

Rob Cookson

[00:00:00]

PARTICIPANT: So I'm Rob, I grew up in Crewe, in the late 70s and 80s. Quite a bog standard, working class, wonderful family. And yeah, now forty years on work at the LGBT Foundation as deputy chief exec.

[00:00:26]

INTERVIEWER: OK. So you were saying that as chief exec- what was, like, your first initial involvements then, especially like, it being LGBT, and then you've said about sexual health. What were your initial initial steps towards where you are now?

PARTICIPANT: Well I volunteered at George House Trust, supporting people living with HIV. And that gave me an understanding of the real damaging effects that HIV can have on people's lives, in terms of the person that I worked with had got real restricted physical abilities, some strong mental health issues, and, of course, most people living with HIV live very long, healthy, happy lives, but it gave me real insight in terms of someone that was really struggling with HIV. And I think that was where part of my passion came from. And then hopefully I've brought that passion into the work that I do at the LGBT Foundation.

[00:01:41]

INTERVIEWER: So when was that around, then?

PARTICIPANT: That was around, probably 2005, something like that? So about 12 years ago. So I've worked at the LGBT Foundation since 2007, so I've been here for 10 years now. And we do some brilliant stuff in terms of trying to... not just tackle HIV and other STIs, but also really get underneath it in terms of, often it's around people's confidence, people's self-esteem, issues around isolation, issues around homophobia or biphobia or transphobia. So part of the wonderful stuff that we do, the LGBT Foundation does, is about trying to... I suppose, deal with the person, not just the issue.

[00:02:41]

INTERVIEWER: So going back to the beginning of the AIDS crisis, when was it you first heard about it? What were your initial reactions when it came about?

PARTICIPANT: Well I remember the ads on the telly, the Don't Die of Ignorance campaigns, and actually when I say that and reflect upon that, what really stands out for me actually is the music, and the very, not just sombre message, but real scary message, really terrifying message, that that left with me. I would have been probably about ten years of age then, and I was at the stage where I was starting, just starting, to question my sexuality. And I think that that would have been the first time that I'd heard the words HIV, or heard the words AIDS, and it left an impression on me of, you know, of HIV being a very negative thing, and being a very scary thing. And I think probably it didn't help either in terms of me questioning my sexuality, and

I think that what... I think if that campaign did anything, for me personally, it made me not say anything to anybody about sex, sexuality, HIV - so you know, Don't Die of Ignorance, what it said to me was actually, don't talk to anyone, you know, don't talk to people about your feelings or sex or sexual health. I think that's the impression it left with me personally.

[00:04:35]

INTERVIEWER: Cos then obviously there's the idea that, maybe not through that advertisement, but the whole AIDS crisis kind of gave people a sort of... kind of made people talk about their sexuality, or made people talk about the fact that they're gay. Do you agree with that and why?

PARTICIPANT: I think the AIDS crisis, the community had to rally round with that. And you know, the reality is, is that if it wasn't for the community, then HIV rates would be much higher in this country than they are today, and actually we stand on the shoulders of the giants really, in terms of activists in the 80s, many that are no longer with us, you know, took a stand, and raised the profile about HIV, mobilised a community. I think... and not just LGBT people, although I think the LGBT community took a real lead with it, but not just LGBT activists. I think, if you think of Princess Diana for example, you know, very famously holding the hand of a dying man with HIV and AIDS, I think that those sorts of symbols were really really powerful. So I think, you know, this country got some stuff really like in terms of its response to HIV. I think the challenge was that you can't have a strong HIV response without having a strong equality response. And where we were lacking was the fact that you had section 28, so you know, schoolteachers couldn't talk about sexuality – well how does that link to being able to talk about HIV or being able to talk about health issues? You didn't have equal marriage, so how does that equate to trying tackle HIV? So I think some of the equality challenges we had in the 80s and beyond didn't help really, in terms of tackling HIV.

[00:06:54]

INTERVIEWER: So, can you describe any involvements you were in, either before the LGBT [Foundation] or during the LGBT [Foundation], that kind of helped with the whole AIDS activism, or anything like that, maybe your part here? Anything you want to talk about.

PARTICIPANT: Yeah... I'd love to claim that in my teenager years I was an HIV activist and was really doing my bit. And I wasn't. I wasn't that sort of individual. I was far too in the closet, and the door was shut, it was bolted, so I was far too in that space to feel able to [do] activism in that way, if I'm just being honest. I think that- I've always been interested in health inequalities, I've always been passionate about equality. I've worked for disability organisations, I've worked with BME communities and I've worked with LGBT communities, so I think I've always had an interest in terms of equality issues and fighting discrimination. And certainly, I've worked at the LGBT Foundation for ten years, and certainly during all that time, trying to end HIV and fight the stigma, fight the discrimination, has always been something that drives me and has always been a key part of my role alongside other things. And I think that, you know, it's about trying to take different opportunities to... activism can take

many different forms, so it's about trying to take action in lots of different ways. So even if it's about encouraging your friends, your lovers to have an HIV test, you know – that message of, reach one and teach one, I think can be really powerful.

[00:09:03]

INTERVIEWER: Yeah, so obviously before, you were talking about trying to achieve the AIDS [missed] [00:09:10]. Do you want to talk about that now?

PARTICIPANT: Yeah, so we had a secret conversation before the camera, didn't we? So what's really exciting at the moment is that Greater Manchester has an ambition to end all new cases of HIV within a generation. And the LGBT Foundation has been an important part in that. So the LGBT Foundation produced a paper that went to the Greater Manchester Health and Social Care partnership, which has meant that ending HIV within a generation is one of only twenty health topics that have been chosen for a particular Greater Manchester focus. And it's amazing that HIV's one of those topics, I think it's absolutely brilliant.

We've calculated that, we estimate that around a thousand people are living with HIV in Greater Manchester but don't know it. So there's a thousand people, today, living in Greater Manchester, working in Greater Manchester, enjoying their life in Greater Manchester, but don't realise that they are living with HIV, they don't know it. So they've not been able to access testing services. Maybe they haven't had any symptoms for HIV, or maybe they've got a doubt in the back of their mind that they've got HIV but they're concerned about accessing a test, etc. So I think one of the key things is about identifying people that are living with HIV but don't know it, and then actually getting people into testing services and treatment services. Because all the evidence shows that if you test more people, particularly the right people, and test people more frequently – so for someone that's perhaps having lots of sexual partners and not using condoms etc., so someone who's deemed to be perhaps higher risk, it may be that testing once a year isn't enough. It might be that someone needs to test much more frequently than that.

The testing's really important, and then you can get people onto treatment really quickly, then, if the treatment's working well, like it does for the vast majority of people, then their viral load will be suppressed and they're not able to pass the virus on. And that, alongside other interventions, like PrEP, like PEP, condom use - it's bringing all those things together, and they call it combination prevention. So it's having all those different things together that will end HIV within a generation. And it's brilliant that Greater Manchester is doing that. It's got a lot of high-level support. Andy Burnham, the Greater Manchester mayor is really supportive of it. You know, lots of key influences in the system are supportive of it. And I think when that work develops next year, and it's built upon everything that's already happening, I think there's a real potential for Greater Manchester to end HIV within a generation.

[00:12:36]

INTERVIEWER: So maybe think about you personally, you said that for ages it was very locked under bolt that you were gay. When was it that you came out? If you don't mind talking about that.

PARTICIPANT: Yeah. I came out in Ormskirk, when I was at university. I would have been about 21 years of age. I remember having lots of deep breaths when I did it. I remember it feeling like a big moment in my life, and a big jump to do it. I told a friend that I went to university with, she was brilliant, she reacted brilliantly. I think I was so pleased that I'd told her and she reacted great, I was a bit like, that's great but don't tell anyone else. But then I got the confidence to- because that was such a good experience, I got the confidence to tell some other friends then.

And then I told my parents - well I told my mum - a couple of years afterwards, so probably about 23. She was brilliant, she hugged me, there were some tears, and she said to me, that's brilliant but don't tell your dad, I'll tell your dad. And at the time I was so relieved that my mum had took that responsibility off me I guess. I was so relieved that my mum was going to go and tell my dad and I suppose I didn't have to, that I was like, OK, you do that then, brilliant. And literally a year later, I'm on the phone to my mum chatting about something random, and she says, oh, just to let you know, I've just told your dad. And I was like, OK. A year later? She's like, yeah, yeah, I just told him. I was like, what's his reaction like? She says, well he's got his head in his hands, OK... So I think at first my dad didn't react very well. And we probably had a period where we didn't talk about it, me and my dad. But now he comes and watches me on Manchester Pride, on the parade. When I'm tweeting at work, he follows me and retweets me. If there's articles in the newspaper about LGBT issues, he really follows them. If he sees any right-wing negative comments about LGBT [people] in the media, he makes some choice words at the television. So he's a real advocate, and I think he's been on a journey with it, really, I suppose.

[00:15:46]

INTERVIEWER: Yeah. So going back to the idea of the advert, and maybe the stigma that there was around back then. What are your thoughts about that? Especially because you were saying it made you not want to say anything. Especially because it was very targeted at gay men-

PARTICIPANT: Well I think that campaign's really controversial. Some people will say, it was very stigmatising and negative and had, you know, had some negative consequences, which I would agree with, I think it had some negative consequences. I think there is the flipside that sometimes people say, well look at the HIV rates in the 80s and actually, the fact- what was good is that we did have a public health campaign. I think it was the wrong campaign, I think it was the wrong message, but it was good that we had one. If you look at the the response in America, say, then you know, America didn't have any government response to HIV. So it was good that there was a response.

I think that the negative consequences of it was about stigma, and I think some of that still plays out today. And I think it's about internal shame, and it doesn't encourage people to talk about HIV, it generates some myths about HIV. I think the other thing I'd say about the campaign is that that had a lot of money behind it. So what was good is that everybody got a leaflet through their letterbox. Well that's brilliant, what would it look like now if we had an HIV campaign on the telly? When was the last time we had an HIV campaign on the TV to the general population?

And that's probably that campaign in the 80s. So there's been some brilliant work done around HIV, but I think because there's been some funding cuts and pressures on budgets, it's resulted in sometimes less information out there, less resources, less opportunities for people to find that information about HIV. And I think that it's tied into things like sex and relationship education at school, and certainly I think we at the LGBT Foundation will often see, sort of, you know, Manchester's a brilliant city, Manchester's a beacon for LGBT issues, and Manchester's got big universities, so Manchester has a big student population. But sometimes when students come to Manchester, their first experience of knowledge around HIV or knowledge around sexual health may be amongst peers. And some of that will be brilliant. But actually, there's a problem that people have gone through school, gone through college, and often we'll talk to people, and often their experience has been hardly any sex education. When I was at school there were a couple of classes which were giggling at the back of the classroom, you know, there wasn't any sex and relationship education of any quality at all really. And certainly not in terms of, as a gay man, you know. That would just not be addressed at all.

[00:19:41]

INTERVIEWER: So do you think that maybe now that, like, there still needs to be more awareness, but, because obviously, it has progressed a lot and there is a lot more awareness now, but do you still think that maybe in terms of politically, or... they need to address it more?

PARTICIPANT: Definitely, yeah, I think there definitely needs to be more awareness. I think that it needs a whole system approach. So, there's an awful lot of awareness around HIV on World AIDS Day, for example, and the red ribbon's fairly well known. There's a lot of activity that will take place over World AIDS Day, there's a lot of work that great voluntary organisations are doing, the sexual health clinics do brilliant work. But I think the next challenge really for HIV is about, almost, how does it break out of the bubble? So that HIV is seen as the responsibility of all of us, in terms of the responsibility to end HIV within a generation. So what can the schools do around that, what can the colleges do around that? How can we link up to youth groups, sports groups, those sorts of things, really. Because that's the next challenge I think really, is getting the message out more broadly.

[00:21:11]

INTERVIEWER 2: So, my first question is, so you've been here for ten years, and over that time, sexual health prevention has changed quite a bit, in terms of especially technologies that are available, in terms of, even testing becoming- you've got the rapid test now, but also like you've mentioned we've had PEP come in, now we've got PrEP coming in, and then the safer sex packs have been there throughout, kind of thing. I was just wondering if, looking at that period of time, how you feel things have changed, in terms of, maybe not only the different interventions, but also the different attitudes that people might have, or the different approaches that you've maybe experienced from the community, or responses?

PARTICIPANT: I think the big change is that there's more tools at our disposal to end HIV. So there's much more opportunities to prevent HIV transmission. So if you

go back to the eighties, then actually the message was condoms: make sure you have condoms, make sure you know how to use condoms, and use condoms. So it was... And really, really condoms and lube were the only tool that we had at our disposal at that moment in time to prevent HIV transmission. Now condoms and lube are still, of course, absolutely critical, really critical, but now you've got not just condoms and lube, you've got HIV testing, you've also seen a huge expansion in the way that people can access HIV testing services, and much more moving towards self-care. So years ago people had to access testing services within a clinic. And whilst that's great, we've now got a situation in many parts of the country including Greater Manchester, where people can get a test done in a community setting as well. We've now got postal HIV sampling kits, so people can order them online, get them posted out, take their own sample of blood, and send them off. And we also get HIV self-testing kits, so people can actually test themselves as well as take a sample. And of course that is cheaper as well. So actually, it gives opportunity in terms of scalability, in terms of getting more numbers of people to test. So I think what's changed is that a lot of the service offer has changed, a lot of the ways to prevent HIV have changed. I think some old favourites have remained, which is really important, so I think, you know, the LGBT Foundation's condom and lube safer sex packs have been around for over twenty years, really really important that they stay and are visible.

I think some of the other things that have been harder to shift is maybe some of the attitudes around HIV. I think that there's been huge improvements to treatment, so, you know, if you go back to the 80s where people had to take lots and lots of tablets... for many people now living with HIV today it'll be one or two tablets a day. The treatment regime has completely changed, but what hasn't really changed is the stigma, so the stigma that people encounter in terms of day to day life, the relationship they have, the knockbacks that people might get from that, the assumptions that people might make. And I don't think that... I think collectively, we've not done enough on that. I think collectively, the system, different organisations, need to do more about that.

But you know, there's loads of opportunities. I think that if you look at - obviously one of the big changes is around gay social dating sites, and that's changed the way in which, certainly gay and bisexual men will meet, in terms of sexual partners, for many people. It potentially has an impact in terms of the frequency or numbers of partners that people can have. But I also think it has a real potential in terms of helping to end HIV. I think there's huge potential in terms of... at the click of a button, you can reach thousands of people, and you can get over the importance of HIV testing message, or the importance of condom usage. At the click of a button, you can also get people to tell their stories and share their stories. And I think that's the most powerful thing about people being able to influence other people, in terms of, you know, you're much more likely to go for an HIV test if your mates have gone for an HIV test. You're much more likely to use condoms if your sexual partners are used to using condoms and have used condoms. So I think that's what's really exciting, I think we've got the potential now with online work, with the community activism we've got, to really grow a movement around trying to end HIV.

[00:27:29]

INTERVIEWER 2: OK, thanks. You mentioned earlier that one of the approaches that the Foundation takes is to engage with the whole person, as it were. And something that's emerged during this project, these interviews, is the ways in which, say, mental health and sexual health are often, you can't separate them. And I was just wondering whether you have found that, or whether you can speak to that at all, in terms of people maybe presenting who aren't confident in themselves, or who have self-esteem issues or other mental health things going on for them and how that might connect with things around negotiating sex and safer sex?

PARTICIPANT: Yeah, and I think that links a little bit to what I was saying earlier in terms of HIV linked to equality. So the way that members of the trans community can be treated, or the way that lesbian and bisexual women are treated, or gay and bisexual men are treated, some of that homophobic language, biphobic language, transphobic language, has an impact on people's confidence, self-esteem, isolation, which results in poorer mental health. So I think that's partly where mental health links to HIV. I think the equality angle to it is part of that story. And I think that's absolutely critical. Because people talk a lot about self-care in public health, so people talk a lot about actually, it's about how individuals can take control of their health, how individuals can take control of decisions, and can click a button and access an HIV test online, or can look at five steps to wellbeing in terms of mental health and wellbeing information.

But of course, you need the confidence to be able to do that, you need the self-esteem to be able to do that. So I think that - I suppose one of the things we try to do at the LGBT Foundation is give people that space to talk, and you know, sometimes we'll get people phone us up or come visit us and say... You know, we can sometimes be the first people that they've ever said they're LGBT to, they've ever come out to. And just the ability to do that in a safe environment, I think is important to people. And I think that giving that space people to grow, by having peer support and learning from each other, I think it's really important. And I also think it's about how services link up, so...

If you take, um... So mental health can be invisible, so it's often the old adage, isn't it, that people see a broken leg, so health service knows how to treat a broken leg. Sometimes you can't see mental health, so actually some services aren't set up that well to deal with and support people with mental health needs. I think you can say that same about HIV actually. I think that sometimes HIV has that invisibility to it, in a way that sexual orientation or HIV can have an invisibility to it. So I suppose what we try and do is work with others to give HIV a bit of visibility, a bit of prominence.

[00:31:33]

INTERVIEWER 2: OK. So we've talked a little bit about HIV and trying to make it more visible. But also obviously, I mean, we've also been considering STIs as well, as part of sexual health, and I was just wondering if you could say a little bit about work that you do here around other STIs and... you know, often they're not separate either from HIV, but yeah, if you could say a little bit about that and how that's changed as well.

PARTICIPANT: Yeah, I think it's challenging. We've done campaigns in the past about, you know, syphilis; it spreads easily, we've done a lot of visual campaigns, we've tried to work on the community with that. We've also done some work with Public Health England, so we've looked at, for example, if someone acquires certain STIs, then that could be an indicator, or likely indicator, to acquire HIV further down the line. We are currently looking to see whether we can do some community testing around other STIs. So currently we do a point of care testing service just around HIV, but we'd like to open that up to be able to do community testing around other STIs. We do have a full screening service which we're run for a number of years with Manchester Sexual for Sexual Health, so that's a nurse-led service where it's a full screen for STIs. And we've also done work with Public Health England when they've got intelligence that there's been an outbreak of, maybe an outbreak of syphilis or gonorrhoea. And then because of our links with the gay businesses and the different bars, the saunas etc. we've quite well-placed to be able to get messages out there quite quickly. But I think it's also something that we'd want to work with others to try and do some more work on really.

[00:34:13]

INTERVIEWER 2: How important is that kind of engagement work? You just mentioned the bars in the Village. How important is that to your work, do you think? And how receptive have people been to, say, over the years, having safer sex packs in their bar, or that kind of thing?

PARTICIPANT: I think the community's been great, I think people have been really receptive. We've often done a lot of specific events with different parts of the community. So you know, LGBT can often get lumped in together as one and be seen as one. But we've had a dedicated HIV testing service with the trans community, around TransForum. We also had... we've done some work with the bears and the skins [?] [00:35:12] for example, in terms of designing specific imagery around condom and lube packets. We've done things with the saunas, for example, where we've produced towels that have a pocket in them that you can keep condoms and lube in, and you have waterproof wristbands that you can put condoms and lube in. So we've tried to really work with the community in terms of, not just us providing a service, but actually the community being a part of that, and actually generating ideas: the community actually packing condoms and lube, volunteers involved in verifying HIV test results and helping with the clinic. And I think that's really important, to get that message out. The reality is that nobody, no one organisation has access to all LGBT people. But what you can do is try and work with different access points; so try and work with the bars, try and work with the saunas, try and work with the different types of venues, all the LGBT sports groups, the community groups, and try and get that message out right across Greater Manchester. We'll be heavily involved in all the Prides across Greater Manchester, for example, in terms of supporting them and having a presence at them, which I think is really important to try and have that visibility on a local level.

[00:37:02]

INTERVIEWER 2: Did you have any other questions?

INTERVIEWER: I don't think so, no.

INTERVIEWER 2: OK. So before we come to a close, is there anything else that you'd like to talk about that you haven't mentioned, that you'd like to cover?

PARTICIPANT: Umm... Don't think so.

[00:37:25]

INTERVIEWER: OK. Well maybe I could just ask the last question about PrEP and where you see us going in terms of- I mean, this brings us back to the beginning I think a little bit, in terms of ending HIV. How do you see the future, in a couple of minutes?

PARTICIPANT: Well I think the future is exciting for HIV, potentially. I think there is a chance to end HIV within a generation. It needs political will, it needs leadership, it needs resourcing, and it needs a real can-do attitude, and it needs the community to be at the heart of that. And that the solution to end HIV is within the communities, and you know, we can play a key role in that.

I think PrEP's really important in that, I think PrEP hasn't happened as quickly as it should have done. I think it remains to be seen how PrEP is rolled out - that needs to happen. All the evidence shows that PrEP can be one of the game-changers, alongside condoms, testing, treatment etc. But certainly one of the game-changers to ending HIV. And all that process just needs to be speeded up.

[00:38:51] End of transcript.