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Witness Seminar

HIV Prevention and Health Promotion in the UK

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).

Funding was generously provided by the Humanities in the European Research Area (HERA) as part of their the 3rd Joint Research Programme under the rubric “Uses of the Past.”



Please cite this text as follows:

Nicholls and Rosengarten (eds.) (2019). *Witness Seminar: HIV Prevention and Health Promotion in the UK*. Disentangling European HIV/AIDS Policies: Activism, Citizenship and Health (EUROPACH).



This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 649307



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Karen Skipper	Spectra
Marc Thompson	Positively UK, PrEPster
Lynne Walsh	Walsh Media
Peter Weatherburn	London School of Hygiene and Tropical Medicine

ABBREVIATIONS

ARVs	Antiretroviral Drugs
BASSH	British Association for Sexual Health and HIV
BHIVA	British HIV Association
GMFA	GMFA - The Gay Mens Health Charity (previously Gay Men Fighting AIDS)
HEA	Health Education Authority
MESMAC	A sexual health organisation (previously Men Who Have Sex With Men – Action in the Community)
MSM	Men Who Have Sex With Men
NAHIP	National African HIV Prevention Programme
PEP	Post Exposure Prophylaxis
PHE	Public Health England
PHLS	Public Health Laboratory Services
PrEP	Pre-Exposure Prophylaxis
THT	Terrence Higgins Trust
UNAIDS	Joint United Nations Programme on HIV/AIDS
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)
WHO	World Health Organisation

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

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

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

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

which people from different backgrounds and with different experiences of the epidemic could come together and tell their stories in conversation with others. As such, the personal narrative 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 *HIV Prevention and Health Promotion in the UK* was held in the Vanessa Bell room of 12 Bloomsbury Square, London on 19th March 2018 and was scheduled to run for two hours. During the seminar, audio recordings were made, which were then transcribed and edited in order to enable a clear reading of the text. Footnotes were then added and the text was circulated to participants with an invitation to further edit, redact or expand on their contributions. All participants signed consent forms agreeing to make the final transcript available for public viewing once they had been given the opportunity to edit or redact their contributions.

HIV PREVENTION AND HEALTH PROMOTION IN THE UK

This witness seminar brought together people who have been involved HIV Prevention and Health Promotion in various ways, including those who have been involved in academic research, civil society and activist responses, and those with experience of working in the statutory sector.

One key dimension to this discussion that emerged was that it was not limited only to what happened or to specific campaigns – although it would of course be remiss not to include discussion of the infamous Don't Die of Ignorance campaign – but also what was going on behind the scenes and the strategies employed. Those who had come from the statutory sector, for example, described some of the difficulties they experienced in navigating government ministers and civil servants, especially when it came to the use of erotic visuals. They spoke of learning how to deal with these challenges, but also some of their 'wins': the first time they managed to obtain approval to use the word, 'fuck' for a gay men's campaign from a government minister, for example. From those involved in civil society and activism, participants reflected on the importance of campaigns created by those who were outside of the statutory sector, but also the sometimes protracted processes by which certain issues for HIV prevention came to be taken up. Looking to the present, and indeed to the future, participants reflected on the potential effects of biomedical interventions on HIV prevention and health promotion, as well as the ways in which activism has changed in accordance not only to the way the epidemic has changed, but also in terms of digital media technologies.

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 and health promotion.

Karen Skipper: I work for Spectra. I started working in HIV in about 1993 for National AIDS Trust and then International Community of Women Living with HIV, and then the organisation that I'm at now. We started off within a local authority, eventually moving into the voluntary sector.

Siân Cook: I've got a number of hats. I'm a graphic designer and design educator. I started volunteering with THT in the early '90s, and then left them towards the end of the '90s, switched over to doing a lot of work with GMFA, I'm currently on the board of directors of GMFA, and I'm also currently building an online archive resource of HIV health promotional materials for the UK.

Lee Adams: I'm currently retired but I had a career in health promotion, and then went into local government management. I think it was the mid-1980s when I was involved in HIV. I worked in Cambridge Health Authority and we did a lot of work there setting up the first helpline, and then I went to the Health Education Authority as a director there and professional on community development. We set up the MESMAC (Men Who Have Sex with Men - Action in the Community) project nationally, and was quite involved in lots of different HIV and AIDS work nationally. Then I left there because it was a terrible time of government. The government did not like our work. Then I went to Sheffield Health Authority for quite a long time, and part of my work there was managing the centre for HIV and sexual health, and then various other things.

Tom Doyle: I'm chief executive of Yorkshire MESMAC. I started working in the late '80s in Nottingham AIDS Information Project, and I've been with MESMAC since the early '90s.

Marsha Rosengarten: I'm the principle investigator for the UK part of the project, and I'm working with Emily. My background has been in HIV since I did my PhD which was partly on HIV in the late 1980's, and in the late 1990's I worked in Australia on a study which was investigating whether antiretroviral drugs were changing people's sexual practices, and responsible for a decline in condom use. Obviously, there was a much more complex situation happening. Since then I'm a lecturer at Goldsmiths but most of my research has been on the development of PrEP, studying randomised control trials and how they have been conducted and so on, and I would like to thank you very much for participating in this. We've had two other witness seminars, and we found them to be immensely productive, particularly because they give a texture to history that one doesn't often hear, a type of 'behind-scene' of what happened in the process of making the history of the epidemic. You hear a lot about what was

achieved, but not much about the detail of what was involved in making those achievements possible, and also the difficulties in doing so. So thank you for agreeing to participate.

Jose Mejia: I work for Metro, I'm Metro's HIV peer support manager, and I joined the organisation about three years ago when I started working on their project with Latin Americans. I have been there since then.

Ford Hickson: I'm currently assistant professor at the London School of Hygiene and Tropical Medicine. I wrote my undergraduate psychology thesis on AIDS in 1988, moved to London, worked for the Terence Higgins Trust, and Frontliners, and joined a research group which was then at London Southbank Polytechnic in 1990, he [Peter Weatherburn] was on my interview panel. There we were working on a longitudinal cohort study of male homosexual behaviour in England. In 1996 that research team joined the CHAPS partnership of which a few of the people in the room were involved, and I carried on since then really, and I'm still doing similar work now.

Peter Weatherburn: I'm associate professor of health promotion at the London School of Hygiene and Tropical Medicine, and I've been director of Sigma Research since 1997/8. I first worked in HIV research, well I have been working continuously in HIV research since the 9th of October 1988 (God knows why I remember the day), both in Wales and then in London, and then away from London then back in London, so it's been a bit of a chop and change thing. Mainly domestic UK until the last five or six years where it's increasingly been about HIV prevention in Southern Africa, Caribbean, a variety of other places not the UK.

Dominic McVey: I worked at the Health Education Authority (HEA) from 1988 to 2000. I worked on HIV/AIDS research and sexual behaviour studies from 1988 to the middle of '90s, since then I've worked on wider public health issues. Much of my work involved developing and evaluating the HEA gay and heterosexual public health interventions including the mass media work.

Lynne Walsh: I'm a journalist by trade, so I still sometimes write about sexual health. I lecture in mass media campaigns, sometimes I teach baby journalists on covering sensitive issues, but principally in this context I was head of press for the Health Education Authority between mid to late '80s and the end of '93 under the Thatcher government, with Clause 28, with The Sun screaming about gay plagues, and Department of Health press office censoring everything. At one point, we were actually pulping publications.

Marc Thompson: I currently work at Positively UK, but I'm also co-founder of PrEPster with Will [Nutland] and Blackout UK. I've been involved in HIV work since about 1988 as well as working with a variety of different organisations in the community. My specialist area has been around black gay men, BME communities in health, and I've worked on a number campaigns and interventions around that.

Will Nutland: I'm an honorary assistant professor at the London School of Hygiene and Tropical Medicine. Along with Marc [Thompson] I'm the co-founder of PrEPster, which is a community based project that seeks to educate and agitate for PrEP access in England and beyond. I started my HIV work in about 1988/89 as a volunteer on Norwich AIDS helpline, and then I went on a couple of years later to set up a Norwich gay men's health project which was broadly based on the MESMAC model. I was also one of the co-founders of ACT UP Norwich, and then became very much involved in the early '90s in ACT UP UK. In 1996, I started working at the Terrence Higgins Trust as part of the CHAPS programme along with four other people in the room here, and then in about 2008 I moved up to the London School of Hygiene and Tropical Medicine to start a doctorate in public health. I did my doctorate on the acceptability for PrEP in men who have sex with men in London. In addition to the work I'm currently doing on PrEPster, I'm also involved in an interactive historical HIV advocate website called 'We Rage On,' which is just about to launch in the next six weeks' time, which is going to provide stories of people who have been involved in HIV activism throughout the world, and cast themselves forwards 25 or 30 years and think about what their activism can teach new activists. At some point, there will be a documentary that comes with that (when someone gives me lots of money!).

Emily Jay Nicholls: I first started researching HIV as part of my masters dissertation where I looked at the different roles the HIV antibody test has taken on throughout the epidemic, its history as an actor. I then went on to do my PhD for which I followed an HIV clinician as he went about creating an archive of the epidemic and later on in collaboration with an archival institution. So one of my interests is how we can record the history of the epidemic and what may get lost in the process.

Maybe we should begin, so the first topic I have proposed that we discuss on the list I circulated is the government education campaigns. I don't know if anyone has any immediate comment they would like to share about those?

Lynne: The iceberg and the gravestone, which unfortunately will still be shown every time anyone on TV makes anything about HIV and AIDS. We tend to sigh deeply when we see those, don't we?

Marsha: What was the history of those, how did they come to be made? Because they are notorious now.

Lynne: They were notorious then. Well, they were before our time, so they were before the Health Education Authority. The government had effectively closed down the Health Education Council, its predecessor, in a row about a publication about health inequalities, which the Conservative government didn't want to talk about, so that had been closed down. I think that this is the point at which Thatcher realises she is cornered and has to do something about HIV and AIDS. Civil servants might say that what was significant was that Reagan had spoken up about it, and so civil servants were effectively lobbying Thatcher and saying, "We have to do something," hence the iceberg and the gravestones which scared a lot of people. I'm not sure how much they informed the public, they cost a heck of a lot of money, £20million or more. Every household in the UK had a leaflet, which baffled people in Wales, where they had them in Welsh regardless of whether the recipient spoke Welsh or not. Bizarre times. Then, the Health Education Authority was very quickly reconstituted so that they then have a quango, the classic arms-length organisation to take on the next campaign. That created a lot worried well I think, a lot of people were scurrying to clinics wanting to be tested, so it caused a lot of problems. It certainly did some harm, I don't know if you think it did any good?

Dominic: Some people claim it did some good because it was putting AIDS firmly on the agenda. But my view, and I think a lot of people who were around at the time would share this view, is that you still could have put it on the agenda using better advertising and better campaigning methods. It was too frightening, there was not much of a 'call to action' that should always be included in these mass media communications. There was talk about using a condom, condom protection and stuff like that, but people took away mainly the sense of fear with little sense of any personal control over it. The useful information about what you could do to protect yourself was masked by this overwhelming sense of dread.

When the HEA took over we brought in health promotion principles and behaviour change theory to the whole area of campaigning in this area, so there was more of a call to action. The message was much more about the situations people might be in, a sexual encounter, what can be done, how can you minimise your risk. But getting to that stage was not easy, because we

had to employ a new advertising agency. The previous advertising agency were TBWA who did a reasonably good job for what they were asked to do, and then we had this new agency BNP, who were also a very highly regarded agency, but they immediately tried to follow The Iceberg campaign with a similar fear message. I was in research so I had to do a lot of the pre-testing. When a campaign is developed by an agency we would then take it into focus groups and in-depth interviews to see how it played out, but even before that we would do strategic research to see where people are with their sexual behaviour, with their attitudes, and understand the barriers to change and what interventions were required. There was very little useful research around then about heterosexual and homosexual behaviour. I have to say it was a very different time to how it is now. Back then we were generating new quantitative and qualitative research findings every few months. We had to turn the research around quickly so it could inform the development of new campaigns. We could not wait for the findings of three year academic studies. We made use of some of the best market research agencies in the country most of whom did a terrific job.

So, getting back to my original point, the new agency decided to go down the same route as the Icebergs campaign i.e a fear based campaign. They presented ads, one of which included four pictures in a quadrant: Piper Alpha (the recent oil rig disaster), another quadrant included a picture from the Bhopal disaster, a third disaster image I can't recall and then an AIDS image in the fourth quadrant. An advertising agency's desire to win advertising awards sometimes took precedence over communicating the correct message. We told them straight, "We're not doing that anymore."

It did take a little time to educate the agency, and persuade the government as well, because there were issues at the time, Section 28 and what have you. There was also just a resistance to talking about sex, having it displayed or talked about in people's front rooms or even in the magazines, there was lots of resistance to that. So yeah, there's lots more I can say but maybe other people would like to add their views...

Lee: I think, just looking at the context in which it happened, I remember the HEA board meetings where we looked – and there were civil servants sitting on the side meant to be observing only – in great detail at every word that was in a document. My experience was that the civil servants at that time were extremely right wing, more right wing than the government, I have to say, and I couldn't repeat a lot of the *awful* things they said about some of the work that was done, and they were very censorious. It's amazing that quite a lot of work we developed managed to be approved and I think over time that the national work improved and got quite

good, and also set the tone for a lot of what was done locally, opened things up so that more could be done.

Personally, I found it a lot easier after I left the HEA and went to Sheffield where although the health authority was run by Conservatives, basically local millionaires, it was easier with them, it was easier because they understood and accepted what we needed to do more really, which was quite interesting. I can't really explain that, not all to do with politics obviously, local and national. But I think the context was quite important. At the same time, you also had WHO doing its thing, and there was the whole Health for All movement internationally, healthy cities work, which advocated looking quite critically at different methodologies and set a lot more store by community development for want of a better way to describe it. So that was impacting on the discussions about what the most effective thing to do in this situation would be in order to try and prevent HIV and to help people. So, I think the context is very important.

Lynne: It was extremely difficult with civil servants, I don't think it mattered as much whether they were right wing or not, ministers and the prime minister were the problems really. Thatcher did ban the national sexual behaviour study¹ which then had to be scooped up and went down the road to Wellcome where it was rescued effectively. But ministers were signing off on the text but they were scrutinising visuals, they didn't like some of the homoerotic photography that we had done. But we also got better at that. I don't want to call it a game but we got better at putting things before ministers and putting an argument to them, so we did get Brian Mawhinney, very right wing, former Plymouth Brethren, to sign off on the use of the word 'fuck' in the gay men's ad, because we put the argument to him. He did say he never wanted to be put in that position ever again, but by then the ad was done. So, I think all of that stuff was developing, we were quite aware of the fact that we were working under the Thatcher government.

Dominic: It was even a challenge just trying to present positive images of gay relationships, because a lot of the ads we produced were very loving images, stuff like that, but there were also images where there's clearly going to be casual sex going on. But as Lynne said, trying to get the images through government ministers was hard enough, but the language that was attached to the images was extremely difficult as well. But the research did help. We were seen

¹ To read more about the history of the study, including the withdrawal of funding referred to here, see Wellcome Trust Centre for History of Medicine (2011).

as a sort of gateway for, “What do the public think of this?”, “What do gay men think of this?”, “Is this going to be useful to them?”

When we presented the research to the government, most of the time they were persuaded by it because it was the public's voice – albeit through the lens of a researcher. Sometimes, however, we had ministers saying, “I don't care what the research says, that's not going ahead.” So you had to play a little game with them to try and get a lot of the good stuff through.

Lee: There were politics inside the organisation as well, between different divisions. In my view, we had quite a narrow minded medical director who was quite limited in the model she would accept really, so there was all that going on inside as well as outside.

Ford: I do think the prompt though for the big national campaign was a widespread, perhaps not widespread, but a feeling in government that there was going to be a heterosexual epidemic. That's what made them act, and the way it was pitched, the phraseology of it was in anticipation or trying to head off this thing. Had they not had that fear that would never have happened and it would have stayed marginalised.

Peter: I find it hard to join the dots historically now because I was so young then, but in my head, there's a relatively long period between the iceberg cinema ads, TV ads and the leaflet through the door and that era, and then there were the HEA campaigns with beautiful men doing fairly innocuous things, but that was much later wasn't it? When was that?

Dominic: About '90.

Lynne: These are 1990.

Peter: And when were icebergs?

Dominic: 86-87.

Lynne: 86/87, and the first TV cinema ads that we did with press ads to complement them were 17th February 1988, which was very difficult to get past ministers, because these show two scenarios: there's a couple where the young woman has got a guy round for dinner or whatever, and there's a clear narrative and there's a decision-making moment, and then the other one for slightly younger age groups, seeing how young you could get away with, I think was a disco, and similarly there was a decision-making, so it was obviously two way communication. It was quite engaging to encourage an audience into a, 'what would you do' sort of narrative. But

because we were showing young people who were clearly considering having sex as you say, which might be being thought of as casual sex, it was really hard to get it signed off.

Lee: The other thing was that there was a lot of, I think lobbying is the wrong word, but liaison and discussion with voluntary bodies, activist groups. I don't think the Health Education Council previously had done that kind of work but we did a lot of liaison with, listening to and trying to bring activists and concern groups together with civil servants and ministers. So, I think that began to have an impact as well, At that time, as well, there were many grassroots projects, not like that now at all, but I think when we were there, there was something like 10,000 community health projects of various kinds that were run by grassroots groups or the voluntary sector funded through European money, urban regeneration funds, that kind of thing, and that interaction did have an impact on policy.

Dominic: We made sure we involved local groups in the campaign work. Integrated campaigns require the involvement and participation of local groups. The more effective local groups believed that a strong national campaign would be a huge support to their local work and were keen to be involved. For example, we set up advisory groups for many of the campaigns to get their input into the work.

Ford: Also, the TV tombstones had followed three years of media feeding frenzy about HIV. To look back now and say its purpose was to raise awareness, you would have to have been living on the moon not to have heard of HIV by this point, and to have a good idea about how it was passed around. Probably a load of fake ideas about that, but the core health education that was in it was already pretty well established, certainly amongst the communities that were being affected by HIV. Communities that it wasn't affecting at all might have learnt something, but there's a question about what the point of that education and targeting is.

Lynne: I think that's absolutely right, and nobody had really looked at what we thought the public knew, or levels of ignorance, a lot of which had been fuelled by the tabloid press. It seemed at the time as if no one had really engaged with the media in a proper way, nobody had reprimanded The Sun or anybody else for peddling lies or being very unhelpful or whatever way you'd put it, which was part of the job really, and in a positive way trying to encourage journalists to write about or broadcast about HIV and AIDS in a certain way. And the HEA did that, and the press corps were pretty much fine with it up to a point, but when I say I was running the HEA press office, there were two of us at the time trying to do all of that. And then a Panorama programme would happen that would insist there was no heterosexual risk, a

programme that at the time Virginia Bottomley and Kenneth Calman who was the Chief Medical Officer refused to have anything to do with, but they were very happy for the HEA to take that on. So, we had to handle all of that. So, of course I would say that, of course I'm biased, I would argue for a press office to be well resourced, but I think that was a major problem. It would be a major problem for any organisation trying to do something similar now that you have to properly engage with journalists, however difficult that is and however nightmarish, it has to be done, because otherwise you will have... that's what the public are reading, that's what they are watching on TV.

Lee: I'm reminded that it's a lot easier on the local level, where we did used to have regular meetings with the press to try and talk to them and get them to be rational, it's much more difficult on a national level. We've still got issues with the press nationally, even local work still gets into the Daily Mail and The Sun, we certainly had that where I worked at local level and you can't do anything about it.

Marc: If there's ever been a campaign that shifted an entire generation's thinking, it's the tombstone and iceberg. I still encounter young gay men who have come out to their parents and their parents recall that ad and that is their warning to their sons when they're coming out now. So, in terms of how that campaign had, and the fact that it stood alone, and there was very little ever done to rectify or to change that narrative – and there still hasn't been – talks to its power and also where it sat at that time.

Tom: And the amount of money that was spent on it.

Marc: If you look at it in maybe advertising terms, it's one of the most powerful important campaigns that's ever happened, so for ad men...

Ford: It stuck in people's heads.

Lynne: Award winning.

Dominic: That's about it. As you say, if you spend that much money on anything, it could have been rubbish but you would still remember it because you have been exposed to it every day and there were leaflets going through the door. In hindsight, there had to be something big put out there because, I agree with what you're saying, Ford, a lot of people in the know did actually understand what was going on, but a lot of people had no idea, and so the government had to

do something at that time. They had to put something on public display about what they knew. Unfortunately, they displayed the Iceberg campaign.

Ford: I remember at the time being pleased, because we had spent a few years trying to get the government to react, to do something, and this is what they did, and just doing something was welcome. But at the same time its imagery, its language, reinforced all the very negative way in which having AIDS was being... in which HIV was being portrayed, and it was absolutely a dividing line between the sick and the well, it's about them and it was pushing people with HIV away, and it was very much addressing people who didn't have HIV. There was nothing in it at all about community solidarity or keeping people in the fold kind of thing.

There was quite a complex musical thing as well. The Catholic mass of the dead in Latin one of the sections is the *Dies Irae*. Do you know this? I found it out a few years ago, do you know about this?

Lynne: I know because when I've used it in lectures the students have recognised it, they have done this analysis.

Ford: Each of the... it's called an incipit, it's a medieval musical tune that goes with the words to help you remember what the words are, and the chisel that's going into the piece of rock, and it's going dong, dong, dong, dong, it's playing the first notes of the *Dies Irae* which is 'day of wrath,' and it's, 'day of wrath will rain down on you,' and it was like a sick joke, when I figured it out I was like, "How did that get in?" Following a load of media about HIV as the wrath of God, and it was like the government were saying, "Yes it is, HIV is the wrath of God," and this is our government public education campaign. You would only notice it if you were Catholic I think, but I am assuming that lots and lots of Catholics at the time noticed it and felt very smug and happy that the government were reinforcing this imagery, this way of thinking about it.

Lynne: Well they were quite a powerful lobby because the Catholics were keen on getting our teaching pack banned and pulped, we're practically into burning books, and this was very early on in the HEA, it's a very good teaching pack which had been piloted, and it started to be rewritten by committee until eventually it was pulped. We had to have a new edition, which had to have, as it was then, the Lesbian and Gay Switchboard number was taken out and the Catholic something or other body was put in.

Dominic: It was the gay references and a belief that there was no mention of abstinence in it. It actually did mention abstinence but they were finding any excuse to stop publication.

Ford: It is the case that any disease outbreak is an opportunity to marginalise the people who are suffering, ignore the structural factors, and the government and lots of people in the country took the HIV epidemic as an opportunity to suppress being gay, not having safe sex, just don't do it, and the things Thatcher said in public really reinforced that. That she thought the way to solve HIV was to not be gay, not to use drugs, and Section 28 is what rode on that. Section 28 for me, it really clearly ties to the HIV epidemic and an opportunity to try and stamp out homosexuals.

Lynne: But we did manage to have a press ad that had two men holding hands.

Dominic: The Bisexual Ad.

Lynne: At the time we called it a bisexual ad.

Dominic: Which went into Time Out and places like that, it wasn't just in the gay press.

Lynne: It went into the Telegraph, it's a visual of two men holding hands and it says, "If a married man has an affair it may not be with a woman." So clearly, Thatcher wouldn't have been delighted with that.

Ford: That's interesting, isn't it? Because who is that targeted at? Isn't that targeted at the wives of men, it's, "Be suspicious of your husband."

Lynne: At the time, the rationale was that it was targeting men who may have sex with men, maybe married to women. We particularly wanted to do some stuff with the Telegraph and the Sunday Telegraph as well, not just advertising but to get editorial. That was in the context of the Sunday Times having a massive campaign against us led by Andrew Neil who insisted that there was no heterosexual risk at all. So, whereas we would have been able to run things in the Sunday Times as we did sometimes with the Observer, we had this barrage, every Sunday we had something that was attacking, so that was the context trying to do something.

Marsha: So was there this very intense period of working against the politicians of the day and presumably learning about health promotion at the same time? If this was a whole new territory that people were involved in, what was it like within the sector? Were there a lot of organisations of people thinking in the same way? Around this table, it seems there's a strong consensus about those ads and the difficulties, but what was it like across the sector do you think?

Marc: My recollection if we're talking about that early period '85 to '88/9 there were small grassroots organisations, you had THT...

Ford: THT, when was the National AIDS Manual founded?

Lynne: '85, '86?

Ford: Switchboard were very active, they had a policy of raising in HIV on all their calls, irrespective of what they were about.

Siân: And in fact, they had to pick up a lot of the pieces of the tombstone and iceberg campaign. Because they were getting a lot of calls that they didn't have enough resources to deal with and a number of the 'worried well' ringing them.

Dominic: Peter Scott and National AIDS Manual are definitely worth a mention, that was a good bit of work. We worked with Peter Scott and he advised us on the HEA Gay Bar Study.

Lynne: Yeah.

Lee: There was also around that time, and just beginning to emerge, health promotion departments around the country which were not in public health, they were mostly separate, and they were a lot more radical really than they are now, and they did align themselves much more to activist work. A lot of them had come from activism, and social science, and some ex-teachers. So, I think that was helpful as well, that opened things up.

Will: But also the way that health promotion units were almost able to Robin Hood some of the resources and give it to people who... and that's how the Gay Men's Health Project in Norwich got set up, it was almost entirely funded through the health promotion unit who felt that they couldn't quite step over certain lines and they funded us to go and do it. I think for me that narrative of having something in addition to what was formally produced was what rings true all the way through. So, I can remember the first day I started at university in October 87, the first thing I was given was a copy of the tombstone leaflet. A few weeks before I had been out at a festival in the summer and picked up THT's first Safer Sex Guide for Gay Men, which gave me information that I needed where the tombstone advert didn't. Lots of the HEA stuff didn't ever resonate with me, there was always someone else that gave me something in addition to that, that helped me to better understand, whether that was the early GMFA or THT work or actually the early MESMAC work. There was always something that was done by activists or

by community organisations that gave me the information I needed. So it was almost like there were parallel processes going on.

Jose: Somehow you wonder how much those education campaigns are really education campaigns or the other way around, more as uneducation campaigns trying to reinforce some of the messages that were already wrong, and people on the other side like activists were doing harder work trying to fight that. Where you were saying there were these two layers and maybe it would have been easier since the beginning if there hadn't been this reaction from the government in which what they were doing was reinforcing negative messages across the society. It was more about an education campaign for a civil servant or for the government itself more than for the people.

Dominic: I think the model we worked on when we did the national campaigns, whether they be in the press or the TV, leave tombstones aside because we would have never have gone for that, but the stuff that we did produce did act like an umbrella to start a conversation. At local level, local activists, local groups, because the HEA did used to fund a lot of local groups as well. We knew we could only get away with saying so much publically and we knew we had to go through different routes to actually get to people on the ground. So, it acted like an umbrella within which you can say well these are the key messages, these are the things, it's alright to talk about this, positive images of gay men, positive images of heterosexual relationships, some of which are casual. It wasn't demonising anybody, it was trying to take us towards that conversation, that space that was created so people could have that conversation, whether it be at local level or even schools with the teaching packs that got through. So that was the health promotion model of it all, and that's worked for many other campaigns.

Lynne: I think also because we have just been reflecting recently on that time at the HEA, and I think we summed it up partly by saying that some of the best work we did was to curb their worst excesses, and by that we meant ministers, occasionally we meant advertising agencies. But those battles were almost on a weekly basis, and then you had the Sun and the Daily Mail and all the rest of it, ministers behaving badly. We had the intervention of Michael Forsyth who I think was secretary of state for Scotland at the time, bugger all to do with health promotion or anything else, but he had the ear of Thatcher so that was constantly happening. So it's coming from all sides. But I think the thing to remember, talking about activism, is that the HEA was quite hurriedly reconstituted and given this massive amount of money and then went on to recruit 200 people. Those of us who came in as journalists, we had been campaigning journalists, there were researchers who had worked in community campaigning, the publishers

had worked on campaigning materials. So there was this activism inside, although we had to cool that down really, and be good little civil servants and just try to see what we could get past ministers constantly.

Lee: I think the context again is important because the organisation as a whole was under huge pressure and David Mellor, remember him? Chelsea fan, odious little man, the HEA had to have a review every year with government, and you are led to this room in Department of Health, all sit round the table, and he literally used to come in and bang his fist on the table about what he didn't like or what we were doing. He demanded having his photograph taken with AIDS patients, it literally was horrific, and then we all left there feeling totally demoralised, and the chief executive of the organisation at the time began to crumble under all that pressure really. But it was very, very difficult, the context that everybody was working in. You would write a strategy, it would come back from the civil servants with all words like 'poverty' and 'disadvantage' crossed out in red pen. It's hard to imagine now, I don't know what it's like in the Department of Health, maybe it's like that now, but certainly it was never like that at local level, I think we had a lot more freedom.

Marc: Something else which comes in with all that context was that we were all aware of the sense of urgency that we all had in the sector – or in the community, as I prefer to say – we were reacting to fill in some of those gaps, also to meet the audiences we knew who wanted to, to make sure there was true representation. I think the other thing that we don't mention a lot is that it was youth, we were all really young, we were fired up, you've got that energy in your belly to actually do something and coupled with clause 28, coupled with the Thatcher government, the racism that was going on, extreme homophobia. We were united in our collective front to really fight stuff, and I think that's why we were really able to put out innovative crazy stuff. Many of us, I certainly didn't come from a health promotional background at all, I had no training, it was like, "Well does this work? Let's see if it sticks and we will come and do it." So, if we just jump forward to some of the stuff the GFMA put out in its early days, it was incredibly radical, because actually you guys [at the HEA] couldn't do it. We don't have to sit and talk to ministers or anything, we just need to speak to a few people in the community and ask, do you like this, does it work, let's sign it off and get it out there and we will fall on our sword after, and there's that wonderfulness of being quite young which I think is something really to hold onto.

Marsha: What was happening with the epidemic at that time? Presumably the numbers were increasing, the number of people who were becoming infected and the visibility of AIDS? Was it a struggle to communicate what safe sex would be? Testing, perhaps?

Ford: HIV was very concentrated in particular networks. The majority of gay men in the country by the end of the '80s probably didn't know someone with AIDS, the people who did know someone with AIDS probably knew a load of people with AIDS, people had their entire friendship networks wiped out. But it was very geographic and socially concentrated.

At the end of the '80s how many people had been diagnosed with AIDS in the UK? A few thousand?

Marsha: A few thousand? So this was a sense of something impending? That people, politicians were fairly resistant to and as activists you were aware that something was happening that mattered, but had to put it out there for other people to take it up?

Ford: Well it's also that the community was responding to the authorities use of the opportunity of HIV to bash them, so there was a greater sense of the social fight as the health fight really.

Marsha: As in the importance of sexuality rather than disease?

Ford: Yeah, Section 28 was very important in terms of taking sides. HIV seemed to create this, you were either castigated and marginalised and damned by the authorities and media or you were part of a rainbow community where everyone was fighting for each other, and the media was really central to that because the government didn't say anything for a few years. We all had to put up with daily assaults by the tabloids and maybe sometimes the broadsheets that were just horrific, in retrospect. Being young, I didn't really clock it at the time what a daily grind to your mental health it was, because you didn't really have that much to compare it to, but it was very assaulting to face that, and a lot of the community response was against that as well as in some networks about fighting for healthcare.

Karen: I think it was stigmatising not just for the gay communities but also for people living with HIV, and one of my earliest memories at National AIDS Trust was drawing up with community groups a *UK Declaration of Rights for People with HIV and AIDS*, and I think that was one of the first rights based bits of work. I was just thinking, when did Body Positive start?

Ford: Pre-1985, because my first Pride was 1985, and it was gathered in Hyde Park, and I remember seeing a bunch of people with their banners saying Body Positive and it was like a body blow. I was just so amazed that some people would stand there and go, “I’ve got HIV.” I was so in awe of these people that they would do that. So they must have formed before ‘85.

Peter: It’s funny what you forget and what you remember. My sense, Marsha, you were asking about HIV health promotion and for me, at least for that decade from the mid-80s to the mid-90s, safer sex was a profoundly simplistic message about condom use, there was nothing about testing, in fact testing was actively opposed by most organisations through to the very late ‘90s, not even ‘97, it was much later than that. So, actually, what Ford was saying about how lots of that campaigning was about your rights to be gay, your opposition to being demonised and stigmatised, and the same was true of prostitute education projects, Body Positive projects, they were a lot to do with, “We have every right to be here, we’re not bad people,” it wasn’t about avoiding HIV. I think you had the background noise of the national campaigns which were very much about, “There’s something you should know about,” without being very explicit about what you should know and how you should know it. But even the smaller community organisations weren’t doing a great deal of what you would call safer sex work. I don’t know, it was about using condoms, that was about it really, because pretty simple times. Tom, wasn’t it the first decade of MESMAC?

Tom: Yeah. Well I think there was probably more, and particularly outside of London a lot of our work was around building community infrastructure as well. It was very much about that community development model, getting groups of people together and getting services up and running to deliver those really basic messages, as it were.

Siân: That is an interesting point about testing, you’re right, because the message on that completely changed between the early ‘90s and the late ‘90s/beginning of 2000s, because all the language around testing earlier on was about having the right not to test as much as it was about the right to test. It was always presented as, “Well here are the pros but here are the cons,” because there wasn’t the treatment, so actually you could be worse off knowing because of the stigma and because that it could affect your job, it could affect your insurance, it could affect...

Peter: Mortgages and all that.

Siân: All kinds of things like that, so actually a lot of the activism was around not testing, and opposing it. Like the ACT UP stuff, I know that Will [Nutland] was involved with the campaign

against Texaco, who were trying to impose testing. So testing, actually, it was a complete flip of messaging that had to happen during that decade.

Dominic: Also the idea, as I said, where you can get a test in the post and you get no counselling before that test. Was that a good idea to promote that? I remember it was a tricky area.

Karen: I think testing messages are much easier now, when there's very clear reasons to test and very positive information to give out if you have a reactive test, whereas back then AZT had very serious side effects. It was all a very grim picture, so therefore encouraging people to test came with its own health warning, so to speak.

Lynne: And we had those stories that kept breaking, breaking stories the whole time. I remember that there was a surgeon who had HIV, who was an eye surgeon I think, and of course the Daily Mail loved that and pounced on it. There was this massive call for everybody in the NHS to be tested, it didn't matter what contract they were on. This is about human rights now, but then you were just constantly firefighting, and public opinion would be shifted by that stuff.

Karen: The organisation that I work for, which used to be West London Gay Men's Project, it's now Spectra, the reason we came about was from a local authority HIV unit which was formed basically to train up the rest of the council. So people going out into communities – teachers, social workers, street cleaners, everybody within the council – training them about HIV policy and procedure. The agenda there was about taking universal precautions, so trying not to treat HIV as particularly different to the rest of the policies and procedures that were standard. But that wasn't helped when stuff like the eye surgeon that you just mentioned came up.

Lee: I think the condom thing is interesting, I've been thinking about it because I think that did at least open up discussions about pleasure and sex in a way that certainly hadn't been in sexual education conversations before, and was difficult to write down, but it was present in the community work and education programmes, and it's still very difficult to get that written down now and published at local level, and our local project in Sheffield has had enormous problems with that recently. But I think it did open up those kinds of discussions about sexuality, what you could do, pleasure, taking pleasure, giving pleasure etc, and that started to spill over, to the heterosexual relationships as well, and I do think it opened up space.

Ford: Prior to the consensus about condom use, though, there had been a debate in the Terrence Higgins Trust in their early health education messages about, "Should we tell people

not to fuck, or shall we tell people to use condoms?” And the compromise there was to tell people to use extra strong condoms. So for quite a few years – only in the UK, nowhere else in the world as far as I’m aware – gay men were encouraged to use extra strong condoms because anal sex was much more robust somehow than vaginal sex was, and that recommendation about extra strong condoms came out as a compromise from that row. Prior to that the health education coming out at THT didn’t mention condoms at all, it was about partner selection, don’t have sex with people from America. I was in Reading at the time and we were not having sex with people in London [laughs], so there was all this partner selection and distancing was going on, and when did the sex with strong condoms thing get dropped?

Marc: I remember us having many big conversations, early 2000 we dropped it.

Ford: Following Richard Harding’s randomised controlled trial, wasn’t it?

Siân: In 2002, GMFA did a campaign about how you can use any condoms.

Peter: Most of us thought it was a terrible thing to do and opposed it completely at that time, vehemently opposed it.

Emily: Opposed dropping it?

Peter: Yeah.

Ford: The extra strong thing.

Peter: When Rubberstuffers was launched in ‘96/97 that was all about extra strong, they wouldn’t advocate anything else.

Ford: Oh yeah, Rubberstuffers was actually launched in order to increase access to extra strong condoms wasn’t it? Rubberstuffers was a charity that no longer exists that just did condom access.

Will: It morphed into Freedoms.

Ford: Oh yeah, it morphed into Freedoms. I suppose as well something to remember is that there’s an almost nostalgic memory, particularly when we get together like this, about the voluntary sector and the community versus the nasty government, but actually the voluntary sector and the community were rowing like hell amongst themselves, it’s a very fractious hot time.

Marsha: About the way that condoms were being promoted or about...?

Ford: About anything, about everything, about what do we tell people...

Marc: Who you're telling.

Ford: Yeah, who you're telling, what do you tell them, whether you tell them what you know or tell them what to do. Certainly, by the early '90s I can think of a major axis of discontent between MESMAC and GMFA. When I started working with Sigma that was the big hot thing and it was the difference between, "Tell them what you know," and, "Tell them what to do," and reflecting on it more recently I think it's also about values around equity of health and everyone has the right to have control over HIV, versus a public health perspective on impact on the number of infections. So doing work with men off the scene, bisexual men, men who weren't gay identified was driven by the recognition that they had not had as much information, as much support, versus work with gay men at the centre of the gay scene because they are most likely to get infected, whereas the bisexual men were less likely to get infected even though they had less. That tension was in the voluntary sector, it wasn't a statutory thing at all.

Lee: There was huge competition with funding as well, that didn't help.

Dominic: We had, as I said, a gay advisory group for the campaigns, and they were always arguing over different approaches. You've written on the agenda for this discussion, 'de-gaying,' and 're-gaying,' that was an issue as well. Questions about how much we should be focusing on gay men without just playing into the tabloid press idea, or should we be going along this path of making sure it's everybody's problem and we should all try to address it as a wider community. But there were lots of debates, some healthy, some not healthy, but that's what you have when you have a diverse group of people working on this issue.

Marc: From my perspective, Big Up for example, a black gay men's organisation that came directly out of GMFA and Blackliners not providing support or advice or information specifically for that target group. We got support from GMFA and Blackliners to do it. So, from that absence many organisations and campaigns emerged, but there were lots of battles about that.

Marsha: Was there a response to other groups like black African groups in the UK, not necessarily men who have sex with men, but women or was health promotion very gay focused? To put my question in a bit of context, in Australia testing was promoted from the outset, there

wasn't any reticence about promoting testing. It seems that the context was very different, the risks of what would happen if you were diagnosed as positive weren't part of the equation in the same way as they were here. I think what you have said is that there was an issue with sexuality that contributed to why testing was not something that people should be encouraged to do, because it was associated with sexuality. Initially I had been told people were discouraged from testing because there weren't drugs and so it was better not to know, but that doesn't add up for me when I compare it to Australia. Sorry if this is a bit rambled, but I'm also thinking about what happened then with other communities that didn't identify in terms of gay sexuality or MSM, were they also on the health agenda for promotion?

Ford: The were the four Hs in the mid-80s. The worst thing about getting AIDS is trying to convince your parents that you're a haemophiliac because the four Hs were heroin addicts, homosexuals, Haitians, and haemophiliacs, and it wasn't until the late '90s/early 2000s that Africans in the UK were recognised as a group, which is weird because when I joined the Terrence Higgins Trust at the end of the 1980s my very first helper cell job was to an African woman in South London living with a couple of kids who had AIDS, doing some gardening and painting for them. So Africans were absolutely part of the client group for the voluntary sector at that point.

Lee: I think it was funded nationally for all of those groups and more. I think that nationally the HEA did try to cover all angles if you see what I mean, tried to do that through funding. But it was very much funding initiatives and projects rather than centralised action.

Marc: There was something slightly different going on on the ground, from about '85 to the early '90s, much of the African Caribbean population were first and second generation migrants from Windrush etc, so the response, I don't recall much HEA work specifically for those communities apart from the occasional person within an advert, but I don't think it was targeted to those communities. I recall that on the ground there were organisations which were developed like Blackliners and Black HIV/AIDS Network, MESMAC did some amazing work outside of London as well. I think organisations like MESMAC took that as a central part of what they were doing, I think in London there were organisations set up themselves, and I think what happens after 94/95 with migration from Africa and we see the epidemic change, and we see more people moving in and being diagnosed etc. That's when we see African populations recognised as an area we have to address, and that's when you start getting national funding, National Black CHAPS (the African version), National African HIV Prevention Programme (NAHIP)...

Peter: That's much later.

Marc: NAHIP came around much later than CHAPS.

Peter: 2004, CHAPS was '96.

Marc: '96 yeah.

Peter: And that was when you had that massive raft of change in migration, Uganda, suddenly you had a lot of in-migration from very high prevalence countries, and then we went back to, having de-gayed and re-gayed we went back to having a moral panic about heterosexuals and black people and all the things that had been dealt with for the previous decade. They all came back to the fore in the red tops, didn't they?

Ford: Around migrants.

Peter: Black migrants.

Dominic: "Using our health services," that kind of thing.

Peter: Yeah, health tourism and all that.

Ford: Coming over here, using our services, shagging our men.

Marc: Talking about Afro-Caribbean communities, I remember there was a massive issue around other STIs, huge numbers around gonorrhoea and that hitting the press, and I can remember those being the headlines: "Afro-Caribbean men with gonorrhoea," that sort of thing, but nothing ever around HIV, and that went in tandem with this.

Ford: And interestingly that coincided with the de-gay/re-gay push, there is a very interesting history about the Public Health Laboratory Services (PHLS) that turned into the, what was it?

Peter: Health Protection Agency.

Ford: Health Protection Agency. They eventually turned into Public Health England, and the press releases about the HIV monitoring data, the surveillance data used to be quarterly I think, then it got to six months and then it became yearly. The press releases would be very carefully crafted statements about heterosexuals and homosexuals, and hiding the fact that the majority of the heterosexuals were black migrants to present it such that it looked like the majority were white young heterosexual British people, to say that more heterosexuals are being diagnosed

with HIV instead of homosexuals, which domestically in terms of domestic infection just wasn't the case. So it both ignored the people who were getting HIV in the country, and ignored the people who were moving to the country and used it as an opportunity for something else.

Will: At THT we started calling it the Ibiza-isation, as in, the PHLS were reporting the heterosexual infections as people who were acquiring it when they travelled abroad and making it into, "Young Becky is going to Ibiza and coming back..." and I think there was actually, I can remember sitting in a meeting in Elephant and Castle and I think Ford you might have been there, and it was to look at the next national strategy. People were actually making an argument that there should be leaflets in Boots next to the condoms to warn young straight people about what they might get from a holiday, and this was despite having all of that data and fights that we had with Barry [Evans] and the guys at PHLS.

Lynne: What year was that?

Peter: 2000, it was the development of a first national strategy, was it 2001 the first national strategy?

Ford: Mike Adler led.

Lynne: Because in '92 there was that horrendous Panorama programme by a man called Tom Mangold.

Ford: Killer in the Village.

Lynne: Yes, who invented this term called 'fast track heterosexuals.' And in that programme they filmed young people, particularly young white women dancing with men in the Bahamas. I think perhaps he got a nice trip to the Bahamas out of it but there you are, and this was just another version really of that, "Who can we blame?"

Will: I think PHLS were trying to do something good, they thought that their intentions were good. That by saying this was about a bunch of young white people going on holiday and getting HIV they were trying not to allow it to be the gays and blacks and migrants, they were trying to say it could be anyone, it could be the kids who go to Ibiza.

Peter: It's just that it wasn't, as a rule.

Marsha: Do you think you can ever get away from the identity politics in this?

Peter: I don't think that the UK ever has.

Marsha: Maybe there's some value in identity politics?

Tom: I think whilst HIV still disproportionately affects certain communities, particularly marginalised communities, then it is an identity politics in communities. It's really important that we keep that, because we use that thing, "HIV is an equal opportunities infection," it never has been, and that meant that loads of services that should have been targeted were never funded properly.

Ford: There was also the necessity of that statement, that HIV is an 'equal opportunities virus,' that came out of the absolutely appalling way that people with HIV were treated, and the opportunity to gay bash and migrant bash and drug user bash. So much of the work that happened in HIV was trying to mitigate the harm done by the response of others to HIV. Most of it, I would say, I would say most of our energy was put into trying to fight very negative reactions to HIV, rather than to fight HIV in any sense.

Siân: What was really surprising was that the needle exchanges came in at the time when they did. When you think about it, with all of this stuff going on, I think one of the few things we actually got right in this country was the early establishment of needle exchanges.

Ford: Which was probably the second public health measure after banning gay men from giving blood. That was the very first thing that happened in 1983/4.

Siân: The needle exchange was around 85/86, somewhere like that².

Ford: So it wasn't that there wasn't a governmental HIV response. They banned gay men from giving blood, they introduced needle exchanges, it was just that community education, particularly gay sex, HIV prevention didn't happen for a long time.

Emily: So, you mentioned the equal opportunities virus and you said that was to try and mitigate harm?

Ford: Yeah, the de-gaying of AIDS was driven by gay communities, I would say, and that was because as soon as you were seen as being gay you were seen as having AIDS, and it was a push against that. The re-gaying also happened by gay communities, particularly GMFA. What

² Official pilot needle exchanges were established in 9 UK cities in 1987.

the de-gaying did do was mean that lots and lots of the prevention we sorted went into education campaigns for people who weren't going to get HIV, whilst the communities that were getting HIV got less.

Marsha: So did antiretrovirals, combination therapy, radically change the field of health promotion?

Peter: Eventually [laughter]. That's the thing I was struggling with, because I was looking at some of our work last week just thinking about it because of this seminar. I wasn't shocked but I kind of was, the first CHAPS was launched as a national intervention at the end of '96, beginning of '97. There were 12 organisations, something like that, all over the country, loads of problems, lots of positive things to say, but also lots of negative things. Lots of competition and *a bit* of collaboration. The first testing intervention from CHAPS was 2002, now we had combination therapies, that was in Vancouver '96, the first demonstration. How did it take four or five years after that to do a testing intervention? There were interventions in the intervening four or five years that mentioned testing in a slightly offhand way, but THT didn't go supremely pro-testing until the early noughties did they, 2001/2? This is when the first CHAPS interventions that were about getting a test happened. There was a little bit about knowing your status in between. My sense is we became so acutely aware of the positive and negative, particularly the potential negative consequences of being seen to ever having tested, that it took some years to get over it and come out the other side. Slightly bizarre though.

Will: It was Camden and Islington health promotion services who really pushed that. Do you remember Mark McGuire's big campaign in the early 2000s? And then I think it was Positive Nation ran a head to head think piece with Mark saying we should be pushing testing and Healthy Gay Manchester saying we shouldn't.

Siân: But THT's 'Think. Talk. Time to Test' was '97.

Peter: Yeah, there were 12 campaigns between 97 and 2001, and that was the only one on testing, there were three a year.

Siân: But that was '97.

Peter: It made no difference because no one could read the words [laughter] it was an across the crack poster that you needed binoculars to read on the tube. I remember several people died leaning over the train edge trying to read it. But yeah, Camden was then wasn't it?

Ford: The first response to Vancouver '96 was, "It's not a cure, don't stop using condoms, it's not a cure," rather than, "There's something you can do about this if you've got it, get tested know your status." That isn't how the sector responded, it was a panic that it would undermine safer sex somehow rather than it being a good thing.

Peter: The CHAPS response was partly driven by lowest common denominator. The problem with CHAPS in those early years was that THT hadn't learnt to bully everyone very efficiently. So you put 12 organisations in the room and get them to plan an intervention what you end up with is nothing very radical. Bizarrely, the censorship of Healthy Gay Manchester was such that if they were in the room, talking about testing was really hard. Actually, for several years that meant that most of the CHAPS interventions were fairly wishy-washy, and even when they went towards testing it was about knowing your status rather than the act of testing.

Tom: But every new technology has been met with that same response, hasn't it?

Peter: PEP wasn't though, Tom.

Tom: It was.

Peter: Not in CHAPS.

Ford: By the time CHAPS responded to PEP, it wasn't a new technology, it had been around for ten years, it was actually about access to something that had been kicking around and who could have it. The response to PrEP was very similar to the response to ARVs, it's a problem.

Marsha: This has really radically shifted though, in terms of PrEP. It's gone from a, "We don't want to know about it, this is highly risky for sustaining safe sex," to now a campaign that PrEP should be available?

Will: I think those narratives still play out in exactly the same way. I was doing a training in Manchester last week and there was a fairly influential person in the room who could not move away from the idea that PrEP undermines condom use, saying that there's no such thing as PrEP use stigma, it's all about, "Men who I speak to who are being stigmatised for wanting to carry on using condoms." So I think lots of the ART '96 discussions are being completely mirrored again now.

Marsha: Even though people are not using condoms?

Ford: Lots of people are using condoms.

Marsha: But the argument for PrEP was really that this is something for people who don't use condoms or who don't want to use condoms.

Ford: Was it? The argument for PrEP depends on who is paying for it, and if the government is paying for it or if the NHS is paying for it who should have access to it. It looks very different from the people are paying for it themselves.

Marsha: But isn't that the argument about how it should be provided? I have tried to stay away from having a position on PrEP, but the people who are involved in developing PrEP argue that people don't want to use condoms all the time or people can't use condoms all the time and so, "It's clear that if antiretrovirals are preventative, why not make them available?" Then there's this the response to that about who is going to pay for it, isn't it? Or you're saying that actually there are other agendas going on in how people think about PrEP?

Will: Yeah, well the best sex with the least harm, PrEP facilitates that.

Ford: The best sex with the least harm is where CHAPS ended up just before it folded as the goal of our programmes. It took a while to get there, but when did CHAPS stop, 2012? So it has continued since then, because I think we all recognised it as having some truth to it.

Marsha: So is that a difficult thing to find a way of promoting?

Ford: PrEP?

Marsha: Yes, in those terms, the best sex with the least harm, ... is what's being promoted now?

Marc: It takes some unpicking to get people to understand what that concept means. I use it in my work very often, either individually or on the macro level with people. But once people understand that PrEP sits within that, along with a whole host of things then they grasp it and it's really an empowering statement. It's a really empowering place to aspire to be as well, and to inform our work. So I think the notion of PrEP being pushed by people for people who don't want to use condoms is a non-starter, it's not where it comes from. I think that's where it came from and that's where its detractors will use that but it's bigger than that, it's much bigger than that. Something else to throw in the pot as well, which I don't want to lose sight of before we completely go down the route of PrEP is also we talked about the impact of ARVs changing the conversation and narrative, but it's also the impact of ARVs in the U=U conversation and discussion and where that is sitting in health promotion, and what that's being pushed.

So if I can, when I do lots of work with positive people who have been diagnosed and then go, “What’s one thing you want?” well the answer is a national campaign like we had with the tombstones but flipped on its head, challenge the stigma, and the whole U=U message – undetectability equals un-infectiousness – has not been pushed, has not been grasped by the community, by health promoters, apart from a small group of people or room of people. So again that’s another thing that’s missing from the work that we’re doing in terms of prevention and health promotion.

Ford: And that came into being because of the insistence on saying that if you’re undetectable it’s ‘*very unlikely*’ that you will pass on your HIV and leaving the gap open for all the negative things that go with having HIV. In fact, the evidence shows that no you can’t, it’s *not biologically possible* to pass on HIV, and it’s really important to say that it’s not possible, not that it’s very unlikely, it’s not possible, and what that does to people’s sense of un-infectiousness when they have got HIV. Infectiousness being one of the worst things about having HIV, feeling that you’re infectious to people that you love. Yet it hasn’t gained traction, no it’s not that it hasn’t gained traction, it’s that it hasn’t been promoted very much.

Peter: Because we can do one thing at a time and that’s not the thing.

Ford: Yes, possibly.

Peter: Because PrEP was the thing, but even that’s a bit weird because PrEP is unlikely to ever be a whole population intervention.

Karen: The last Do It London campaign had U=U in there.

Lee: What’s the state of health promotion now in HIV and AIDS?

Peter: It feels much more fractured now to me than it has for a good long time in the sense that competing messages seem more common these days than they have since about ‘95. That’s partly because whoever survived is doing their own thing, both cities and organisations within them, which I kind of get, because we have seen a massive contraction haven’t we? There were probably 300, 400 or even 500 organisations actively involved in HIV prevention 20 years ago and I don’t know if there are even 30 now.

Karen: Nationally we’ve got HIV Prevention England which THT holds, so that’s the national one, and in London we’ve got Do It London.

Peter: And you have regional interventions as well, although they don't tend to be as media driven is my impression, even in Manchester and places like that.

Will: We also have a national programme that's about delivery rather than strategy and research, so from '96 through to 2012 both the national CHAPS programme and the NAHIP programme that followed, had investments into *Making it Count* (Beaumont *et al.* 1998), *The Knowledge, the Will and the Power* (Dodds *et al.* 2008) that were documents that set out where we agreed and where we didn't agree, and our ethical approach, and what our priorities would be. But there's nothing like that anymore, so even nationally in the voluntary sector, community based organisations don't have a consensus statement or even a place to come together that's funded that helps us to work out the consensus statement.

Emily: I think it would be good to think more about the current challenges and the future of health promotion, but I also am aware that PEP was mentioned but we moved swiftly on.

Ford: PEP was available for healthcare professionals for needle stick injuries from the mid-'90s if not the early '90s.

Will: '93 Berlin AIDS conference, I have one of the conference newspapers where it's talked about at the conference session.

Peter: When was the first CHAPS campaign about PEP? 2002/3.

Ford: Yes, about ten years later after it became available to healthcare workers. CHAPS partnership were aware of this drug, and there was a feeling that it was being denied to gay men because of homophobia, and the CHAPS partnership took it on its shoulders to change that situation. I don't think anyone really thought that it was going to have a population level impact. It wasn't really being argued for as a public health intervention, it was a personal health intervention and therefore the people who got it, it could make the difference between being positive and not being positive but that it was never going to have a major dent on incidence, and, oh gosh that was a convoluted way in which it happened wasn't it? I just remembered, there was a real catch-22 with the clinics saying, "We can't make it available because no one is asking for it," and the community not asking for it because they didn't know where to get it, and what CHAPS did was a pre-emptive education campaign about it, and a couple of guys who had contracted HIV saw the education campaign, said, "Why didn't anyone tell me about this?" Wrote to the Department of Health, threatened to sue the Department of Health. The

Department of Health told the health authorities to make it available, that was the short route way wasn't it?

Peter: What did PHLS call it at the time? Did Barry, as head--

Will: PEPSE.

Peter: No, before PEPSE, it was no-no PEP. Non-occupation PEP it was called 'no-no PEP.'

Will: We thought we called it a licence to bareback [laughter].

Ford: And again that was another health technology that was seen very suspiciously because it would undermine the preferred method of prevention, and it didn't impact on incidence, and it did prevent some people from getting HIV.

Peter: And A&Es weren't flooded with people demanding it every... because that was the other half of that story, the story was every A&E will be full of people who made bad decisions on Saturday night all day on Sunday.

Will: So one of the strategies we used was to pilot the national campaign in London and Brighton, and Manchester wouldn't join in the pilot. We piloted a website where you could do a self-assessment and then it would take you to clinics where we knew that you could get PEP for sure. We worked in collaboration with those clinics and they kept initial data on how many people had come through the clinic based on the self-risk assessment. So, we were able to provide some data very early on that showed that clinics weren't being flooded, and we also worked with BASSH and BHIVA to start writing guidelines on PEP provision at the same time. One of the arguments there, I remember, was about what would happen if someone continually used PEP. So, if someone was using PEP instead of condoms on a regular basis and whether PEP should be rationed, and if it was going to be rationed how many times it should be rationed. Then, of course, men worked out this was being talked about and if they were consistently using PEP, they just clinic hopped and went from one clinic to another and didn't go back to the same clinic. And then some of those who were clinic hopping started to use for PEP for PrEP, so once guys worked out that two of the three pills that they were given for PEP were the pills that were used for PrEP and PrEP wasn't available, then we started seeing people, particularly in London, using PEP for PrEP, and hopping from different clinics across the capital.

Ford: Very creative.

Peter: But Will, we had all those arguments with PEP that you had again with PrEP, because the fundamental problem with PEP was thought to be that you couldn't trust men to make the right decisions about condoms, and the risk compensation thing that actually we shouldn't be allowing them to do anything other than use a condom effectively, and that happened all again ten years later with PrEP didn't it?

Will: They might not take their pills properly, they might share their pills.

Peter: They might have sex with a condom, God forbid.

Will: They might have sex whilst on PEP despite being told not to.

Marsha: One thing that's struck me, connected with what you were saying Peter, is that it seems that very early on in the epidemic this sense of responsibility was very important, using a condom was a shared responsibility. This was not an individualised act of self-protection but a community relationship to the epidemic. Now it seems – you can throw what you want at me because I am just testing this out – it seems that PrEP and this notion of 'disinhibition' or 'risk compensation,' whereby, "People will start behaving recklessly if they have this prevention technology," re-appropriates this earlier notion of responsibility. It is as if gay men showed that, "Okay, we will embrace this notion of responsibility, we will take up using condoms, we will establish a sexual culture which is about prevention," and now that is turned as, "Oh, now will they continue to be responsible, will they become very irresponsible with this possibility?" It strikes me that the notion, the risk... I appreciate that medical technologies change cultures, but this way of talking about PrEP as, "This will introduce potentially a reckless relationship to HIV," is kind of a backhanded way of thinking about what people have done in the history of the epidemic of dealing with HIV. If any group has demonstrated their preparedness to take on dealing with something, it has been gay sexual cultures. I don't want to leave out women and so on, but now PrEP invites this new scrutiny of gay men as, "Will they be responsible if this is available?"

Ford: I think the fear is less about irresponsible behaviour with regards to HIV than irresponsible behaviour with regards to everything else that might occur or arise because of sex. So obviously, if you're taking PrEP you're not going to be picking up or passing on HIV but you might be picking up other STIs. I also worked in a drugs service, the stories that get told about a very diverse population get homogenised in both directions. So if you make PrEP available to a population, then every conceivable response to that will be in that population, and the political arguments that get deployed for or against PrEP tend to homogenise that and say,

“No, people won’t do that,” or, “Everyone will do that,” when actually it’s some people will and some people won’t. So there are individual level stories that are occurring about everything that you could imagine as a response to PrEP, and the argument about PrEP access has behind it a whole load of other arguments about how gay men should behave irrespective of HIV. Drug resistant gonorrhoea is the new thing, which is real, it’s here, it will get more common and it will get used in the same way that HIV got used to cast gay men in a particular light and tell gay men what to do.

Dominic: But it’s in heterosexuals as well. This comes out in research with heterosexuals. When ARTs came out some people stopped using condoms because they believed they could get treated, and you occasionally got that coming back in a focus group, that you don’t need to worry about it too much because you will be treated now for HIV.

So, it happened, obviously to a lesser extent, but it could happen in any community in that way. There will always be people with a range of behaviours and reactions in any particular community. It’s just accepting that this is the real world, that’s how things are. People want there to be homogeneity but it’s never the case.

Marc: But it comes from so many different angles, so as Ford said, it’s about policing or monitoring people’s behaviour, but it’s also about us as a community and making sure everyone has the ability to have a mature sex positive conversation, and that’s what we’re not allowed to do, and even when we do some of the work with gay men sometimes we get the biggest resistance, because they have been so torn and turned by so much around their sexuality and their sex that it must be protected, that it must be this, and anything that steps out of that immediately suggests you’re promiscuous and what does that even say about you as a homosexual? So to be a good homosexual means that you must do this.

Ford: Get married.

Marc: Yeah married, and I remember us having conversations around harm, around the suggestion of reducing the number of sexual partners being put on the table. We were saying, “No we can’t, we’re not going to say that because it’s about sex rights,” then thinking actually no that’s quite a smart move, that is probably one way that you might avoid your risk. So, again, having that conversation is right.

Ford: And it reflects the very longstanding strategy of, “In order to respond to anti-gay sentiment I will present myself as a good gay, and it’s bad gays over there who are bringing us

into disrepute,” and that dynamic gets repeated over and over again. James Warton when he said that we should shut down the saunas because obviously these days you don’t need them and people just do filthy things in them, and got married and moved to the Cotswolds with his husband and his dog, then six months later he got divorced and moved back to town and went on chemsex here.

Peter: There was also the narrative around condom use that presented you as being a hero or an angel if you can just use condoms. There’s actually a THT campaign with someone with a condom image with a halo around them, and that’s never been presented as the case for either PEP users or PrEP users, or someone who is consistently using their ART as treatment as prevention. So, I don’t think it’s any surprise we expect consistent condom use to be seen as the good thing, the responsible thing to do when that’s been imprinted on us.

Ford: And that’s interesting as well, because it only works if you have a massively optimistic perception of how effective condoms are at preventing HIV, which best evidence suggests is around 76-80% from a population of consistent condom use, and even less for...

Marsha: It’s estimated to be 95%.

Ford: Okay, what about gonorrhoea, what would you say about gonorrhoea? You wouldn’t say that was 95%.

Marsha: The answer would be, “Use your condoms you don’t have to worry about it.”

Ford: Yeah, but condoms don’t reduce the risk of other STIs to the same extent that they reduce HIV, so having high partner turnover even with 100% of condom use there is a risk of passing round STIs, incurable STIs. The halo of the condom only works if you ignore a load of things we know about how un-perfect condoms are, and it’s like a compromise position again. It’s an inability to be honest about what we know the data shows about the efficacy of different tactics in order to invest a particular tactic with a goodness about it in contrast to other tactics.

Siân: But condoms were useful because they were a very visual thing. It was a thing that could be seen to be being used or being bought, you could give them out to people. So, the normalisation of condom use in the early days was partly because it was an object around which you could message things, whereas taking drugs and taking pills and things like that is a lot more discrete, so it’s much more difficult to build messaging around it in the same way.

Lynne: It also seemed very positive to be saying to young women particularly that there is some kind of negotiation around this. There was some work that we worked very hard to get that negotiated, and I don't know how that ever evaluated, were we just incredibly optimistic youths at the time, thinking that we could empower young women?

Dominic: I remember some good stuff came back from evaluation with people saying that you have to be very sex positive. It's important, it's come out a few times in our discussion today, because the HEA did become very sex positive for gay men and for heterosexuals. So, there was always a message in there, "Use a condom and do what you like," that sort of thing. It was like, "Enjoy yourself," it wasn't trying to demonise sex itself. That happened in the early days and that used to come through in research where young blokes in particular were afraid to have sex, some of them, that's a terrible impact on a community. So, I think that's important, if you have that underlined you can get a lot of good stuff out and a lot of messages out there. Some people start to listen to you, because they are not being judged for their behaviour. Also many of the later HEA campaigns were sexual health campaigns not just HIV campaigns. They covered things such as sexually transmitted diseases, unwanted pregnancy, positive relationships, that sort of stuff. So they're actually more centred around, "What is your life like and how is this going to help?" rather than segmented messages. The underlying rationale for this approach is that the best interventions view a person holistically rather than as a set of behaviours and then target specific issues, having demonstrated that you understand and empathise with their life.

Ford: Part of the reason I like, 'the best sex with the least harm,' though, is it implicitly recognises that sex always carries the risk of harm, and that 100% condom use and you can do whatever you want doesn't mean that you're not going to come a cropper with something, it might not be HIV but might be something else. GMFA's very early campaigns were very promoting partner change, promoting lots of different behaviours, it was very focused on HIV and disregarded all the other harms that might arise from sex. We still have a real problem in sexual health promotion with that tussle as well as the problem between, 'tell people what to do,' and, 'tell them what you know,' it's still going on, and will continue, I should think.

Karen: There used to be a lot of stuff around serodiscordance as well, which I don't really see that word used much anymore, maybe different angles.

Ford: Negotiated safety was the name the Australian research team gave to the tactic of couples finding out if they both had the same HIV status then not using condoms with each

other, but using them with people outside if they had sex outside. So, there's a kind of partner selection, subgroup partner selection which also got turned into serosorting for casual partners. And there was another one, strategic positioning, about being insertive and receptive in anal sex depending on what your status was and what your partner's status was, all of which were in the mix in gay men's thinking and decision making and what health promotion, well what research did then and what health promotion did, was reify them into tactics. You don't really hear about any of them anymore.

Karen: It's gone down a much more medicalised model, I suppose.

Peter: Testing and pills to the point where we can't admit when we don't test, even if we don't need to test. So, having not been a testing culture compared to Australia, still 20/25% of all gay men in England have probably still never tested, although that population is constantly being refilled from below. But when we ran a load of focus groups last year to look at the idea of HIV self-testing kits we noticed that none of the men – and we knew this from their entry questionnaire – that had never tested would ever say it in a focus group. So we got focus groups of men and we said, “This group is full of men who have never tested,” and they still couldn't talk about it, even in a room full of men that had never tested. They had become so convinced that it was a terrible thing to admit that they couldn't admit it. My sense is that there's an awful lot of tests being done by men just to be seen to be good men, without really any notion that they actually might get a result.

Ford: Well that would be a success wouldn't it, in terms of PHE shift of... it was in the early 2000s PHE adopted a policy to promote annual HIV testing for MSM...

Peter: Irrespective of risk.

Ford: Irrespective of risk, and that arose because they recognised that men were pretty poor at judging their own risk, and that if they had a universal population level recommendation that was going to pick people up, and what the group 'gay men' does is test rather than always use a condom, it has been successful in that.

Peter: Well, except you've got the same number of diagnoses every year, you still have 3,000 gay diagnoses every year and you've gone from having the 200,000 tests per year in the whole population in England and Wales to over a million, but the number of diagnoses hasn't changed, which suggests an awful lot of the tests are a waste of everyone's resources including my own

if I'm the person testing. It's all driven by that 90-90-90³ malarkey, in that testing negative repeatedly is an end of itself these days.

Marc: And that's led to the biggest campaign that we've got, which is national testing week, where pretty much all of the energy nationally goes.

Peter: Even though there's absolutely no evidence that it does anything other than redistribute the number of tests you would have in a year anyway and concentrate them in one week in late November, because the absolute number of tests hasn't really changed in all the years that national testing has been there. There are clearly, there's a massive spike now towards the end of November/beginning of December when we have testing week and World AIDS Day.

Ford: There is an argument though to say that the increase in the number of tests taken has eaten into the undiagnosed fraction, that people live with undiagnosed infection for a shorter period of time, and that actually that's one of the major contributors to the number of diagnoses dropping recently. It will be another decade before there's any consensus about the relative contribution of these things.

Marsha: Siân, I wanted to just take up your point about, that condoms were something visible, and now the reliance and antiretroviral drugs, U=U and PrEP, that one doesn't know about their casual partner anyway, whether that person is on antiretrovirals or not. The person can know whether *they themselves* are, but not their partner, does that throw a spanner in the works of how you address prevention in the future?

Peter: This condom is just like an icebreaker or it's a thing you can package and write down the packaging of.

Siân: Yeah, well it works on all levels. It was a useful signifier, if you like, for campaigns and, as you said, being seen to be responsible. But I suppose, if it's something that actually is used at the point of sexual contact then you both know that it's being used, do you see what I mean? Whereas, I suppose there could be a case of not knowing whether people are taking medication effectively, or telling the truth about taking medication, or not taking medication, or having been tested or not been tested, or they are in a test window – it is a lot more

³ Joint United Nations Programme on HIV and AIDS (UNAIDS) targets, set in 2014, that by 2020: 90% of all people living with HIV will know their HIV status; 90% of all people diagnosed with HIV will have received sustained antiretroviral therapy; and that 90% of all people treated with antiretroviral therapy will achieve viral suppression.

complicated. Whereas if somebody is actually taking a load of condoms you know a little bit more where you are, as well as being that really convenient thing around which to rally campaigns.

Emily: Is it also that you could take condoms to places and use them in a sense of having conversations with people? I know, you have this fabulous collection of all the different designs and there's something interesting about them as well.

Siân: Yeah, in the early days it was the whole novelty thing around condoms, because up until I think pre-mid-80s, condoms weren't allowed to be advertised on television, it was actually banned⁴. So there had to be a quick switch around from something that was previously banned and not shown, you certainly never saw an unravelled condom in any type of advertising, to then having celebrities on TV putting them on cucumbers. There's that whole normalisation thing, and then it was an easy giveaway for health promotion units – novelty condoms, novelty condom keyrings, novelty condom everything you could possibly think of, which as you know, I have a huge collection of, because I find it absolutely fascinating. And it was an easy win for a health promotion unit to be seen to be doing something by making their own individual versions of condom packs. So, everybody had one, everybody had a brand, their condom pack with their logo. So it was a way of promoting the organisations as much as anything else.

Lynne: Was it Levis that came out with jeans that had a condom pocket, which enabled us to do quite a lot of a rolling story about how that's probably not the best place to keep them. We got loads of coverage off the back of that, and they were obviously very unhappy.

Ford: We haven't really touched on the impact that the HIV response had on the broader sexual culture as well. The HIV education, safe sex education was the front end of liberalisation around pornography. The first sexually explicit imageries in the public domain that were argued for were on the basis of their educational value, and as soon as that chink was open the pornography industry piled in. So, its ironic that the bareback porn that we're now watching is the Trojan horse for safer sex education in a way. The condoms as well, generally the liberalising effect on sexual cultures was massive in a way that we're not seeing with PrEP at all. But I think that's a broader thing that Karen just alluded to about the biomedicalisation of sex, we like PrEP partly because it's a biomedical solution, and we're increasingly looking to biomedicine to solve all our problems.

⁴ Regulations prohibiting commercial advertising of condoms in the UK were lifted in 1987.

Emily: So one of the suggested topics for discussion that I circulated includes learning from the past and the future of HIV prevention. What do we risk and what do we risk losing with the biomedical model?

Will: Keyrings and condom packs [laughter].

Peter: Dicks on sticks, bet you've got some of those at home haven't you?

Tom: Urinal sponges. Those sponges that...

Marc: They expand.

Tom: Expanded.

Ford: Oh in the shape of an arse?

Peter: Oh, Will, you've got a lot to answer for haven't you?

Will: They're all bobbing along the bottom of the ocean.

Peter: They're all micro plastics now.

Ford: I think possibly it's just a much less broad-based response, so the responses are much... they're very narrow, they're very targeted on this solution and there's much less opportunity for the social change that was argued for around community development, the bio-medicalisation means that it's, we can solve this without changing anything about the context.

Peter: Doesn't it feel really individualised again? For me that was the big change, suddenly it feels all about me, you, rather than about you in the context of a community.

Tom: But that's what you get with that biomedical model isn't it? Because you're having that relationship with your clinician and having that space for community groups is really hard to...

Peter: "I don't need to, I can test without talking to you," all those things.

Tom: And I think one of the real challenges going forward, is we have a whole generation of young gay men who have never known what it's like not to have services that have paid workers. When we first started we were unique really in terms of... So it's like, how do we grow those activists that can take this forward, the prevention messages forward? I really don't see it.

Marsha: That's quite interesting. There has been quite a lot of inventiveness around sex, about introducing condoms, realising that antiretrovirals mean undetectable and so on, by men presumably talking to each other, not just to clinicians. Obviously clinicians have been some help here, but cautious. But what you are suggesting is that in the absence of dialogue amongst people, something of a more inventive response to an evolving epidemic is lost?

Tom: Yeah, I think so. I think particularly with that biomedical model, and that reliance, we have different gatekeepers, and we have different hoops to jump through, and I do think it's often, it's almost going back to that notion that gay men were the problems not the solution, I think there's a real danger of that.

Siân: But the whole nature of activism has changed, hasn't it? In a digital age it's so different. So, for example at GMFA, whereas in the mid to late '90s you would have loads and loads of groups of volunteers who would be coming and meeting in person, and devising strategies and campaigns and things together, for a lot of people now, activism means tweeting something or liking it online. It's not just the epidemic that's changed it's how we communicate has changed radically these days.

Lee: I think there was a social movement, that's how I saw it, and also it was useful and good because the HIV and AIDS movement did link up with the women's movement, did link up with the black health movement, there were comings together, and it seems to me that most of that has gone.

Will: I think I must be looking through this from a completely different lens, because I think my observations are 180 degrees in the opposite direction. So the work that Marc and I have been doing over the last three years has absolutely seen queer men come together with trans women, with the women's movement, with BME movement. Hearing talk about not being able to get people coming along to do things, the work that Marc is doing at BlackOut has dozens of men coming along and volunteering. Right now in PrEPster I am turning away young gay men who want to do something, who want to get involved, who want to do activism, either because there's no capacity to support them or they don't know what it is that they want to do, and I think biomedical prevention makes things more complex and people want to have more conversations about the complexities. So I am seeing way more activism, way more discussions and way more involvement than I have in the last ten years.

Lee: That's fantastic. Is that because you're all there, there is a bit of an infrastructure for that? Because why isn't it happening elsewhere?

Marsha: Maybe you're seeing it's coming online a lot, it's happening online?

Will: I'm seeing it face to face way more than online.

Marc: It's happening. I think the biomedical model and PrEP and ARVs has leant itself to the individual taking control of their body, what they do, in a way that they probably feel they couldn't before. But I think in terms of the activism getting the message out there, people are engaging, but they're engaging in multiple ways across lots of different platforms, and there is... We didn't have the internet and those apps to do that, so we needed, there was a necessity for us to come together to pool resources, and people now have the resources at their fingertips. So in some ways it's a question of how do we utilise that better. I think also in terms of the messaging that we put out, it depends on who is developing the campaign and doing the work, so I'll praise myself for a minute. We just put a campaign out last week, GMFA, which was clearly about individual partners and community, and we were very clear from the beginning that the driver would be how do we get community involved in this message again to take it forward; to testing isn't just an individual act, it plays into a wider picture as well. So I think there are still drivers there, it does happen. I think we're outside of the loop sometimes, so I'm not always clear what a 22 year old is doing or engaging in, and I don't necessarily have to know that, although they come to us for advice all the time. But generally I think it's happening, I'm heartened by it, I see it.

But I think on a national scale when we look at some of the big bodies that are doing the work, that's not counted, and that isn't influencing the work that happens, and that's why you do have some of the blander work which is happening which is as Will often describes as that, "Prey and spray," approach, so, "I will do a big campaign around testing, I will tell you it works, put it on the back of a bus and it's all I need to do, job done." Where it's not looking at the nuances.

Some of the work that we do through CHAPS was a Trojan horse to get the work that we did around the social stuff, that we did around mental health, that we did around community building and development, and that's what's missing. So whilst I can get you to understand what PrEP is, I might get you to advocate for it, I might even get you to tell your friends about it, what I'm *not* doing in that work is... I no longer have the ability or the resources to say, "Well actually this is why you're taking a risk, your mental health and your drug and alcohol

use and all the rest of it,” or if you’re a migrant here, ‘These are the things that are impacting you.’

Ford: Yeah, which is what I mean by it narrows the range of problems that the response is about.

Emily: I think we have run over, so maybe if anyone has any comments to make before we wrap up, we should let you all leave. Thank you.

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APPENDIX**PROPOSED DISCUSSION TOPICS CIRCULATED PRIOR TO SEMINAR**

- The government's public education campaigns
- The role of the statutory sector in health promotion
- The relationship between the statutory and voluntary sectors
- The role of research in health promotion campaigns
- Discussions around the 'de-gaying' and 're-gaying' of HIV
- The effects of Section 28 on HIV prevention and health promotion
- Antibody testing
- PEP
- PrEP
- Current challenges in HIV prevention and health promotion
- Learning from the past and the future of HIV prevention and health promotion



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