially on a study that was to investigate whether and if so how the introduction antiretroviral drugs, this was around 1999, whether the drugs were responsible for the decline in condom use. What became apparent in that study was that it seemed to me, and working with a very close colleague Kane Race and also Sue Kippax (who some of you will know), that positive men were really quite inventive about how to negotiate sex without condoms, having faced the prospect of a life of always using condoms and now drugs had shifted that demand. But, by contrast, many HIV negative men were not situated in a way that would enable them to talk about why they were having unprotected sex. It seemed from what they said in interviews that unprotected anal intercourse was a real no-no, it was to, 'put yourself at risk.' I left Australia and moved to the UK for personal reasons, and worked with Graham Hart and Paul Flowers on a project where I became very interested in how the clinic was changing because of the introduction of antiretroviral treatments, and I met a number of people in the field then, like Jane Anderson, and Simon Collins who I don't think remembers me knocking on his door a few times...

**Simon:** I do, when I was at ATP.

**Marsha:** And much later I also met Edwin. I am now a Professor of Sociology at Goldsmiths which is part of the University of London, and much of my work is teaching and administrative work as part of a conventional academic role. My interest in PrEP came about in the late 90's, actually it's maybe 2004 I think or 2005 when the controversy about PrEP trials in Cameroon and Cambodia came out. I don't know why I became interested in PrEP. I don't find randomised control trials at all interesting, I don't think I have a particular feeling for PrEP either, I certainly don't live in a situation where I would require PrEP, my life is really pretty boring. But I found myself following the development of PrEP and the controversy and then the establishment of the big trials mainly in Africa but also Asia. I put a lot of effort into getting to know Bob Grant who led the iPrEx study. And one of the things that I was intrigued by was how those trials with MSM and with heterosexual couples were very successful, but with women the trials were not successful and the onus seemed to be on the women. They basically didn't take the pills and lied, and so I wondered what we can learn from our research participants when they are recalcitrant.

So I think this connects with what some people have said about the ways of knowing the field differently to that of the scientific knowledge, even though the scientific knowledge in the HIV field has been major. And from there I have become interested in other infectious diseases like Ebola, TB, and Zika which I think is particularly interesting because of the onus placed on the affected individual, the responsabilising of the individual and the absence of any medical intervention, just, "Don't get pregnant," or "Have an abortion," when you live in a country where abortion is not legal. Lately I've also become interested in malaria through a strange set of circumstances. But I remain now, I suppose my main connection with the HIV field is PrEP, and how to think about PrEP in a way that doesn't responsabilise the individuals that it's targeted for. Although I do think that there is a very strong culture of responsibility in the gay field, because I think historically that's how prevention happened.

So I think there's something very interesting about the way that people understand responsibility and engage with it in order to sustain a sexual culture in the presence of a virus, and I think Graham, when you said that careers have been built on the basis of this virus, I think it is an extraordinary field, and I don't think that other fields know how much can be learnt from this field as a consequence of the history of it. But nor do I think that the field has really plundered what it can learn from itself either, so that's how I'm here.

**Ingrid Young:** No pressure to be the last one [laughter]. I'm not entirely sure why I have been invited to this but I'm pretty pleased to be here. I've come to this relatively new, I have been

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working in research on HIV in the UK for about ten years or so now. Before that I suppose my first experience with HIV was, or my first memory even, was a friend had taken me to see a musical, I grew up in Canada, we went to Toronto and saw a musical in Toronto. At the end of the musical they had, this was in 1990, they had requested at the end, the Actors Guild Fund had been depleted through people accessing it because they were living with AIDS at that time, and they were asking the audience for contributions, and my friend's father grumbled horrible things about how, "They don't deserve it." Horribly homophobic stuff, and I had no idea what he was talking about, I had no idea what they were talking about, and I think for me that was quite significant.

So my engagement with HIV has always been through a rights based approach, so recognising not just the experience of people living with and dying from HIV and AIDS but also having to fight those really horrible responses to HIV and AIDS, and to LGBT communities. So I said I've been working on HIV in the UK for about ten years, I have never worked in London, my research was in Newcastle and more recently has been in Scotland, and what struck me has been, I'm really interested in the narratives of HIV and histories of HIV, and the histories that people tell, and I think they're really important, and I've been really lucky to be able to hear and listen to it and share some of those histories through my work. And what struck me in the work in Newcastle and similarly in Scotland has been the role that the memory of the early experiences of HIV and activism within that and living and fighting within that early period have continued to play a role in experiences of HIV and stories of HIV as we go through into the 90's and 2000's and now.

And as I came to HIV here about ten years ago, at the beginning of the treatment as prevention, so not the treatment era, I suppose people recovering, but also the treatment as prevention. So it's been an interesting point to enter and to work with communities actually to think about how do we think HIV in the light of a long history and a particular history fighting for rights and fighting for treatment, when treatment now means something entirely different, or perhaps doesn't mean something entirely different but is situated scientifically as something different. And again, I've been really lucky to be able to work with community organisations throughout my research and to learn a lot from them. Most recently I have been working with HIV literacy but I suppose not just how do you understand how to take PrEP, so Simon your point about you just need to learn what pills to take, but also I'm interested in the broader conversations about how communities facilitate those discussions and those conversations, so how communities can take in the new scientific knowledge and make it their own and employ it in ways that are

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appropriate for them, and how communities can teach clinicians and work with clinicians to shape health experiences and access to treatment, and access to other things that are necessary to live well with HIV in the current period.

**Marsha:** Well there's a wealth of experience here, and I am in two minds about whether to ask you to think about the present and how we've come to this or go back to the beginning, because you have all spoken about that, but I think maybe it might be good to talk about the first recognition of AIDS in the UK and what you recall happening around that from the political context to the situation. Jane you mentioned, and I don't know whether this is significant at all but you mentioned that there were two wards in major hospitals and one closed, and I was wondering what were the two wards and why did one close?

**Jane B:** At Chelsea and Westminster, the Middlesex Hospital, the Royal Free I think, and St Mary's, there were two HIV wards, because when I first went to the Middlesex Hospital there was just Broderip, but they had already been planning at that point, so that was in 89, that we needed another ward, because of the numbers of people coming through. But obviously once antiretrovirals came in, then we needed to shrink, and the same with Chelsea and Westminster, so they had two wards, one of those wards shut. Actually, it was an amazing time to think that's what was possible, but of course it was also a very difficult time for the nursing staff, because we were losing our jobs, but also you had known which patient had been in which bed, and memories are also about the environment and the bricks and mortar that are there. Also for the patients, it was very difficult for people who were coming in constantly to suddenly realise that they won't be coming into Broderip anymore because it was going to shut and it was the Charles Bell ward that they would be going to instead. And the same with Chelsea and Westminster, that they shut. And I'm aware of that because I went on to work there, and the wards had slightly different cultures, the way we nurse was slightly different, patients preferred one ward or the other, and so that was a strange time, because it was obviously a huge step forward because of the advent of treatment and that meant that people weren't coming in sick as they were. But of course it was also a time of sorrow and loss for the people who had been working there, and for the patients to a certain extent.

**Graham:** But that was much later wasn't it? Very early on there was quite a lot of denial around HIV. It seemed to be very American, lots of numbers there, although a number of activists, particularly through THT and other organisations started responding to it in the UK. I remember being on Gay Switchboard in Manchester in '83/84 just doing a routine evening answering the phone, and somebody rang up and was asking me about AIDS, and I said, "Oh yeah you're

more likely to be hit by a bus than you are to get AIDS.” And I was in complete total *denial* because it was *over there*, relatively few numbers, and it seemed very distant. So I can’t have been on my own in that experience of denial, obviously very rapidly I changed my perspective. But not everyone was immediately out on the streets fighting this, it was really frightening, and denial seemed like a good response actually.

So I think by 1990 I was in a clinic where people could barely walk up those steps into James Pringle House because they were so ill. But by then it was also extremely exciting professionally, because suddenly you had a set of skills that people were interested in. I could actually talk to the men. The first study I was involved in they were going to interview men in clinics, I said, “Well why don’t you go to bars and clubs?” And the response to that suggestion was like, “*What?*” And so that was my innovation, going out into communities and asking people about this. We couldn’t have done needle exchange if it hadn’t been for HIV, we opened the first needle exchange for injecting drug users, but because of a political environment in which even though we had a Tory government, Norman Fowler just said, “Yes.” So again, that doesn’t sound like a... it’s not an activist thing to say how marvellous a Tory government was, but in fact it was immediately responsive through Norman Fowler to our request for DoH funding for the needle exchange, which allowed us to demonstrate that needle exchange was safe, it was a means of prevention.

So there are several histories here going on, and colleagues were activists as well, weren’t they? So I remember in the clinic there was a huge debate, a lot of doctors didn’t want to provide condoms to gay men because, “If you provide condoms to gay men you’re going to encourage them to have anal sex, so you shouldn’t provide condoms.” So, some people from THT came, and said, more or less, “This is mad,” and there was a big debate in the clinic between the doctors who were in favour and the doctors who weren’t on providing condoms for gay men, and this sounds like dinosaur times, but this was very urgent and meaningful and the politics were in the clinic as much as they were in...

**Simon:** The same old tired arguments all appeared over PrEP, and they appeared at a regulatory level. The reason PrEP took four years to be approved in Europe was because the EMA said, “But we’re a bit worried about what will happen if we do this.’ That’s a regulatory level, there’s nobody decides whether a statin should be approved depending on whether you’re going to change your diet and eat more healthily, it’s outrageous, and that is rooted in social inequalities that still find their way through the systems that make decisions about people’s lives.

**Deborah:** And you saw that in the press release from NHS England in the UK as well and in their attitude, that same kind of thing.

**Matthew:** Yes, this is a lifestyle drug rather than actually... and people who take it are irresponsible rather than admitting that people who take it are actually taking responsibility for their own health.

**Graham:** Resources will be taken from children with rare disease or arthritis or whatever. The idea that you then take money from other people and put it into this is not quite the way it works.

**Deborah:** And the argument that PrEP might in some way make people stop using condoms, and the logical extension of that is, if there was a cure would you not let people have that in case it encouraged people not to worry about...? There are few other diseases that I can think of where there's that level of...

**Jane A:** We had the same discourse around the pill in the 60's, "If you give women the pill and they won't use condoms then goodness knows what will happen then," or women will have sex for pleasure, goodness me, heavens. So the same discourse was fought by women in the late 60's and it's come round and some of those arguments are just coming back round again. But I was just reflecting on what you said, I think this ties in because my first experience was in the ward, an infectious diseases ward that was full, it wasn't a designated ward, it was the infectious diseases ward at St Mary's and it was full of young men dying, and my next job was at Middlesex where there was a designated ward and the next job that I had was to go and make a ward like Broderip and Charles Bell at Barts. I got there in 1990, armed with having seen and worked in those areas, and I remember a question from a very senior colleague at Barts who said, "Oh my dear do we do that here?" I said, "Yeah we do." "Oh I didn't think we did that at Barts." So this is now ten years in and I suppose, coloured by having seen and worked at the places I've worked, "Well of course we do it here, and we've been doing it really well," so I got enthused. But the idea that then leaping forward 20 year to whenever it was, 2014/15, having been in that medical environment, to then be in a position where there is a tablet that you can take that stops it, it was unbelievably exciting, and the idea that anybody of my generation would not want that like *now* and quickly. I think we've seen things that have just, they have been so powerful, that the idea that you would not want to do something and have it available straight away, I still can't understand how we can be in that position. And your point about regulation and politics is absolutely right, it's shocking.

**Simon:** It would have been in the beer kegs at the Market Tavern really, if PrEP was available in the 80's. I'm not saying pills are the answer to everything, but really, if you get sick you want a way of curing it. I remember James Pringle House, I remember Thomas Macaulay and Elizabeth Gaskell ward, and the support that came from health professionals on the whole. If you were coming at it from someone who was positive, you just offloaded a lot of your responsibility and your trust in your doctor helping you. The doctors and nurses, care and their roles as activists is absolutely right on. You couldn't be involved in this unless you had some sort of activist level.

But the brief<sup>1</sup> starts at 1996, and I was a bit worried about that because there's so much that happened before then. If you go back to individual experiences about when you first heard, if you first heard in the early 80's when it was first discovered, when this thing was discovered, it was very science fiction. It's exactly what you're looking at in films and in movies, and all this sort of stuff on there, and because it's inexplicable and it's completely out of the blue, and there was no way of making sense of it. So you would get a crystal and you would go to some crazy Cass Mann thing and you would do the whole lot of things that you would in the absence of even viral load, you couldn't prove there was a virus. There was all that nonsense that was going on about the virus, and then the overlap with such a slow access to treatment, for it to take six/seven years to have your first drug and that drug was so... I remember running around to the newsagents to get newspapers when you heard about... this is all before an easy way of getting information, I ran round and got the newspapers, and I heard about AZT.

And America – unless you had some money or you were very resourceful, I didn't go to New York, I couldn't get the air fare together. The only way most of my friends got the air fare together is they did that, was it a Hoover commercial, or a washing machine commercial? It was a big giveaway of tickets, and that's how most people got there. But the people who were affected in the UK really early on were connected to that network. You were broadly, there was a set of gay men who were pretty well off, pretty sorted out, they were pretty, basically if you're in the leather set really, into that, then there was the international network which was Berlin, Amsterdam, San Francisco, New York, maybe LA, maybe a few other places as well and if you overlapped in that then you were clearly at a high risk. So there was a little bit of that in the UK and some of my friends were involved there or connected through there. But that didn't overlap at all with my politics, their politics were horrendous most of the time, and so I had disconnects,

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<sup>1</sup> A document was circulated to attendees before the meeting took place (see Appendix)

where you fit in with different places. But the idea of steps going up to a clinic, this was in terms of whether there's access to somewhere, and the association with places is really important. There were times when I couldn't even go in that area where the hospital was, because of experiences there, and then there were also places where I kept having my care where my partner died, and that's a tough thing to do.

**Marsha:** Actually it is pre-1996, not from 1996, and I think it is interesting...

**Simon:** So the activity before then was huge amounts of community activity and it was really about fundraising, and then entrusting people. A lot of British charities are based on doing things for people, and luckily there were people there that made sure if you were sick or if you were positive you could get benefits. The US experience is completely different to that, you actually had people who were on the streets and you weren't admitted to hospitals because 10,000 people were positive in New York when they first had the test.

**Jane B:** I was just going to pick up on Graham using the word innovative, and I think that's really important to capture about those times – and now, really – because as a ward sister I was just left to get on with it. Nobody really wanted to have anything to do with the ward, particularly at a senior management level. So we could do things that had never been done before really, and that was what was so exciting.

**Graham:** But it was individuals as well, people like you and [Clinician 1], [Clinician 2] they pushed ahead. [Clinician 1] couldn't originally go into the consultant's dining room because they wouldn't speak to a junior physician, so this was before, because it was just too low a specialty.

**Jane B:** And [Clinician 2] was so important in that.

**Graham:** So [Clinician 1] persuading [Clinician 2] to come on board allowed the thing to go forward, so you had to make allies of people who were much more senior so that you could get things done. But it's funny how that individual action so to speak has these massive consequences.

**Jane B:** Yes, and people being prepared to take risks.

**Graham:** Which as a sociologist, I trained as a sociologist, you never think in terms of that kind of leadership and innovation and direction, but it's absolutely critical to getting things

done in the same way, as activists obviously get it immediately. But when you're in an organisation...

**Simon:** But Jonathan Weber said things didn't really change in the UK until you had the Horizon programme. You had to make those links in terms of the social response. Lots of things went under the radar until then, and actually the response afterwards wasn't entirely positive because the 80's, if you actually pull out some of those ways that HIV was reported, or anything was reported, this is a very hostile climate to have been living in, and the healthcare services were these little islands of calm and when you went into the wards. Even something as simple as having a kettle or a fridge or a toaster, or the ability... hospital food has never been great really at the best of times that you had, you changed approach to healthcare for all sorts of other areas. I'm not sure holding on to the smoking room [laughter]... because basically it's a quality of life thing that was going on there. So you made sure people had TVs and videos and stuff to do, and all that stuff which in terms of receiving care, you were being given kindness at a time when outside it was incredibly hostile.

And actually some of the hostility ran through places where you wouldn't have expected it. There was a lot of division because of fear in most gay clubs if somebody was positive, there was discrimination and hostility and then there was another set of discrimination depending on whether you were actually sick or not. So there was this whole protective thing, "But my CD4 count is okay so this is going to be okay." And having learnt the science afterwards, the stuff we didn't know back then, all the world's experts, the bit that keeps me interested in science is when experts get it completely wrong. Through the whole of the first ten years Fauci and all the top scientists believed that actually this was a latent stage of infection and then what on earth could be the trigger? At some point you have this infection and then there's latency, and something as simple as a viral load which just happened to be developed in the 80's, shows that actually it's a slowly progressive illness and this is something else that's going on. And so it's interesting, incredibly interesting, and incredibly conflicting in terms of the emotions as well.

**Jane A:** I think the thing about the support and the end of the wire thing is really important because the support I found as a clinician came from really unexpected places, and so I had exactly some of those experiences about colleagues going, "Oh, I don't think we do that," and then some of the most unexpected colleagues at Barts absolutely being committed. I remember a very senior surgeon, incredibly stiff pinstripe suit, with a man who needed to have a splenectomy and he got a platelet count of two, it was blood absolutely all over the place, and I remember talking to the surgeon, Barts surgeon, pinstripe suit, and he said, "Of course he

needs an operation, I'll do it tomorrow. What do you mean bottom of the list? Of course not." And suddenly I realised that there were real allies in some really unexpected places, and the professor of medicine at Barts, the most terrifying man said, "Of course, yes, what do you need?" And suddenly there were people really supporting, and the thing also I remember very clearly from starting at Barts is that I didn't have a proper office, I didn't have space, I didn't have a place to see patients, and somebody who was part of ACT UP came in and he said, "You can't work like this." [Laughter] and he said, "Well who should I complain to?" [Laughter] and he said, "Well I don't think this is adequate, and I think we could do something about this, let's say six weeks shall we and see whether you've got the proper facilities by then, and if not well we could bring some chaps in," because there were all the people doing chainings, and he said, "We can bring some guys down and do a chaining for you." [Laughter] six weeks earlier I had got people, "Oh do we do that here my dear?" So I said, "Look can we just put a hold on the chaining?" But nonetheless the very fact that one of the people who I was there to care for cared for me back to that extent was transformative, and I thought okay between us... and we got an office, and we didn't do the chaining. But again the unexpectedness of some of those things was fabulously important.

**Graham:** But another time you might want to look at other diseases and the relation to HIV, because I couldn't understand later on why there was such a focus on PPI, public patient involvement, because that's what you had to do. You could not do things to gay men, they were very articulate and often coming from quite powerful backgrounds themselves, they weren't going to take this stuff, and so you just had to engage otherwise there was no permission to do the work, and certainly for research you absolutely had to engage. And I did the same with drug users, because you couldn't progress without them, and so then PPI comes 20 years later and it's really bizarre, and you look at cancer services probably now still, and none of the learning or it's just coming through now, the learning from what HIV did, but that's another story, but what we take for granted elsewhere is just not the same.

**Marsha:** There are a couple of things about Ebola that resonate there, that Ebola relapse is thought of as if the virus stops dead for a number of years and then just re-emerges, and when I'm reading it, I'm thinking, "Have they read about the history of HIV?"

**Graham:** And sexual transmission as well.

**Marsha:** Well sexual transmission yes that was definitely not considered, but also about working with communities rather than actually isolating them to the point that they had no

resources for everyday life. I think there is something really extraordinary about the dynamics of the HIV field, but I was wondering when you said earlier about how Norman Fowler agreed to needle exchange and so on, what was it, because much of what's also been said is this incredible sexual moralism that purveyed the epidemic and who is responsible, and the stigmatising and so on, and yet it seems that this figure in a Conservative government made an enormous difference in terms of responding to the initiative of you and other people.

**Jane A:** He made it a health issue and there's that amazing quote when I come... there's something in parliament when he was asked some difficult question, it's the guy from Manchester, Anderton<sup>2</sup> the chief constable, and Norman Fowler sat up and he said, "We do not have the time for moral discussion, this is a health problem, this is a health emergency, we do not have time for any moral debates, we've got to do something about it." And I just hold that as a quote thinking okay yes, and for us as health professionals hearing this is it's a bit like alcohol dependency and drug use now, is it a criminal social issue or is it somebody who is ill?

**Graham:** But he was quite clever in a sense, using health politically. So if it's health it's permissive and you have to deal with this. But of course, health is absolutely morally bound up with a whole set of ideas as we've just been talking about, in terms of regulation for example. But it's a nice short hand that is for the moment permissive because if it's cast as a health problem then maybe unusual things have to happen for it to be addressed. But it was politically astute to cast it in those terms given the moral mess that we were surrounded by in terms of the views of government generally and Thatcher in particular.

**Jane B:** And he had a big battle within the Tory government, Thatcher and Willie Whitelaw etc, all trying to stop some of the initiatives. But that's where he had that link with clinicians as well and activists that I think made a bit of a difference in terms of what he was able to get through.

**Graham:** And he was highly regulated. The needle exchange wasn't just opened up, it was very strict about where you could be, what you could do. At one point it was the number of needles and syringes you could hand out, it wasn't a free for all. But again, I went to a conference in Sweden and they were completely opposed to needle exchange because they were so concerned about the impact on drug use, and again a moral conceptualisation that if you

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<sup>2</sup> James Anderton, the then chief constable of Greater Manchester in 1986 referred to gay men, drug users and sex workers living with HIV as "swirling about in a human cesspit of their own making"

facilitate it, it will just go crazy and there will be many more drug users. And I was, by talking about this, and because I again used HIV as the excuse because actually if you provide clean needles you don't get Hep C, you don't get abscesses, there are other kinds of positive sequelae from this, and I was trying to think in a more holistic way. But that was just not considered to be an acceptable way of thinking, and I was really shouted down at a conference about introducing this, I was immoral for facilitating drug use, and that was from health people. So there are debates within, it's not hegemonic, it's completely fractured and fragmented like any other area, it has those elements.

**Simon:** I think it's nice that there was a success that came with needle exchange, but I'm really uncomfortable with trying to rewrite that as a positive HIV response from government because government did absolutely nothing for gay men, it was all done by community activity, fundraising, health information, the Kobler Centre was set up by charity awards, by charity fundraising, and actually you had a government response, and Norman Fowler is uncomfortable about it now because every time he speaks he has to muddy up the water about, "Oh it's lovely we've got gay marriage," actually that was a government that was absolutely hostile and is directly responsible for the reason so many gay men are now HIV positive to say you cannot talk about sex in schools. And there was a raft of gay teachers who were immediately put in a really terrible situation and health education, we come from a constricted sex negative culture and that was used to make people feel, to twist the knife when people are particularly vulnerable, these governments, the government's response back then was shocking.

**Graham:** I agree absolutely, and the reason that Fowler put it through was, you're absolutely right in terms of gay sex and so on, it was because they feared a heterosexual epidemic, and so what they were doing they were doing this in support of preventing that, because of course it didn't. Not that it didn't matter about gay men, but they were not so very bothered in the way that you're rightly saying. They did it because they thought it was the bridging idea that injecting drug users would have sex with innocent heterosexual people and they would be infected, so bring in needle exchange and that will stop.

**Simon:** But it was a crazy response to put a leaflet in every house, it was a scaring teenagers from having sex response, and that knocked through directly onto prejudice and stigma against HIV positive people, and to gay people, and to anybody else who got caught in that net. It was a shocking response, it wasn't a good strategy, and it didn't come with the resources for the people that really needed it. It ticked a box for a leaflet and it was a scare campaign and I don't think that it should be rewritten without a balance there from response.

**Jane A:** The same thing then has happened again. And going back to TasP and PrEP, because the history of how to treat everybody in this country was also very flawed and government didn't want to treat everybody, and we had to fight extremely hard to make sure that people who didn't have the right citizenship were able to access to care that they needed, and we made arguments for many years about human rights and that migrants had human rights and should be treated, and that it was about decent medical care. We got *nowhere* at all until TasP, and it became clear that people who were treated were not infectious, and then the discourse became, "Oh, actually, it would keep the population at large safe if migrants got treated," and it went through. But it was exactly the same discourse, but 20 years later.

**Simon:** That is absolutely remarkable that this country provides HIV care irrespective of residency status.

**Jane A:** But we had to get it because it was that thing that we needed to happen.

**Simon:** It's an example of how policy people working behind the systems with the way things work can have remarkable effects without any level of grass roots activism. You get this amazing response because a few people pick it as a target and decided, "We're going to go for this," and then you get this amazing response which is remarkable, but it happens without people having to necessarily have been so involved, so it makes you vulnerable as policy organisations or as activists behind the scenes, because it doesn't necessarily come from a grass roots perspective. You definitely need both, you need people working on every front doing everything you can, wherever you can, and luckily we move forward a bit. But the history of treatment as prevention it's just cracking that through now, it's cracking it through, and yet you've got US guidelines 20 years ago were suggesting that would be a reason to start treatment earlier to protect your partners.

**Jane A:** And we had to fight for NHS England, that had to go through and we got that through whenever it was, and we still don't have universal commissioned treatment for everybody, it's free for everybody, but the commission...

**Simon:** It's commissioned at CD4 350.

**Jane A:** We've still got that in the service specification in this country so that's still waiting to be dealt with.

**Marsha:** What does commissioning relate to?

**Jane A:** So what's happened is in 2012 the Lansley reforms went through, 2013 when they went live, HIV specialist treatment and care sits under the control of budgetary control of NHS England, a new statutory authority separate from the Department of Health, and they are holding the budget, and whenever you want to do something new or different a full application process has to be made to the top, that's when PrEP got sucked into that.

But the TasP piece we got the data, we had all of the information and Simon was on that writing, you helped write that I think Simon, you were there for the TasP writing piece. But the whole thing had to be written out with every bit justified, and then it goes to a committee, and it took a year even after getting the first thing written before it was considered and actually it was funded. There's lots and lots of good scientific data that starting treatment early is very good for everybody in many ways, and yet that has not yet gone to NHS England commissioning board, I think it's going in the next month or two, but the policies have been written, and so in this country NHS England pays for treatment for everyone with a CD4 count of 350 or below, the national guidelines say everybody should be able to access treatment, international guidelines say the same, but our funders don't yet pay for that.

**Ingrid:** In Scotland it's different, but I think this is an interesting division and policy.

**Simon:** The workaround is that doctors take no notice of that.

**Jane A:** We do it anyway.

**Simon:** And there's a cover that if you are concerned about transmission then you can access treatment earlier. But the reason they start at a higher CD4 count is there's clinical evidence. I love randomised clinical trials because it shows that everybody benefits from treatment even at high CD4 counts, and that big study that looked at whether you start at 500 or below in the UK. When that study was being planned the feedback from doctors was that nobody will ever start treatment at 500, you can't have that in a randomisation, we might get away with 450, but you could never do that. Now it's completely changed, and the first response to treatment on the one hand is you've had these remarkable responses, Kaposi's Sarcoma (KS) disappeared. I had friends whose faces were covered with KS, and it just edged all back and melted away, and so the activists then who knew treatment worked then had to... the phone line we set up, all that people wanted to know was, "Does treatment work?" And it was coming from the fear of side effects. And so you could have 20 people who did a few nights a week, and we had pizza and the phones would ring, and people would just ask, "But do they work?" And the fact that you

were there and taking the meds you could say, “Yes, they’re not perfect, you might need to balance them with this, to balance this side effect or manage this, or switch round,” it was so important that we can’t miss in the time we’re talking here. And then the next thing that happened was the fact that those drugs weren’t all so good.

So two issues I would like us to talk a bit about is how we felt when treatment arrived and then how we managed the fact that it wasn’t perfect. So actually, even though you had this treatment the consensus for the first ten years, more than ten years, at least through to 2005 was that you would wait until as long as possible before you needed treatment, and yet now you’ve got clinical evidence that shows that’s not a good thing. It’s not all the CD4 count, it’s the ongoing viral load going on in the background that is much more serious than people realised. So I would be interested to hear, Edwin, how did you feel, because you must have been that situation of having... because I remember we had the Delavirdine discussion, you were the only person in the UK who was using it [laughs].

**Edwin:** Well, I was in Canada

**Simon:** But that point of did you recognise that you... because the whole need to understand about resistance was a new field, brand new field, well HIV was a new field, if you asked people who were scientists what immunology was in 1981 it was two big textbooks, and now it fills libraries.

**Edwin:** Resistance wasn’t on the agenda. So I was in the saquinavir registration study, taking saquinavir, DDC, and I took delavirdine, I did all kinds of all the monotherapy, dual therapy...

**Simon:** Saquinavir and DDC, you poor thing.

**Edwin:** ...everything... and actually I went into the saquinavir registration study because I knew they were doing viral load tests, and this was ‘95, I was living in San Francisco at the time, and I was expecting to get my viral load, it was like, viral load? It was amazing, at the time, that you got to know your viral load, and I was so disappointed to discover that the drugs were like... Okay, I was ambivalent about the drugs because my own history with them was that, just like you were Simon, I took AZT and DDI and they didn’t even work for me, just had lots of side effects. But I wanted my viral load, and then they were like, “Well actually we won’t give you the viral load until we have finished the study, because it’s double blind placebo controlled.” So after that I sent the pills off to a lab, and there was... I can’t remember, it must have been AIDS Treatment News I think, there was a little mail order ad, you could send off

your drugs to be tested to find out if it was placebo and it came back and it said this is protease inhibitor. I was so excited [laughter] I unblinded the trial! But when I left the trial, when I moved to Vancouver in '96, because I wasn't feeling any better, and then they gave me the results and it turned out of course that I had acquired resistance to saquinavir within three weeks, and that I had a viral load that it had maybe I think gone from 300,000 to 50,000 and then back up again. So that was a waste of time.

But my own personal experience with treatment was incredibly ambivalent for a really long time, because it was all about toxicity. You talked about Cass Mann, I remember going to Cass' workshops. You talked about denial earlier on and that's how I experienced my HIV, I didn't take a test until '88, I didn't start using condoms until '86, it was just, "Avoid Americans". I didn't know I had HIV in '86, and I just avoided Americans until someone said, "You really should use condoms with me because you don't... I don't know if you've got HIV." And I felt dirty when he suggested it, but he was right of course because who knows how many people I may have exposed to HIV unknowingly during the time I was undiagnosed and wasn't practising safer sex. But the treatment stuff was just, it was all "Poison." It was like, we weren't particularly excited as individuals about AZT, or in fact any of the early monotherapy, even in '96. So I was there at the Vancouver conference, and everyone talks about this as the amazing moment, but not only did I not benefit personally, but so many of my friends continued to die. It wasn't like '96 and everything got better, there were many people who didn't benefit from the early PIs, and those early PIs were not great, they were particularly... full strength ritonavir for goodness sake.

So for me, and I think for a lot of people it was Kaletra, it was the second generation of PIs that certainly made the difference for me, once they discovered that low dose ritonavir could boost PIs, and that made the difference, and that really overcame the resistance. So when I moved from Vancouver to Brighton, although interesting side note, because I was living in the US and Canada for nine years I was getting benefits in the UK, and I was still sort of in the health system, but I was working the system in both US and Canada and got the best treatment there as an undocumented migrant basically, I found ways of getting documentation. But I remember Julio Montaner was my doctor in Vancouver, the salvage therapy expert and now "Mr TasP," and he had recommended Mike Youle to be my doctor, and I went to the Royal Free in 2001 preparing for my move back to the UK to have an initial, it was an audition really, because by that time having worked with Julio and learnt to be an expert patient it's like I wanted... And just before I went in to the appointment I was stopped and they said, "Actually you're not

ordinarily resident, you're going to have to pay £400 to see Mike Youle." So I went okay then I won't see Mike Youle. But then I got into the Brighton system and apparently, in the history of the Lawson unit in Brighton I have had more resistance tests than anybody as well as therapeutic drug level monitoring tests because of the salvage therapy I went through with Julio. And it was only in 2001 when I achieved my own undetectable viral load that I actually started to appreciate treatment, and that's when I wanted to write about it, and everything that I had experienced and all of the concerns I'd had about side effects and resistance, and TDM and all those things I had learnt myself. It was like I need to figure out how to help other people understand that. So that was my way in.

**Simon:** I like the way you said when they realised that ritonavir could boost saquinavir. So because I was doing treatment activism back then some people knew that as soon as saquinavir was virtually available.

**Jane A:** Well we had grapefruit juice, we used to prescribe grapefruit juice.

**Simon:** And so it's off at a tangent, a geeky little tangent is the history how some of these things that we take for granted as medicine actually got accepted, and I can tell you both the companies Merck with indinavir, and Abbott with ritonavir, they fought against that data. You had someone going from 600 milligrams twice a day to a booster dose of 100 milligrams, that's all you would need, and the option it settled to 400 in each of those companies, but ATP had a meeting where we pulled all these people in the room, and indinavir manufacturers would say, "No you need 800 milligrams of our drug and just 100 milligrams of the other." These people fought. I've got a letter somewhere where I've written to the head of my hospital, and got a very friendly response back, asking for viral, the importance of viral load tests, and the response was that, "It sounds like a very sensible idea but unfortunately we have no randomised clinical trial data that supports that."

**Jane A:** But we had a debate, I remember the meeting, about whether we were going to do viral loads and, "Shall we or shan't we?" "I'm not sure it's worth it," absolutely those conversations.

**Simon:** And those medical things you don't hear about, Professor Clive Loveday who developed the first viral load tests and he was charging the companies £10,000 a kit to test or something, or huge amounts of money in order to tell them whether their drugs worked, had an application to the MRC to develop viral load technology for individual patient care, and a letter came back saying, "There is no circumstances where we could imagine a virus being managed

by individual viral load responses,” that sort of interesting stuff, and I’m glad you mentioned Mike Youle, Mike Youle I think plays a significant role in why PrEP is even available. To stand up in 2002 or 2003 and to Bill Gates say actually, “As a gay man I would quite like to take a pill maybe if it would protect me,” and Bill Gates was like a rabbit in the headlights, he just is, “Well why wouldn’t you use a condom?” The complete disconnect between a rational way about the world works and the reality of the messiness of the way the world works when each year a whole new generation of people become sexually active with absolutely no support information, and very few resources, and in the context of dynamics about expectations about what you’re supposed to do sexually or not do sexually, and how on earth you navigate all that.

And so these people played key roles, and so I hope you add them to your references. But all the lead doctors that came in as junior doctors and thought, “I’m going to go with this and see where it takes me.” I don’t know how you people do it, when you take on something where there’s no treatment, the numbers of people you have to see. Joseph Sonnabend who is back in the UK now, gay man who was a researcher, he was researching, I forget what he was researching, I think that will come to me. He was related to basic science research at the MRC and ended up working in New York as a doctor where he had a sexual health practice, and played a crazily important role in managing for seven years people without treatment and how you managed opportunistic infections, and he went on to found things like amfAR and did all sorts of things. It was uphill all the way, he doesn’t have good press, didn’t have good press, he had to fight all sorts of difficulties. So all the doctors and the nurses that took this on when other hospitals were pushing trays under the room, or leaving food outside, or asking that you fly in a body bag even though you’re still breathing.

**Ingrid:** I was just going to ask a different question but it’s related to, we’ve been talking a lot about the science and whether we can trust the science and what we can do without the science, and I’ve been thinking about the Swiss statement in 2008. So I was very new to the research field, but there seemed to me to be a wholesale rejection of the Swiss statement in 2008, and it wasn’t until the RCT HPTN052 that said, “Oh actually, treatment as prevention does work, it is a thing, we can think about...” And so I’m interested in your experiences actually of reaction to the Swiss statement and reaction to something that wasn’t an RCT, how that played a role and how that was negotiated actually, because I did some interviews and there was one man who was living with HIV who introduced it to me actually and said, “They’ve said this thing about if you’re on your treatment you’re not infectious, I’m not quite sure what to believe about that,” and he had been back from the US for a few years, and had been living with HIV, and

was really actually struggling with what it meant to be living with HIV at that point, and he wasn't sure how to engage with that information as someone living with HIV. So I wonder actually about your engagement with it.

**Marsha:** I would like to add to your question if that's okay, which is that when you say that actually people couldn't accept it until there was an RCT, and I am thinking about, it seems to me that what we're still living in is an amazing experiment, you could say everything is an experiment in life, one doesn't know what will become of things. But from the early days pre-treatments, and where RCTs weren't required for what you could do or even determining what kind of social research you could do, it seems that now we have become very much regulated by a certain mode of evidence making. I am not discounting its contribution, but it does seem that actually there's a lot of inventiveness that went on before treatments - when you talk about what did you do in the absence of treatment, like what forms of palliative care or just *care*. And I think care runs all the way through, even how people have done politics, is a kind of caring. So I just wanted to expand the question about the response to TasP and the Swiss statement and connect it to the response given to every aspect of the epidemic. It has demanded people taking risks in thinking as well as taking risks with drugs. I'm just staggered when you say that you were in this trial which was a blind trial so you don't know that actually you're developing resistance while you're in it.

**Edwin:** I think I wrote the first English language story on the Swiss statement, maybe you did at exactly the same time Simon, I remember January 30<sup>th</sup> 2008. It came in French, I was sitting in the office at NAM and Sylvie Beaumont who I work with still, Francophone, I remember reading it because I have rudimentary French, she translated it, and it was like, "Oh my God, they've actually said this!" We had known anecdotally about the link between viral load and infectiousness for a long time, from the Rakai studies<sup>3</sup> from 1999/2000.

**Simon:** Rakai was amazing.

**Edwin:** And I had written a number of articles for AIDS Treatment Update about the link between viral load and infectiousness previously, but the Swiss statement was a huge pivotal turning point for us. But I'd like to just talk for a moment about terminology because for me the Swiss statement is not about TasP, the Swiss statement was about the individual impact of treatment on infectiousness whereas TasP – treatment as prevention – is a policy to me, it's a

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<sup>3</sup> This comment refers to a study undertaken in the Rakai district of Uganda, by Quinn et al. (2000).

public health policy, and to me they're very different, and what to me is still remarkable about the Swiss statement is this empowerment which of course now lives on in the U=U campaign, the empowerment of people living with HIV and what it means to us as individuals living with HIV and we feel about ourselves both internalised, anticipated and external stigma, and how we feel about not being a risk to our partners. I remember being involved in a number of meetings at the WHO and UNAIDS that year, also International AIDS Society I remember there was a big pre-conference of the IAS, when was it? It was in Vienna was it?

**Others:** Yes.

**Edwin:** Mexico, it was Mexico City 2008. A huge debate about that. But later on at the Autumn BHIVA conference I remember Bernard Herschel was there, and I presented on the gay men's community response to the Swiss statement, and I framed it through Elizabeth Kubler-Ross' theory of grief, because we were all going through so many different process that there were people in denial, there were people bargaining, there were people angry, there were people... a few people were at acceptance, but I wasn't personally, I was still wanting to use condoms for many years, probably until HPTN 052 to be honest. So it's interesting I was in a trial for saquinavir, it failed me, but 052 actually gave me the confidence to actually realise that I was no longer a risk to my partners (in the plural). So yeah that's just my experience.

**Matthew:** I did a presentation at BHIVA on Friday and I talked about Edwin talking about the five stages of grief. I think what's extraordinary about the whole U=U message, treatment as prevention, or however we want to frame it depending on the context, is that it's taken so long to get to the point that we have. I developed a campaign when I was working at GMFA about ways that people can reduce the risk even if they don't use condoms, and it was that very much "*even if*" they don't use condoms, but at GMFA they would always recognise that gay men had their own strategies and we would much rather someone had a strategy which was at least partially effective than that they had no strategy whatsoever. So I produced this campaign called 'Enjoy Fucking,' because it's GMFA, and it said something like, "Most gay men use condoms, but not all gay men use condoms, if you choose not to use condoms for whatever reason these are things you can do which can reduce your risk of HIV transmission or HIV infection." We actually did three different executions, so one was for people living with diagnosed HIV, one was for people who knew they were HIV negative, and one was for people who didn't know their HIV status, and there was not that much text in the one for people who didn't know their HIV status because it's like, "Well we don't know what to say to you" [laughter].

But on the one for people living with HIV it said that it will reduce your risk if you have a low viral load on treatment, and that was in October 2001 that campaign came out, and the Swiss statement wasn't until 2008, BHIVA two years later discussion, and you saying stages of grief, and it's only really in this last year that we've seen real traction for that U=U movement. And we still see enormous pockets of resistance within HIV positive communities as well as with HIV negative communities. I was looking at – back to GMFA – they have just done what I think is an excellent video called the Undetectables, and it's very accessible and funny and sassy and great, but if you ever want to feel really depressed go and read the comments underneath it on You Tube, because there's all these comments saying, "Oh well you're just saying that because you want to infect other people, I would never touch a diseased person like you, you're all disgusting and vile" and all this kind of thing, and you go, "God, we have come so far" but actually we have still so much yet to journey on this path because of people's attitudes.

**Jane A:** But I think the other thing which again going back to the issue of women, we have known that women taking antiretrovirals in pregnancy prevented vertical transmission from late '90s, even before and before and before, but it was never computed across the epidemic. So pregnant women and their children were in one little box, and that discourse I don't think went across properly, because actually that was something we were promulgating for a small population, although again it overlaps with the toxicity of treatment, because the idea that you would give an unlicensed toxic drug to a pregnant woman, but the time the professor of paediatrics at Homerton said to me, "I wouldn't give AZT to my dog and you want to give it to pregnant women, it's toxic." But actually that discourse has coloured the prevention and the treatment piece, but actually it worked, and that got itself into reproductive health discourse before, or it wasn't properly acknowledged as being what it was I don't think.

**Simon:** But on that point in Geneva, the AIDS conference in 1998...

**Edwin:** Actually it was Mexico.

**Jane A:** Geneva was in the '80s.

**Simon:** No it was 1998, it was in Geneva, it was the first one I went to. So, Karen Beckerman from San Francisco had a cohort of 70 women who she treated on the basis of their health needing triple combination protease therapy and she reported zero transmissions, and it came out just at the same as the UK had found C-section and AZT worked. As an activist group, we

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brought Karen Beckerman to the UK, and she talked to Body and Soul, and afterwards she had 50 women, mainly women, in a line to talk to her afterwards about how fantastic this was. And unfortunately after the talk to healthcare workers where we thought it would be just as important for them to hear this data there was not one question, and the UK guidelines continued saying AZT and C-section for at least five years.

The interest and the response is difficult, and it's so weird to be in this position as somebody who hasn't gone to university for seven years to become a doctor. It's interesting how you accept knowledge and what is accepted. The Swiss statement was completely refuted, Bernard Herschel had a real rough time after this and for years afterwards, and actually HPTN 052 didn't make that much difference because the US CDC only now has said that we see this as something that's important. But behind that there's a difference between a slight impact on reducing or an impact that reduces transmission and actually being able say something doesn't happen. And so it's very interesting the way that this knowledge took 20 years to settle, and the way that we knew that PrEP worked, we knew Truvada or before it was Truvada, tenofovir stopped transmission five years before Truvada was even approved, but there wasn't political will to study that as a prevention means, and there wasn't any interest actually from Gilead who owned the drug in studying it as a prevention means. They kicked against it and just about provided drug, because politically they couldn't have not provided the drug. But all those large studies were funded by Gates in the NIH, public research funds all this stuff, and then you have the fallout afterwards when you see there's no reflection in the costs that the drugs are charged for.

**Jane A:** Isn't all this going back though to Marsha's point about risk, and I think there's something really important here, and if I put my healthcare professional hat on first, "Do no harm." I think there's always been this anxiety about whether you're going to make something worse, and I think that pervades, and it's getting much more the case. In today's medical world everything is protocolised, you have your list and you tick your boxes, and one of the things that I found really, if I think back, the people who were teaching us, as a junior doctor we had, "The grown-ups," they were much more risk accepting, and they allowed risk to happen. Brian Gazzard isn't risk averse, Mike Youle isn't risk averse, nonetheless we have that sense always of, "What could go wrong?" With the Swiss statement, "What if we as doctors tell everybody it's alright and it isn't?" So there was that kind of, "And what if you give a pregnant woman something and the baby comes out all wrong?" I think that has held us back, and it's getting more so, and I think we as a profession are getting much...

**Simon:** But Edwin's example about most HIV positive people not going anywhere near the Swiss statement thank you very much. We have perfectly evolved to have great sex with condoms and not put partners at risk, and so there's... that happens on an individual level as well.

**Jane B:** I think the whole thing about HIV has been that everybody has lived with uncertainty in many different ways. Your example Edwin of how people approached treatment, that uncertainty: are you going to get side effects, the community were so full of stories about terrible side effects that put people off. But then we always lived with uncertainty about how would you advise people anyway, even the simple thing of, "Should I tell my family I am HIV or not?" Well we have people who it was really successful with, and we have people who it was an absolute disaster. So that level of uncertainty has been there right from the beginning, and I think still when people went into clinic to talk about the Swiss statement or the other things people would... the doctors found it difficult to be certain about things, but also there was that level of uncertainty from the patients as well. So in and amongst all of that people then are prepared to take risk, and that's unusual for biomedicine because biomedicine doesn't. Our culture of biomedicine is not really risk taking, and that's what's been so interesting about HIV.

**Graham:** Yes, exactly, it's so distinctive. So it's been demonstrated that a new intervention that absolutely works takes 17 years to get into practice, that doesn't happen in HIV, it's much more rapid and iterative... [laughter]

**Graham:** Well, PrEP, yeah—

**Jane A:** We had to take them to court to get—

**Simon:** It takes three years to fix a dripping tap.

**Graham:** I think HIV there seems to be much more, let me see, there's things, ideas that come out of the community then turn into scientific questions which are addressed, and this might take time but compared to other areas I promise you it's really quite rapid, and I thought your point was really well made about the Swiss statement, about that being about individual understanding that you wouldn't transmit. But that's quite a different thing from turning it into a policy, a public health policy, but it sets off really good science that demonstrates that. Now I know that's slow and it takes a while, but you do need equipoise, you need to be uncertain that something is actually the case. If you're absolutely certain from observational data you don't need a trial, it's absolutely unethical, you should absolutely go for it. And I believe the

first treatments weren't trialled at all, they were introduced and people started living. So the very first treatments were not trialled, they were discovered and it was observational data that demonstrate... now then improvements and changes and so on and so forth were trialled later, but the early...

**Jane A:** But the official data there's that curve of people stopped dying, and it felt very difficult to not do anything other than give AZT in those industrial doses that made everybody deeply anaemic and very ill. That curve showed a death rate that went down.

**Edwin:** The reason I think that it's so important to differentiate between the individual benefit of treatment on prevention and TasP is because of the dark side of policies around TasP. So right now we're fighting policies in Zambia and a law in Malawi that would actually criminalise people with HIV for not taking treatment. I know one thing you want to talk about is what TasP and PrEP mean for responsibility for prevention, and I think when we look at the Swiss statement and the U=U campaign as being incredibly liberating for individuals, the policies of TasP, on the one hand they're very useful for fighting for universal access to treatment and to viral load testing, on the other hand there is this other side of making people with HIV responsible again as we always pretty much have been. And that's why PrEP for me has been a revelation working on issues of criminalisation and responsibility because finally there is something that someone who is at risk of acquiring HIV takes it.

So my partner Nick is Germany's top PrEP activist, has made the Proud documentary and PrEP 17, he actually wants to have a t-shirt saying, "Your status and viral load is none of my fucking business," and in fact it's interesting, there's a lot of work now being done about disclosure, the criminalisation of non-disclosure and I just, there was a GMFA article about how best to disclose, that is being shared on Facebook. And it makes me cringe a little bit because I don't believe that we need... that disclosure in many ways leads to false sense of security, disclosure is a process not a one-time event, all of that. But I think the disclosure, what are we disclosing these days anyway? Are we disclosing I'm positive? If you say I'm disclosing I'm undetectable that still means the negative partner needs to trust something that's completely invisible in the absence of condoms. PrEP means that the person who is taking PrEP knows that they are taking something that protects them, and I think when you look at how that will translate into policies, particularly if that will improve the legal environment for people living with HIV, the jury is still out, it's never been tested in any court yet. But there are lots of people who take PrEP as well as use condoms and have a huge fear of people with HIV and acquiring HIV, and I think there could still be a complaint from someone taking PrEP that you didn't disclose and I'm still

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potentially exposed. So there are just some thoughts about the difference between Swiss statement, U=U, and TasP.

**Matthew:** I just wanted, to pick up on the disclosure thing because I think I've been campaigning quite a lot on issues around disclosure, and the reason why I've been doing that is because I really associate it with the LGBT equality movement, and I think that absolutely we've made enormous strides forward as a result of people being open about their sexuality, and it's that experience of knowing there are LGBT people in your church, in your barbers shop, at your home, in your office, in your family, that has actually really helped push forward an LGBT equality agenda, and I think there's a similar battle to be won in terms of HIV. If it's hidden then people don't realise what it is and don't realise that actually treatment can be effective and people living with HIV are living full constructive and sometimes messy lives, and that's why I think disclosure is really important. I'm not saying that everyone needs to disclose, I certainly would never argue that people should be compelled to disclose but I think people should be supported in disclosing because I think there is enormous social benefit from disclosure.

**Edwin:** I would just like to say that England is probably the only place in the world where it's legally safe to disclose, because you can only be prosecuted for reckless or intentional transmission. In pretty much any other country including in Scotland you're basically one disgruntled ex-partner away from an allegation of non-disclosure and potential exposure. So on the other hand of course the visibility is really important, but there's always two sides, there's always a bright side and a dark side to everything.

**Jane A:** Can we just go back to your point about it always being the responsibility of a positive person? Because I think this is being played out now. I want to talk about women and PrEP, because the whole business of PrEP for women is being promulgated and run and led by women living with HIV, and it is those women who have picked up this parcel of stuff and are really pushing for it. If you go to the places where women's health is discussed and you ask about how do women feel about taking responsibility for staying HIV negative, that conversation is not happening anywhere. So the Royal College of Obstetrics and Gynaecology, women's health, sexual health, the faculty of Sexual Reproductive health are not even beginning to think about how women take that responsibility for their own wellbeing, and it's still the positive women's movement that's doing that work, and I think we've got to change that round. I don't know what the answer is but I still find it quite shocking to not have any of that conversation

happening amongst places where women either don't know their status or are negative, they're not talking about it, it's somebody else's problem.

**Graham:** I have to go I'm afraid, I'm not walking out but I've got a meeting just round the corner that I do have to go to.

**Marsha:** I don't know whether people are happy to continue, but I want to say that before you go anyway that this has been immensely... it's been terrific. We have immensely rich material thanks to all of you, and I fully appreciate that we've been here for two hours and I feel excited that we've covered so much [laughter]. It's been so fabulously...

**Graham:** But it's been so random [laughter].

**Marsha:** I don't know, I think...

**Simon:** You avoided your randomised clinical trial [laughter].

**Marsha:** I think the dots join up, and so it was really great because it wasn't like, you can read a chronology of the epidemic, the presence of AIDS then HIV, identify the drugs, treatment as prevention. I really appreciate the distinction that you made, it's so helpful, and PrEP, and now here we are. But actually what we seem to have done is move between medicine, between individual experience, between policy, health promotion, we sort of got to drug companies briefly, obviously...

**Matthew:** We could do two hours on that.

**Marsha:** So maybe if Graham if you have to rush off then do please, and I'll just ask if there are other things that people would like to add then before we...

**Graham:** Just before I go, I think what you're saying is absolutely right. There is a, let me see, objective chronology of events in HIV which is very clear, and what's wonderful I think in our careers, Jane, is that a disease appeared, treatments came in, and then there is the possibility of the elimination which to some people, because, actually because we've lived with it for so long it feels really weird at the prospect of it going away. But it is possible. But the psychosocial, psychosexual dimension of it for those of us who lived through it, and particularly friends, colleagues here is actually it's not that series of very clear events, it is as the conversation has gone on it's actually, I'm still living with some of my early feelings about it, and it hasn't gone away in that sense. So I just feel that there are the narratives that are really important, because

they're not purely historical and neat, there's a lot of mixed things going on there. So anyway that's all I wanted to say. You made me remember that.

**Jane B:** One thing I would like to say about when drugs first came in, and it goes back to that issue about certainty and uncertainty. Before effective drugs came in, obviously there was a degree of certainty about how patients would be managed in terms of that holistic approach to care, because it was care and there wasn't that sense of cure. And so decisions about withdrawing treatment and moving to palliative care, those decisions were easier because it was a decision with the patient, with the doctors, with the nurse, that non-hierarchical level playing field really, and very much about the individual decision, and involving people in those discussions, by and large, obviously sometimes that wasn't always so easy. But when treatment came in all of that got turned upside down, a good thing, I don't want to sound negative, but it nevertheless it made decisions about who to start on antiretrovirals, when to stop if it wasn't working and people were going to die, and so all that certainty we had about how we were caring for people became much more uncertain because you didn't know what was going to happen.

We saw people with terrible side effects, and so it was that period that I found very challenging as a nurse in particular, and it affected particularly, the hierarchy seemed to change, and I think that traditional role of the doctor is the father, the nurse is the mother, and the patient is the child, which we'd ditched, and got that equal relationship, seemed to slightly come back, because of the hierarchy of knowledge, and the power of knowledge, which was invested in a smaller number of people. Which to a certain extent because it excluded some of the patients very much as well I think in terms of what their knowledge was about drugs and what was happening, because it was all quite quick, I suppose. So I think that's something to think about, it links into that concept of moving away, to a certain extent, from that individualised care, and the responsibility the patient had about their care. So it's one of the things that we've had to live with and work through I think to get back to perhaps patients being more involved in the decisions about their care.

**Jane A:** And I have a very strong memory, you've triggered something I hadn't thought about for a long time, I remember being taught early on, that if you don't know how you're going to stop the antiretrovirals then be very careful how you start them. Because you knew that some people were going to have to stop, there would be a stop somewhere because something happened.

**Simon:** I like your reflections on that, it's very interesting, and it has reversed the other direction. Now you have five minutes and in the five minutes you will get your prescription or not.

**Jane B:** And it becomes more and more about, so it's that thing about what's after undetectable? The whole focus and psychosocial issue has become less important.

**Simon:** It was in the context of all these positive responses. We live in an amazing time, but I still do treatment workshops and training and all those sorts of things, and most of my training, at one point it was giving people the option of where they saw themselves in a model of care, if the doctor was at the top of the pyramid, "Does this feel like what you're in?" And all the hands went up. And I said, "But what about this model where there's these things around the circle, and you're in the middle of care because it's about your health?" And nobody felt like that, and it wasn't scientific, it was just, "How do you feel about your structure of care?" And for all that work in developing different models of healthcare and how we translate knowledge and pass on knowledge and make people empowered hasn't really worked through, and we're going against that with the cuts in funding for the NHS, it's getting very much more difficult.

**Jane B:** Because we assessed people using that model when they came into Broderip, we would have the patient in the centre, and ask them who is in that circle.

**Edwin:** It's so interesting because on a global level, I was working with the Global Network of People Living with HIV on a person-centred policy called *Positive Health, Dignity and Prevention* which is the nicer way of talking about positive prevention or prevention policies, which is very much about the person here in the centre holistic model where treatment is only one part of it. And there's now, because we've moved to this incredibly medicalised model both for treatment and now potentially for prevention, there's this now policy the International AIDS Society is leading called *Differentiated Care*, which is basically this idea that instead of everyone just following WHO guidelines which is a public health approach and everybody just takes everything first line and then everything second line, differentiated care is again trying to move to a more individualised model. And again we haven't learnt from the fact that of course people living with HIV and people at risk of HIV if they're going to be on PrEP need to be at the centre of our care, and needs to be holistic approach, because in the end we're relying on adherence.

We don't have to be expert patients anymore, we still need to understand what it means to take pills every day and to also deal with the stigma that's associated with those pills, whether you have HIV or whether you don't, and then all the socioeconomic and cultural issues. And so we're going round in circles again, and it's interesting to have a nostalgia about the time before treatment when the patient was at the centre but of course many of us were dying, and we have to balance that with this idea that we're not. But that's, to me, when talking about the impact of treatment on larger policies, which is my concern these days, HIV criminalisation really only began to have a huge traction once post-96, even actually 21<sup>st</sup> century of course, Scotland had a first prosecution 2001, England 2003, and even though there had been laws and prosecutions previously, particularly in the US and Canada and a few in Australia, it's this idea that we are... this move culturally from us being patients and to have sympathy for us, because actually there's no point worrying about what we might do in the future because we're likely to die. The moment we all came back to life we started to be seen by society and particularly by law and policy makers as threats to society, and that's why HIV criminalisation is growing even now, even in the context of treatment and treatment as prevention, and that's why I'm constantly alert to the punitive approach of treatment as prevention because on the one hand we're all very excited about what the impact of U=U and the Swiss statement might have on individual cases, and people are able to use those as defences, we've been highlighting this for many years. The Swiss statement was written primarily to help in defence of criminal cases, because you couldn't consent to condomless sex in Switzerland, and so people were being prosecuted even despite the partner having consented. And we've seen that rollout in Canada and in Sweden, Australia, and now we're working together with UNAIDS, the IAS and IAPAC on a globally relevant consensus statement on science in the context of criminal law.

But we are very mindful of the fact that so many people don't have access either to treatment or to viral load testing, that we're not going to say that the only defence is if someone is on treatment and they know they have an undetectable viral load to risk. So HPTN 052 wasn't about viral load it was actually about treatment, it was that people on treatment after a few months that basically didn't pass on HIV to their partners and phylogenetics showed that any HIV acquired in that study was actually from sex outside partners. So I think it's really important to make sure that we understand that the culture of treatment and treatment as prevention, I keep saying it has this positive side. It's amazing we're all alive and doing well, and we can look at the potential of the end of AIDS as UNAIDS likes to call it by 2030, or the end of AIDS as an epidemic or HIV as an epidemic by 2030. But I think there are more... I have more concerns now, I think the stigma of people who are not on treatment and who are

not undetectable is actually worse now than ever, and I have concerns about the religious fervour around the U=U campaign, despite it being amazing and empowering for lots of people, I think it really can have a negative impact on people who have not been able to achieve undetectable for whatever reason, who don't have access to viral load testing, and it creates this other division of there's 'good' people with HIV and there's 'bad' people with HIV. And that's something that's happened throughout the epidemic, and it seems to be perpetuating even now.

**Simon:** I probably should add a caution that all my pharma references shouldn't all be negative [laughter] these other guys, people that developed the treatments by and large. But also as companies they are not unified, there's different pools that happen within industry and we've all had to... my first idea that I had to learn the name of drug companies when I started working on the ATP phone line was crazy, how do you pronounce Boehringer Ingelheim, and why should I know about it other than the fact I might get some funding, or I might lose some funding. So my first published article was about saquinavir and the Roche funding disappeared overnight because it was titled 'is saquinavir safe?' And it clearly wasn't safe, people weren't getting the right dose. Sometimes you get away with things as a community person, activist or whatever you call it, that you know is not going to be said in other settings, if everybody else is being funded by someone, sometimes you can say something without worrying about that. If your career in the NHS is dependent on what the person at the top thinks about you, maybe you won't challenge their decision to randomise everyone to just dual therapy or something crazy. Or to save a bit of money we'll put everyone on forsamprenavir which are all real examples, we've been in meetings where that has been suggested. And so that balance is interesting, and I've also met the scientists generally that work at companies, and lots of the other people that work in companies are really targeted on. They got there because they can see a way of making the world better, and they're smart people and they did well at school, and now they've got the prospects for doing research and developing drugs there's very few places where you can do it. The marketing approach for what happens and how this good intention becomes a monster is completely different, and it does become a monster.

I've just been at a meeting on Tuesday, which was about this interface about drug pricing and drug costing and how it does it, and regulation and the EMA are looking at whether you don't really need randomised data, whether there's a faster pathway, all being promoted by a cheaper way of developing drugs, or not drugs, but just saying, "Here we have something and would you like to try it on the basis of very little evidence?" In the US the dynamics for reducing regulations for drug approval is serious, that's the way it's going, you will not have good data

on the way it's going. But somebody from a company there stood up and justified the price of new hepatitis C drugs as potentially being cost saving. There is... and you can't price... drugs have to be priced at certain, at levels that healthcare systems can afford, and you can't twist it around and say that in this one person if you're not going to give them a liver transplant because actually it's much cheaper to give them this drug, those are crazy, and that dynamic is the way the companies are being driven, it's because governments allow them to get away with it and regulators allow them to get away with it, and there is no cap pricing on there, and that's a really negative side of that particular industry. It's not across the board.

I remember when treatment first came and I was working at a group of the African activists there in terms of HIV denial, they say, "Listen we went through this, we learnt if you see someone who is ill" – it was Hope Mhereza actually – "Your village sees someone who is sick and you kill a chicken, but then somebody else would get sick and you kill another chicken, you learn soon that the killing of the chickens isn't going to help with this health complication you have". But when treatment came, THT who have done fantastic work and provided amazing services, I should add to that as well, there was definitely a move where the buddying system. The buddies were really upset that their services weren't being used, and they fought to have this service continued in the lack of need, because it was remarkable. You got good treatment, you get on with your life, and that was where being an active patient made a big difference, and I'd argue it still makes a big difference now, unfortunately we still get cases where people fall through the cracks, they're on inappropriate treatment. Sometimes it's not any conspiracy theory it's just the messiness of stuff, and so having people from different specialities being able to get involved I think is really positive, and you started with being a model for other health areas, it definitely is I would hope.

**Edwin:** You know there's this movement in the US to recognise long term survivors, and there's the Kick ASS, the long term "AIDS Survivor Syndrome," and there's been a number of activists in the US who stopped taking drugs or did chemsex and died, is that something that happens here too? Because although I had a nervous breakdown for a few months coming to terms with what happened to me and then moving on, I've always wanted to live, is that something that we know much about in the UK, have we lost people recently who we know as long-term survivors because for whatever reason they have just given up the fight?

**Simon:** I don't think in a big way, but we still get people contacting us who don't see any open doors, they don't see any avenues for their life to get better unfortunately, and sometimes they get to that point because they haven't had the opportunity to be aware of some of this stuff that

we take for granted if you're connected in terms of advances and knowledge and treatment, all those sorts of things. So it does, HIV still has an impact that it does push you... can push you towards a community response and a network, but it can also for more people I think it pushes you down to a smaller world and a more narrow set of options. Most people still close doors, they make decisions about, we still have people who think they can't have children. I gave a talk in Manchester a year ago and the women there were saying, "You mean I can have children?" And that was just heart-breaking. And so unfortunately there's lots of stuff that is really helped by people having a public profile.

**Edwin:** We're talking about the long-term impact of taking care of people with HIV, that people have died, really important people, and in response have taken their own lives and I'm just wondering if that's something we need to recognise or think about. I'm sorry to end on a downer but it's like I think the legacy of this history, we're all living with it still.

**Marsha:** And it makes me think of Primo Levi who was the extraordinary author about the Nazi genocide who then much later in life committed suicide, and one doesn't ever know really what produces that particular act or happening of suicide. But I think it's easy to assume that there's a certain temporality and that things just move on positively rather than some things catch up with you at certain moments. But I think, I'm not into psychoanalytic theory but how we understand the epidemic is a history of trauma in lots of ways, isn't it? And yet we have got these technologies and there's incredible practices that have changed doctor patient relations and organisations, and information, and so on, that I often think about. In fact, on Monday I showed this set of slides that William Yang who was an Australian photographer did of somebody dying, a close friend dying of AIDS, I showed them to my students and I've shown this for years, and every time I just start crying, which I think maybe this is good for my second year students to see that this is... that it's incredibly moving. But I'm staggered that I still have this emotion, and just there.

**Simon:** So there's big issues. In a way, HIV was so bad that it prompted a whole set of responses, a lot of which were quite amazing really. But there's similarly huge areas which as a society are completely neglected, mental health is one of them, and psychological health and wellbeing are other ones, ageing is another one, ageing will push you to be isolated unless you're very lucky and have a good network and you work on it and you have thousands of grandchildren running around making sure you don't make a fool of yourself. I think these are big issues where you can overlap some of those experiences and learn from them, and then people have the potential. All sorts of things in life push you away from your potential,

including self-policing or deciding, “That’s not for me,” or “I’m not clever enough to do this,” or, “Maybe I shouldn’t do that,” or, “Maybe I shouldn’t behave because somebody will think that way,” and I think all the points you raised are valid.

**Edwin:** I was steeling myself for this meeting, and I think I’m going to have to take some time to process it too, because there’s an awful lot of things that I have buried, it’s not like I haven’t necessarily thought about these things but to hear them also as a communal experience is quite special, and I’m keeping it together right now, but I’m sure I’m going to go and lock myself in a bathroom and cry very soon, because this has really quite been an intense conversation, and I feel so remarkably privileged to have lived through it all and survived as well, because that’s what continues to motivate me to be an activist. And I think it’s so important to honour all the... I can’t even imagine what it must have been like for you [Jane A and Jane B] to care for so many people and die, to see them die. I have only lost maybe scores rather than hundreds or thousands of people that you probably knew, but this must be an emotionally fraught thing, because we’re all human even if we’re all professional.

**Jane B:** You talked about the dark and the light and I suppose that’s what I have experienced throughout my time in HIV is there has always been that light there, whether it’s the people you have nursed and you’ve nursed to a good death, or the people who you’ve worked with who have been inspirational, and it seems to for me personally it’s that kept a certain balance and probably why I’m still here and interested and want to share those experiences I think. That’s not to say it hasn’t been hard but there is a balance, there does seem to be a balance, and the fact that people like yourself are still here, that is just an amazing thing, and there have been obviously lots of people who are not here. Yeah, it’s a journey that’s been very up and down that seems to have been balanced.

**Jane A:** I think it’s been really interesting because there’s this flurry of these sorts of looking backs recently, and I don’t think I realised when I was in it what I was in. I think I realise now. I think at the time you do what you do, and it was extraordinary and all sorts of things which I recognised at the time but there’s loads more I’m looking back, thinking, “Blimey, I hadn’t looked at that like that before.”

**Jane B:** This has been amazing though, this has been extraordinary to be in a conversation like this with people from many different backgrounds and yeah, it’s been really thought provoking.

**Jane A:** It has, I agree with that, and hearing the same thing from different... somebody seeing it from the other side.

**Marsha:** So that says something about the epidemic itself, doesn't it? I don't know what else, what other condition could have a group of people and this conversation about the experience of it. But I was thinking what about what Simon was saying about drug companies and how to think about how there are scientists in them who are working really hard and doing their best, but also you've got the market and so on, and I was thinking about the connectedness of these things to what matters in the experience of HIV. Because sometimes when I'm talking to my positive friends about PrEP and the debates and so on, I'm conscious that their experience is made absent in the nature of the conversation and I think it's right what you were saying Jane, about the how do you... that it's positive women who are talking about PrEP for negative women, I think a lot of work is done by positive people in this epidemic. I don't know, there's something about the presence of the virus that's very hard to... I don't think words are adequate to capture it, maybe other art forms can do that work and we don't have much of that anymore. I feel a bit frustrated with the academic response to it, the risk of turning things into academic work.

**Jane A:** I was thinking as you're talking a word that's coming and it sounds incredibly sappy and I'll probably take it out when you send the transcript, but there's something about love that comes out of all this, and the fact that so much of this whole thing is about people being in love with each other, and there is a connectedness, and I don't know whether it's something to do with the fact that it's all bound up with emotion and people's love for each other, and sex has led to all sorts of other complications, and then you end up in a situation with no drugs that you're caring. There's something which I don't think happens in other bits of medicine, because you're not tapping perhaps into that bit of life, people's... just somehow, I haven't got proper words for it but I think there's something about emotion in there.

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**APPENDIX**

## PROPOSED DISCUSSION TOPICS CIRCULATED PRIOR TO SEMINAR

- HIV Pre-1996
  - Monotherapy
  - Clinical trials
- XI International AIDS Conference 1996, Vancouver
  - Responses
  - Availability and rollout of combination therapy
  - How/what it changed for medical practice, care, advocacy and activism
- Access to treatment and treatment activism
  - Patient involvement
  - The circulation of information regarding ARVs
- Treatment as Prevention (TasP)
  - The science
  - What new questions or problems did TasP raise?
  - If/how TasP changed activism, advocacy and the role or form of prevention efforts/campaigns
  - If/how TasP changed notions of responsibility
- Pre-Exposure Prophylaxis (PrEP)
  - The science
  - Activism
  - Resistance
  - The future



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