Monica Pearl

[00:00:00]

PARTICIPANT: So my name is Monica Pearl, I'm a New Yorker living in Manchester. I was born in Manhattan, actually, and then grew up in Queens for the first part of my life, and then moved to New Jersey, so I'm from that area, the New York / New Jersey area, and then as soon as I was an adult I lived in New York again, and that's when I was involved, very involved in activism. Um, but, that's what I'm here to talk about, I guess.

[00:00:33]

INTERVIEWER: Ok. Great, so um, maybe, could you say a little bit about that, sort of how you, um first got involved— or maybe actually, before we get to that point, do you remember the first time you heard about this thing that you eventually got called HIV/AIDS? Do you remember the first time you ever heard about it?

PARTICIPANT: I... can't exactly remember when I first heard about HIV and AIDS but I believe it was, in— very early on in the 1980s, early 1980s, and I might have read it in the Village Voice, which I was an avid reader of, or, I heard it on television, although that seems less likely. I probably heard about it before it was called AIDS, um when it was called GRID or some other euphemism, but I remember the feeling of frustration of other people not— my milieu, say, I was still in college, sort of not getting it, and me feeling like it was, already like it was connecting to other important issues.

[00:01:38]

INTERVIEWER: Mhm. Where were you in college and what were you studying?

PARTICIPANT: Um, well I was at Smith College and I was studying... well, English and philosophy, and I'm now uh, a lecturer in American literature, so that's been another consistent theme in my life: activism and, I guess philosophy and litero studies.

[00:02:02]

INTERVIEWER: Cool. Ok, um... when there was more public awareness, when there was a growing awareness of this new virus, retrovirus, can you describe some of what the atmosphere— maybe the political atmosphere was like in 80s America, New York.

PARTICIPANT: Yeah. Well I graduated from college in 1986, and I moved to New York soon after that, and I suppose my early involvement with any sort of politics or activism was feminism. I um... yeah, I was involved in various feminist groups, and maybe some queer groups, or "lesbian and gay" as we called it then, and it was lesbian and gay, it wasn't, no other letters, at university. And I think one of the things that a lot of people don't remember, is that lesbians and gays were really very separate groups, politically and socially. And so it wasn't an obvious collision of

issues or ideologies or politics for those two groups to come together. So I would definitely have called feminism my political home, and one of the reasons that the AIDS crisis concerned me— well, many reasons, but one really was as a feminist it seemed to me that it hit all the issues that mattered to me as a feminist.

[00:03:30]

INTERVIEWER: Ok. And, were there others who had the same analysis as you, and did you— was there a group of you or was it something— a realisation that you came to by yourself, and—

PARTICIPANT: That's a good question, I mean I, I'm trying to think— trying to account for years between my graduating from college and joining ACT UP which didn't start 'til 1987, and I didn't join right away, and I would— and there wasn't that much activism going on actually around HIV and AIDS outside of what ACT UP started to do, and a few small groups before that.

One of the early things I remember was um, I was trying to donate blood, I think as a normal civic duty, and I was refused, because I admitted on a form that I had— now how did it go? That I had "homosexual experience"? I can't remember exactly how they put it, but they had completely conflated gay men and lesbians into this question, on the— on the— and I... I was rejected from donating blood, even though according to already the CDC findings, the Center for Disease Control, I was in what would have been thought of as one of the least— lowest risk categories. Forget um actual sexual practice, this was just a question of identity, so it wasn't about homosexual experience— "Are you, are you gay", probably, "Are you homosexual". Um, and I really railed against this and remonstrated against this, but they wouldn't hear anything about it. And I remember calling a phone line, it must have been— I remember it was the... Lesbian and Gay Anti-Defamation League maybe? That's what I— and I never heard anything back, but the next thing I heard, was that there was a blood drive at the Lesbian and Gay Community Center that I hope was in response to my phone call, and I think there was a article about that in the Village Voice soon after that, which I've been in communication since then with Sarah Schulman and it's quite possible she wrote that, that article. But anyway. That was one of the earliest things that I remember doing politically, as it were, around HIV/AIDS in New York City. Um, yeah.

[00:05:57]

INTERVIEWER: Ok. You mentioned that feminist politics was your— your roots, your perspective, and I was just wondering in terms of like— could you just say a bit more about that in terms of the period when you were being politically active, and what that meant to you, and what kinds of issues—

PARTICIPANT: Yeah.

[00:06:19]

INTERVIEWER: —that you were facing then.

PARTICIPANT: Well I guess it— it became obvious to me that HIV and AIDS was an issue of sovereignty, or decision-making over one's own body, and was an issue for feminism for... ages, right, that was the, what— [you] might think of it as a primary feminist issue. So, it seemed obvious to me, the emergency, the AIDS emergency, was one that grew out of, um, individuals being able to agency over their own bodies and being able to have communication about their bodies and other bodies. Reproductive decision-making, for example. So, you know, it's always really important to me that my engagement with AIDS activism and with ACT UP was not about me seeing that gay men were under attack and I had to lend my... energies, and skills, and political fervor, to [a] gay male issue. It was always an issue for me. I always felt personally involved in the AIDS crisis, and I think a lot of the women that I worked with, a lot of the women and men that I worked with at ACT UP, I think felt similarly, right? That this was something we were doing for our own lives, we were saving our own lives, we weren't trying to save other people's lives.

And feminism made that obvious to me. I mean it's hard to say what feminism makes me understand and what it makes me see because, it's just how I think, how I see things, but, it seemed to me that the questions around HIV/AIDS were questions that women and feminists have been dealing with for a long time and one of those was about sexual agency, and sexual freedoms, and sexual rights. So, suddenly sex was dangerous for some people, but in fact, sex has always been dangerous for women, in terms of it being dangerous reproductively, in terms of it being dangerous in terms of stigma, so that women were always in peril for sex and sexual desire. They might get pregnant outside of wedlock, they might um, uh want not to bear a child that they have to— that they are impregnated with and not have choices about that. So, all of those issues that were always true for women were still true during the AIDS crisis. Women were suddenly vulnerable in a new way, but they were always vulnerable, and now there were some men who were seeing their bodies as vulnerable in a way very similar to how women have always felt vulnerable.

[00:09:09]

INTERVIEWER: Do you think that analysis was shared across the activist movement?

PARTICIPANT: Um, I think that there was some— some of— I mean it's hard to answer that. On one hand, we were doing a lot of talking and a lot of thinking, but we were also acting, so there wasn't always— you know we were doing demonstrations, and we were responding to the latest crisis, the latest emergency, so we weren't always theorising and philosophising, but we were sometimes. There were those nights that we would all, after an action, and if we didn't get arrested we'd end up in a bar and we'd be talking about what happened and we'd be talking about the issues. There were a lot of people— mostly women, but not only, who had already had a lot of political experience who came to ACT UP. My theory about the great success of ACT UP as a political organisation— the reason that it was able to achieve so much success so quickly and fully, is that, it was this very unusual collision of a great amount of political acumen and experience on the part of mostly women, not only, who had been involved in reproductive rights movement in um, prisoners' rights movement, in all sorts of um— feminism. And the collision with a lot of middle-class white men, who were very privileged, very resourced, and suddenly very panicked

over something terrible that was interrupting that privilege. And that collision of privilege and resources with great um, acumen and wisdom really, and experience, meant that a lot could happen very quickly. Besides which, it was an emergency of sudden illness and sudden death. So all of that was very, very potent.

[00:11:10]

INTERVIEWER: As a prelude to you talking more about that, could you describe the kind of political climate at the time in which ACT UP emerged [missed] [00:11:21] political climate in the States at the time.

PARTICIPANT: Mm, mm. Well, uh Ronald Reagan was the President, and he did not utter the words AIDS or HIV until... I think it was 1986? But it was very, it was very late, it was years into the crisis, when a lot could have been done. And because HIV seemed to afflict people who were already disenfranchised and marginalised, it was not seen as a mainstream emergency, it was seen as, um, a gift from god for some people, right? "Let those people die off". And it became an epidemic and a genocide really because of the negligence of the government. There's a clip that one can find online now, that I was aware of at the time, where a reporter, I think from the New York Times, asked a question at a press conference about HIV/AIDS, and Larry Speakes, who was the White House Press Secretary, makes fun of the reporter for asking the question. "Why, do you think you might have it?" and there are giggles and laughter all around the room, and when the reporter persists, it just generates more of this kind of derision, and mockery, and laughter. And that's the first time that AIDS is really discussed publically in a setting at the White House.

So that's how bad it was, I think it's hard to remember— I mean on one hand it's easy to remember, there's homophobia, and there's prejudice against queer people still, but, it's hard to remember how fundamental and endemic it was, so that many, many, many people would rather kill themselves than come out to their families, or communities. I mean that was an obvious equation for many people. There was a great deal of shame in being gay, and one of the paradoxes of the AIDS crisis is that it forced people to come out because they became ill, so they were obviously— they seemed to present with symptoms that suggested they were part of a disenfranchised community. I mean there was a joke at the time that said um, oh god I can't remember exactly how it went, but it was, "You know, how do you convince your parents you're Haitian?" Because that was one of the communities who's seen as a target for HIV, and you wanted to tell you parents anything except that you were gay. So, um... it forced people to come out, and that had the affect of— that and the great political response— had the affect of creating, or galvanaising a political movement, that was at that point in existence but still pretty nascent, pretty small..

[00:14:27]

INTERVIEWER: Were you aware— and we're going to talk about that— were you aware of, you mentioned the media at the White House, what kinds of— and derision, which sounds horrible. What— up until that point, how had the media treated HIV/AIDS?

PARTICIPANT: Well. Um, I... Women— I mean, in the same way that women had always been seen as vectors of infection, so if there was a communicable— a sexually communicable disease that people could get, it was often seen that men were in danger of getting that disease, and women were the culprits in potentially passing that along. And this was applied almost exactly to homosexuals, and HIV, is that the general public was seen as vulnerable and in danger of contracting HIV from person who is not admitting that they are gay, and that they have a "double life". There was a lot of this language of secrecy, and of getting away with things, and that you might be victim to someone, a woman for example, who was sexually promiscuous and was going to give you HIV/AIDS, and, um, so. The people who were suffering from AIDS were often treated by the media as the— the culprits, the ones who might infect the general population. And there was talk um, William F Buckley proposed that people with AIDS be tattooed, that gay men get a tattoo on their bum and that intravenous drug users get a tattoo on their arm so that anyone who was tempted to engage with those people, either by sharing needles or having um, penetrative anal sex, would um, be alerted to the danger of who— of the vector that they were about to, um, consort with.

[00:16:44]

INTERVIEWER: So, it's in this context that ACT UP is mobilising, so maybe you could go on to talking about that, and kind of the early days of ACT UP and your involvement especially.

PARTICIPANT: Yeah, yeah. Well ACT UP was very much about targeting the— any problem that cropped up, immediately, so um. One of the things it did, in relation to what I was just talking about, is it completely undid the language of victimhood, that we just stopped saying "AIDS victim", that was just not part of our vocabulary anymore, because we didn't want to think about victimisation. That language, that vocabulary was not working. ACT UP— well, one of the phenomenal things about ACT UP that I now know more about than I did then, because I was part of it, was how much was going on in ACT UP that any individual might not have known about. There are some great films about it now, I think that the best one is United In Anger, A History of ACT UP New York, made by Jim Hubbard— directed by Jim Hubbard and produced by Jim and Sarah Schulman. And that film makes a great attempt to show all the variety of approaches to how ACT UP was working in small groups, cells, or affinity groups.

So, I can tell you a lot about what I did, what I was a part of, but I know less— or I know a little bit more now, but not first hand what other groups were doing. But there was as I suggested a lot of resources, a lot of media savvy, a lot of connections to the— the bases of power. So there was a lot of ways into the heart of the institutions that were creating bad um, you know creating a bad world. The New York Times, the CDC as I said, the Center for Disease Control, the NIH, the National Institutes of Health, um, all of the um, you know the big institutions that seem like you can't infiltrate or approach them, we did. So, ACT UP functioned on many levels, huge action where there were big demonstrations and a lot of arrests, it created a lot of media attention, and a lot of press. And then, a lot of smaller actions, that sometimes were publicised and sometimes weren't. And a lot of art. And there's a lot of graphics that are still recognisable from that era. So really on so many different levels.

[00:19:31]

INTERVIEWER: What drew you to ACT UP and do you— what's your first memory of maybe going to a meeting, or getting involved?

PARTICIPANT: Well. I mean ACT UP seemed like such an obvious, an obvious political group for me to be part of, because I— well, before ACT UP, I was aware of GMHC which was the Gay Men's Health Crisis, and they um, as far as I understood, were much more involved in direct care for people who were suffering, who were ill. And, I thought that I might try to do that, but I also knew that that was not my best arena. So I was really glad when I became aware that there was this direct action group, because I thought, "That's more what I'm likely to be good at, and to want to do".

And um, I went to a meeting, they were held on Monday nights in the Lesbian and Gay Community Center on West 13th Street, and it was in a ground floor main room, massive room, and it was always absolutely packed. The meetings lasted a few hours, and there was always a table at the front— I mean they started at the Lesbian and Gay Community Center, eventually the— the group became so big that we had to move to another um, venue. That was years later, I think it was maybe around '90, '91, '92. I can't quite remember, but late on in my tenure there. Um, and that was a Cooper Union, and that was in a different part of town, and Cooper Union has its own history of political activism, I think Abraham Lincoln gave a speech there or something like that, but. The mood of the group really changed around that time, partly because of the different venue.

But, when it was still at the Community Center, you'd walk in and it was really chaotic, and people either attended— asking questions, shouting things out, or, huddling in small groups, talking— there was a long, long table when you first walked in that had all of these piles of paper with various bits of information: data, I mean, some— [audio skips] [00:21:51] maybe an action, or raising money for something that ACT UP was going to do, and you would just walk in, and you would just collect a pile of paper from these various um, piles set out, and you'd have your own packet by the end. And uh, it's hard to remember it was all paper then, that's how— that's how— that was one of the main ways we communicated with each other. And the other— I just, now that I'm saying the word "communication" I'll just say for a moment, I was asked recently, "How did people communicate with each other before the internet when they wanted to plan an action or wanted to do something?" and I think it's such a funny question, because I think it's hard to think back on how anything happened before the internet, but in fact we um, we used phone trees. And phone trees were simply, one person or several people calling a list of people, and everyone on that list called a list of people, and even if you were just called five or ten people, within a very short period of time you would contact hundreds of people to let them know there was an action happening and that your presence was requested, or that there was a new bit of information that needed to get out. And people would either, when they were called, they'd either answer their phone, or they would have an answering machine in their— in my case, apartment in New York. And that's how it worked, so it was very efficient. And the other way of course, was in posters, right? And I refer to the graphics, but we would do wheat-pasting all the time

around the city and that was just making posters and putting them up wherever we could, and stickers, but mostly posters. And of course these Monday night meetings were— it was all about exchanging and giving information, and we— the meetings were run on what we call Roberta's rules of order, based on Robert's rules, but kind of loosely based on Robert's rules.

[00:23:50]

INTERVIEWER: Ok, could you say what that is?

PARTICIPANT: Well Robert's rules of order is an actually recognised system for running meetings, and you can buy a copy of that, and I suppose people knew about that and didn't want to be so strict about it, but it was a kind of— for example I remember that um, there would be an initial presentation of an issue or a topic or a theme, and then there would be a time where you could, um, you could ask questions but you couldn't— I can't remember which order it was, but you could say something and you couldn't ask a question, or then you could ask questions, and then there'd be a vote. So things were somewhat systematic, and that kept things organised. And, um, but it wasn't, it was— you know, it was loose, because it was fun to be at a— I mean it was boring, and it was fun. It was boring because it was long and you weren't always interested in everything that was being talked about, but it was fun because you were there with the people that you were um, working really hard with, involved with emotionally or sexually or friends with, I mean it was this amazing amalgam of camaraderie, and eroticism, and frustration, um and people would sort of gravitate to groups that they had affinities with. I remember there was a kind of women's corner, or the corner of women that I would hang out with, and I remember always gravitating toward that corner. And um, we would all— people if you knew each other even a little bit, we all kissed each other on the lips when we, when we saw each other, that was always our greeting. And I didn't really think about it til later, but um, it wasn't just that we were all incredibly involved with each other, and intimate with each other, but we were also kissing because we were showing we weren't afraid of HIV transmission, and that was a way of, I don't know, just of exposing that fact, or sharing drinks, or whatever it was.

It's hard to describe the feeling of intimacy and anxiety and frustration in those groups, in the main meeting on Monday, and in the smaller meetings on almost every other day of the week. Not that anyone went to a meeting every day of the week, but you would at least, probably, be at another meeting besides the Monday night meeting, if not more than one. So there was a lot of stuff going on all the time. The frustration was that people were ill, people were dying, and that the difficulties that we were fighting against were intractable and we couldn't make them go away right away. Sometimes it seemed like we could, and other times, of course we couldn't. So it was great joy, and love, and bonding, at the same time that there was kind of terror, and frustration, and anxiety.

[00:26:44]

INTERVIEWER: Um, it's really interesting what you were saying about the kissing, and then also, the— that this was an activist space, but also a kind of very interpersonal space as well, and I was just wondering in terms of, thinking about um,

for example safer sex and how that emerged and how that got adopted, um, I was wondering whether that ethic— in a way it was kind of a new ethics to emerge, or, but based on pervious ethics. And I was just wondering how— and I guess I see the kissing as part of that, of showing, you know, kind of performing that ethics in a way, showing that it's—

PARTICIPANT: Yeah.

[00:27:35]

INTERVIEWER: —yeah, and I was wondering if you could say a bit more about that because in some of the interviews I've done, like there was an ethic that someone was saying about how— a gay guy was saying about how there was an ethic in Manchester ACT UP of assuming someone was living with HIV if you were gonna have sex or do any kind of sex with them, as a kind of, as a safer sex strategy, but also in a way as a form of solidarity, um and I'm just wondering how, in that kind of interpersonal, or maybe in your own personal, how those strategies, how those ethics played out, how they emerged.

PARTICIPANT: Yeah, I mean, there– safe sex is a ethics of self care, and of care for others, right? So the idea was that you— our ethos was, I think— I mean, "our ethos", it's hard to say, because ACT UP didn't really have those sorts of things, but, um. It seemed to me that an ethos that emerged from my experience of ACT UP was one of having knowledge, of education. That the more knowledge you had, the more you were able to make independent decisions about what you did and what you didn't do, and the more you knew what was possible and what was not possible. So a lot of those, you know pieces of paper at the table in front and a lot of the presentations, and a lot of the conversations going on were about, "What do we know now? What— do we have new information?". And that more information was better.

And one of the things I did in ACT UP was to give safe sex workshops to groups: whether it was school groups, or lesbians groups, or a gay group, or um, other foundations, whatever it was. And safe sex workshops were always about giving the information that was necessary to have agency, right? It's a feminist ethos for me, you have agency over your own body when you know what's what, what's dangerous, what isn't. So, some of the people in ACT UP were making films, safe sex films, "safe sex shorts" I think they were called, and they were really sexy films about how you might have sex with someone, all kinds of configurations, men with men, women with women, men with women, that were safe, and sometimes that included a condom or a dental dam, some sort of barrier, but often, also, it included all the many things you could do sexually that would be very thrilling and satisfying that is not in danger of transmitting HIV or AIDS, or and STDs, or causing pregnancy. And one of the things that I would do when I gave safe sex workshops, I'd say, you know, that the great um, benefit of safer sex practices for heterosexual sex is that it also prevents pregnancy, right? So that you are not just preoccupied with HIV/AIDS, you're also doing something that you might be concerned about anyway in your practice. And one of the things that I would do as an ethos of education was I would give all the information I had to anyone I was talking to without assuming what sort of things they might get up to. So I would give, you know,

all the kinds of sex you might have with whomever, and it was always about— it was always about behaviour, not about identity, right?

And that was the shift from what we thought of as lesbian and gay categories to queer. The emergence of queer came out of the AIDS crisis because it was a shift from identity to practice, and you might do any number of one of these things with the person that you're having sex with, not based on who you are, but what you might want to do with that person, and what you might not want to do with that person because it also, I thought, gave agency to people to not do things they didn't want to do, which I thought was a strong feminist principle. And, "If you're going to use HIV drugs, this is how you want to do that safely". So there was no judgment, it was just, "Here's the information you need to do this safely if you're gonna do it. You might also need to know that drugs can be dangerous in all sorts of ways, for one thing they might imperil your capacity to make safer sex decisions, but, here's the information you need."

[00:32:04]

INTERVIEWER: Ok. Is there a particular action, a particular event, or even a meeting or any of those things that you remember most vividly that you— that sticks in your mind?

PARTICIPANT: Gosh, so many, so many, really. Um...

[00:32:23]

INTERVIEWER: I mean you can talk about a couple if you like.

PARTICIPANT: Yeah, well the big meetings, you know as I've described, were really intense, and then there were smaller meetings that were sometimes official in the ACT UP workspace, which was in the building, the huge cavernous warehouse that's now Google, it's owned by Google, but was just the sort of— it wasn't abandoned, I guess, but it seemed to me, I think 'cause our meetings were at night, it seemed very very empty, and you had to go through all these doorways, and up various uh— I don't know, goods elevators to get to the— and then, across— I was very proud of myself by the end, I knew exactly how to get to the office from the door without having to uh, remind myself of the directions.

And then sometimes meetings were in people's apartments. In fact, I suppose one of the times I remember best was, I was a part of a group that wrote a book on— the first book, the first collection of information that was published on women and AIDS, and it was called Women, AIDS, and Activism, and it was written, at least collated if not written, in my apartment. And it was just— I mean I remember it as days, and days and days of women in my apartment, eating, sleeping, writing, um but it probably wasn't that until the end, maybe it was one night a week or something like that. But toward the end it really felt like people were just there, in this wonderful communal sort of way, but that book came out from South End Press in 1990 I think? And that was— that was based on work that had been done previously in the form of the women's caucus, I think it was, and put together um mimeographed collection of information. Um, and we made a book that was based on that material, but also

expanded it, and that included writings that we did, but also writings of other women: women infected with HIV in ways that we maybe didn't have the experience of, and also the prison section was written by the women incarcerated at Bedford Hills Prison, so it really is a rather amazing book, and it was translated into Spanish as well, and it had lots of resources, information at the end. Um, so that's something I really remember, um.

And again how urgent it felt to be in ACT UP but also how really— how much fun it could be, to be in that group. Um... I also remember I was at my— my first arrest was for needle exchange, and that was um— an event that we staged, even though I was doing needle exchange every week, and other people were doing needle exchange every week or more often, and that was exchanging clean needles for used needles on the street, on the Lower East Side, we made one of those needle exchange days an event that we knew would bring media and press, and that we would— like, we would be arrested. Because once you're advertising that you're doing something illegal, the police sort of have to arrest you. And the reason that was so important, besides that it was a normal demonstration um about an issue that really mattered to us in ACT UP, it mattered because we went to trial, and— and we purposely went to trial, as in we didn't accept the plea bargain, which is the sort of the normal outcome, or often the normal outcome of a political demonstration, you— they don't want you to go to trial or serve time in jail, they want to um, work out a deal where you do community service, which is, my other arrests all ended in community service but this one we were trying to challenge the law, so we went to trial.

[00:36:17]

INTERVIEWER: And how did that play out, like—

PARTICIPANT: Well, that um, it's a great story. We— our clever attorneys, who were also ACT UP members, Mike Spiegel and Jill Harris, defended us using something called the necessity defence. And that is, where you plead guilty to what you've done, but you've done it because you were saving a life, and you're allowed to— you're allowed to get away with breaking some laws if you're trying to save a life. So for example if you run a red light on the way to rushing someone to the hospital, you might not have to pay for that crime. And uh, it's also called the justification defence, you're justified for what you're doing. And, we were acquitted. Um, yeah, we were acquitted, and it was written up in the New York Times, and it was uh, not that the judge made a point that her decision was not precedent-setting, so it didn't change the law, but it was the beginning of, I like to think, changing the law, which did change. And one of our main witnesses was um... oh, I can't remember his name, but uh he was the Health Commissioner, and we had previously demonstrated against him. I can picture him but I can't think of his name right now. And later he was a witness for our defence and he felt very strongly that what we had done was the right thing to do. So it felt uh— I almost have it, I almost have his name.

[00:38:07]

INTERVIEWER: We can come back to it.

PARTICIPANT: Yeah, thanks.

[00:38:09]

INTERVIEWER: Um... I was gonna ask, you mentioned that you were in a group— a lesbian and gay group at university, and you talked about in a way ACT UP was a collision of certain— different groups who might not usually be working together.

PARTICIPANT: Yeah.

[00:38:29]

INTERVIEWER: Um, I was just wondering, and then, kind of this idea of queer coming through. I was just wondering, the kinds of transformations that took place in terms of being involved with this movement. Um, I mean I guess that's what I want from what you're saying about the emergence of queer, and stuff, and whether people are newly politicised through it, or not, and I know you can— I don't want you to speak for other people, but maybe just your general sense of–

PARTICIPANT: Well there were two main political groups that were offshoots of ACT UP: Queer Nation, and the Lesbian Avengers. And, I was um, involved with both of those, and by involved I mean I showed up to demonstrations; I was not a part of the organising of those groups, but being an activist is often just being a body at a protest because the more bodies you have, the more media attention you get and that's the point. Um, and Queer Nation is important in this regard, in the response to the question you asked, because as I say "queer" really came up as a response to AIDS and it was partly based on this change and conceptualisation from identities to practices, and also because what seemed like an intractable division between women and men, lesbians and gay men, suddenly... didn't dissolve, I mean that sounds too magical, but, there was something about seeing common, um, necessity and urgency. Now, ACT UP fractured, ultimately, due to— not between men and women, but due to differences in vision for what activism might do. So it wasn't all a kind of magical elixir of everything coming together, but queer, um queer as a concept came out of this idea that anyone might have any kind of sex, so that, anal sex for example wasn't something that gay men had and therefore it had to be— gay men had to be careful about it, or that um... uh, any sort of act you could imagine— sexual act you could imagine, was something that anyone might practice in some way, so that queer became the term for thinking about how to refer to acts that were not necessarily normal or normative variety. I mean, I think there's probably a lot more to say about that, and people have said more about it, and queer theory of course, the unmentionable— I am an academic, so, I do— I am interested to think of how that came out of this time, and I really believe it did, but I'd say that's the crux of it.

[00:41:25]

INTERVIEWER: Ok.

PARTICIPANT: And that one of the things we were fighting against in ACT UP was the CDC um, taking statistics based on identity, and not based on acts. And taking

statistics based on identity meant for example that lesbians were never counted, and a lot of women were never counted, and a lot of those very lesbians were dying or dead from AIDS, so it wasn't working.

[00:41:53]

INTERVIEWER: Yeah. And there was also— there was also the issue that comes with being united in anger around... [phone vibrates; laughs] around the definition of what... uh, illnesses correspond to AIDS.

PARTICIPANT: Yeah, yeah. So one of the major success in ACT UP, led by um, Tracey McGovern, who is a lawyer, and Katrina Hasslip, who is a woman who had been incarcerated in Bedford Hills and was living with HIV and later died of AIDS, um, spearheaded the fights against the Centers for Disease Control for exactly this categorisation, and the reason that it was considered such a problem was not just because, who gets counted and who doesn't, but, benefits and medical care was provided based on, not just who fit these categories, but healthcare providers, doctors, would look for certain symptoms based on what they knew to look for. So for example, women often, um... uh, first came— one of the main symptoms that women with HIV would get would be a terrible vaginal yeast infection. Now, women get yeast infections all the time, so when doctors saw that they didn't think there was anything to worry about. So it was simply a blindness. And then, even when it was seen, even when a doctor or a care provider could see that this was clearly a chronic problem for this woman, and even knew that it was HIV related, if it didn't count, then they couldn't get benefits, or they couldn't get an AIDS diagnosis and therefore couldn't get medical benefits, housing benefits, all sorts of care. So women died faster because they were not diagnosed in the same way that other— that men were. So changing that definition was really crucial. It was a matter of life and death.

[00:43:58]

INTERVIEWER: Um, so that was one of the big successes I guess, and I was just wondering whether, thinking about ACT UP and it's— looking back, reflecting back in a way, um... it's difficult to do, but if you could kind of speak to or summarise how you felt maybe it changed, as well as these quite material, very material things, as well as those, the kind of conversation in the United States about AIDS and about HIV, the cultural landscape in a way.

PARTICIPANT: Mm. Well, the AIDS crisis and, I'd like to think ACT UP's part in it, changed the healthcare system in the United States. It led to the Affordable Care Act, there's no question that one led to the other, um which is now of course under threat. It also led to same-sex marriage. There's no question that the urgencies of AIDS and the ways that activist group, mainly ACT UP responded to it, created the necessary for the privileges and benefits that marriage confers. I would have preferred that everyone would be entitled to those benefits, and that you wouldn't need to get married to get them, but, it seemed like the most immediate solution was that um, the exclusions that marriage produced, for the people who couldn't get married, be eradicated. So, no question, those things came out of AIDS and AIDS activism.

[00:45:43]

INTERVIEWER: Um, as a way maybe of moving on to your current work, I was wondering whether you could talk about um, the— maybe the psychological impact of the epidemic in terms of loss, if you could say something to—

PARTICIPANT: Yeah. Well, I mean... I'm now an academic, and I've written quite a bit about HIV and AIDS, and the main piece of work that I've written on AIDS is a book called AIDS Literature and Gay Identity: The Literature of Loss. And in that book I really look closely at the ways that— mostly looking at fiction and other kinds of writing about HIV and AIDS, but how identities and communities are consolidated by certain kinds of representations of HIV and AIDS, one of which is honouring the way that mourning works, which is a process of, um accepting a loss and letting go and getting over it, and the other is melancholia. And, I'm not the only queer theorist or gender theorist to write about melancholia, but it really applies here because there's another kind of writing and representation of loss, which is not so um, methodical, and in fact melancholia's defined as a refusal to accept loss. Now, that's often seen as a pathology, it means you can't get over it, and you're forever mired in the loss, but there are ways I think of seeing this kind of melancholia as potentially productive, and I write about that in this book. And by productive I mean that it creates communities, right, and ACT UP is certainly that kind of community, where there was terrible grief all the time, and one of the big actions that I remember was an action called Day of Desperation where we were all just so riven, and just soaked with loss, and grief, that we had to really do something, you know, "don't mourn, organise" is that phrase from ages back, not just from ACT UP but from ages before, labour— I think labour movements used that phrase, that imperative. But in fact we wanted to mourn and organise, and ACT UP was the AIDS Coalition To Unleash Power, a group united in anger, and anger really was our modus operandi, and it was acknowledged all the time, and we were angry because we didn't even have time to get over loss, and... So, I think that mourning— sorry, melancholia is a, in some ways, the capacity to get over loss, or to believe you can get over loss is the aspect that marriage is connected to, because it's the same kind of sort of neat package of understanding that things can be consolidated in a certain way, and in some ways civilisaiton is based on believing that kind of consolidation. We all do it, and we all want it in various ways. But the other side, melancholia, which is sort of accepting fragmentation, accepting that things aren't going to be neat, is also I think more akin to the ways that the queer community was not necessarily destined for marriage, but was already, um, a kind of conglomeration of people who were in different kinds of affective kinship networks, so that there were lovers, and there were friends, and there were families. I mean the queer community— I mean "community's a hard thing to define but the idea that there were people who would sit by an ill person in the hospital in shifts, not because they were the partner or the husband or the wife but because they were part of that close-knit community, and that was hard to define whose role was what based on, um, um government-sanctioned roles. And I think that that still exists, and I worry that it's lost a bit in the fight for marriage equality. I understand the fight for marriage equality, but I think that there is a lot more that we could do to honour, celebrate, and invest in the queer kinship networks that were not made by the AIDS crisis but were really illuminated and consolidated and sharpened by the AIDS crisis.

[00:50:35]

INTERVIEWER: Um, great. Um, you mentioned before we started recording that at the moment you're doing other kinds of work, kind of almost like consultancy work on different projects. Would you mind talking a little bit about that?

PARTICIPANT: I find that there's a great interest in the activism and activist engagement at the time that I was most involved, and I'm often asked to speak to a film or a reading group, or any kind of moment of thinking about how we might remember that time of activism and connect it to activism now. I guess I'm now old enough to see that history has certain cycles to it, and that we're living in different but very terrible time of crisis, and that people want to be able to, um, use the experience and skill and knowledge of the past, but also to foam it and galvanise their own activism in the moment. So I guess I feel like, besides that I'm a lecturer at the university and I feel like that's not exactly activism but I suppose where a lot of my activist energies goes to education again, or still, teaching. Making sure that people I'm teaching have the information to make their own decisions and to have agency for themselves, and to be able to critically engage with the world, which I just think is the point of teaching, is you get people to have sharp minds and critical minds. But, in terms of the community engagements, I think it's about being a voice of experience and inspiration, and— and maybe even empowerment, to use a loaded word, right? "You can do it too".

[00:52:34]

INTERVIEWER: Have there been any, um... particular groups that you liked talking to, aside from your, uh your academic work lecturing? Has there been any...

PARTICIPANT: Well, I'll give you one example. I do— I run a monthly reading group here at the Lesbian and Gay Foundation— LGBT Foundation, and my experience is that— what I'm discovering is that, outside of— people want to talk about ideas on all different levels, and that is happening in academia, but that's not the only place where people want to do it. So, I— I'm really thrilled by that. And a reading group is an intellectual community. It's a quasi-activist community because I do think that thinking about lesbian and gay representation, writing, the past, is a way of getting people to feel that kind of agency and empowerment. So that's one example.

[00:53:40]

INTERVIEWER: Mhm. And to me, I think that's something that I like about ACT UP as well is that, in a way it was— it took a space as a public intellectual space as well as an activist space—

PARTICIPANT: Yep.

[00:53:54]

INTERVIEWER: —and I think in a neoliberal moment that is quite difficult to do, and increasingly it's either you're in academia or— where ideas are legitimate and that kind of conversation is, or you're not, kind of thing.

PARTICIPANT: I think that's right, and I think that there's a— um, I’ve done a few— as I say a few talks in various places, and— that around different media, so film, books, um activist events, and there's this great hunger for intellectual exchange that is connected to everyday life and activist propensity, right? Not everyone wants to call themselves an activist but they may be able to do some activist thing, and having it recognised, even if they don't want that as a life or as an identity. And people want to be taken seriously in their ideas, and they want to learn things. So, I agree, I think that the— the world we live in wants to separate out intellectual life and call it sort of ivory tower and useless, and the rest of the world where you don't really need to think beyond what you're doing to earn your money and take care of your family, that's the idea.

[00:55:19]

INTERVIEWER: Um, Molly I was just wondering if you had any thoughts or questions?

INTERVIEWER 2: Um, no. I was thinking a lot, that was really interesting. Maybe just about coming here, and maybe activism here, sort of 'cause you got about back then, and obviously that comes into modern day sort of activism. Maybe even just in terms of like America and then coming here.

PARTICIPANT: Yeah. Yeah. I mean I came here— it's hard to– it's hard for me to... I don't exactly know, because it seemed to me, I think that when I was— when I first came to England which is, in late 1993, and I did some work for the Terrance Higgins Trust because I wanted to continue doing some activist work, but I was also embarking on a degree and I didn't want it to take all my time the way it did in ACT UP. So I wasn't as much connected to or involved in activism at that time. And now that I have a better sense of what's going on in terms of activism, I feel like we're in a different moment in history, so I— I guess I do feel like it's really resurgent, there's new, um technology so it's hard to compare. Except I’ll give you a great example. I gave a talk to a London activist group, just about— there was a screening of United In Anger and I spoke to that, and there was a question about a recent event there that had happened— they were protesting a speaker who came, it wasn't about AIDS, it was about something else. And they were very frustrated because they were banished from the room, or they weren't allowed to do— or they weren't understood. And I said, "Did you hand out press releases?" And they said, "Oh, no, we didn't even think of that" and I think that, while the new technology is fantastic for dispensing information and gathering groups and getting people together at a moment's notice, there's some of the old technology, "technology", that's really valuable, and that is letting the people know, whose lives you're disrupting by your activism, what's going on and what your demands are. And that has a way of— it won't bring everyone together, but it will do the work of conveying your message, and it will also, um, I think mitigate the chaos that an action or demonstration can feel like for people who aren't part of it.

[00:57:56]

INTERVIEWER 2: I think as well you said about how it's— there's still sort of a lot of issues now, but in a totally different way. Maybe just about that as well.

PARTICIPANT: Yeah.

[00:58:08]

INTERVIEWER 2: Um, yeah. Like you say in uh— 'cause obviously you've gained so much from ACT UP and everything, queering everything, then yeah you said that today there's other issues that are maybe just as serious and [missed] [00:58:21].

PARTICIPANT: Yeah. I mean, you know, I think there are new issues, but I also think that a lot of the issues are the same, and one of the— you know, I'm a feminist from way back, so I believe in coalitions. You know I believe that we might not always want the same exact things that another person or another group wants, but that feminist activism has always invested in making coalitions for the common gain and the common good.

[00:58:53] End of transcript.