

Carole Truman

[00:00:00]

PARTICIPANT: So I'm Carol Truman, and I've always lived in the UK. My dad was a prison officer, so we moved around quite a lot as I was a child growing up. We settled in the North West when I was a teenager, and that really became my home the rest of my life, until I moved down here to the Isle of Wight a few years ago.

I did an undergraduate degree in managerial sciences and as part of that degree I learnt how to do social research. I liked doing social research so much that when I finished my degree, I went on to be a contract researcher. And eventually I got a teaching job at Manchester Poly as it was at the time. I was teaching research methods to students on an applied community studies degree. So I was teaching right through from statistics in the first year to doing big projects in their final year. And that's really where I became involved in the research that I did with – at the time it was called MESMAC, but very quickly it became Healthy Gay Manchester.

[00:01:15]

INTERVIEWER: OK. Would you be able to say some more about that, and how you first got involved with that?

PARTICIPANT: Yeah, so I had students who, in their second and third years, they go out on placement. And I can't remember, I have a feeling that one of my students was on placement and may well have been on placement with a guy called Gerard Gudgion, who was the chair of MESMAC at the time, and he subsequently became chair of Healthy Gay Manchester. And they wanted a piece of research doing, so they asked me if I could help with them a bit of methodology.

So I was introduced to Paul Martin, who even at that time was chief exec I think of Healthy Gay Manchester. And we talked about the kind of things that they were interested in research. They'd done some qualitative research, Let's Talk About Sex. Because what I was saying to them was actually, it's really quite hard to get people to talk about sex and personal issues like that. And they said, well no, we've already done that, we've been very very successful, and men will talk to us about sex, but what we want to do is scale it up so we can generate a body of data that we can use as evidence to influence health authorities when they're making spending decisions about who should be paying for safe sex equipment and the safe sex packs that HGM were distributing at the time, and needed funding to continue their activism in that way.

So I went back to basics in terms of how we could develop a methodology there. I suggested that what we might want to do is develop a community sample. So we'd think about the population of men who have sex with men as being quite diverse, and we'd think about the ways in which they diverse. So we knew that the gay community, even by that time, was quite diverse. You'd have men who were into opera, you'd have men who were into pubs and clubs, who'd never go to opera. You'd have community activists, you know, there's a whole array of different types of gay men. But we also knew there were men who have sex with men who would

never identify as being part of the gay community, and it was really important for us to be able to contact them as well.

So, in research terms, we talked about how it was going to be a stratified sample that we wanted to contact. We also talked about the kind of language that we'd need to use in order to get men to talk about sex and sexual activity. At the time, the language around HIV and AIDS was very medically driven, so it was very much around routes of transmission and high risk groups and high risk activities, and all those kinds of things. But what we knew straight away was that that wasn't how people, how individuals, saw their lives or saw what they were doing, in terms of their own sexual activity and social lives. So it was really important to us all from the beginning to use a language that was actually true to how people experienced things themselves.

So we designed a questionnaire that enabled us to capture those different types of experience, and we designed a sampling study, which enabled us to reach as diverse a range of men who have sex with men as we thought could be possible. So it's very much a learning curve, both for me as a research methodologist, but also for HGM in terms of taking their research to this kind of level, really.

As part of what we did, we trained up men from the gay community to actually administer the questionnaires. We also designed the questionnaires in a way that people could fill it in themselves, so we made sure it was distributed, not just across Greater Manchester, but actually across the whole of the North West. It was distributed around venues where we hoped that men who have sex with men might see it, or come across it. But we also sent out our team of trained researchers, which was quite hilarious. [laughs]

[00:05:49]

INTERVIEWER: Can you say a little bit about that? Why was it...?

PARTICIPANT: Well, I think it was a Saturday morning and we'd got a room about the doctor's surgery in what's now the Gay Village, and we were talking about the ethics of doing research, needing to be consistent asking questions in a way that would give us good data, but at the same time were actually going to be easy for men to actually talk about. One of our interviewers was actually a finalist in Mr. Gay UK, very nice looking chap, and he basically just exuded charm and charisma. And when he went out into pubs and clubs with his questionnaires, he had a queue of men waiting to answer his questions. And it was very counter-intuitive, because we thought we were asking very personal questions on a very difficult topic for people, against a whole backdrop of HIV and AIDS, but actually we found the opposite, that people wanted to talk about, men wanted to talk about what they were doing. And we realised that the approach we're taking was actually getting research evidence that, no one else would have got it that way if they hadn't gone back to the basics of how we might design a research study to actually address the kind of issues that we wanted to address.

[00:07:14]

[Interviewer adjusts mic.]

[00:08:10]

INTERVIEWER: OK, so... so you were all in this place in the Village, and then you went out and you did the questionnaires, and people responded differently, how? People were quite willing to talk about...?

PARTICIPANT: People were very willing to talk about it. I mean, interestingly, I didn't administer any of the questionnaires, it wasn't right for me to be doing that as a woman. But what we did do is we sent men out, we just said, go anywhere that you can find someone who'll fill in the questionnaire with you and talk about sex. They were administering questionnaires in car parks, as men were coming out of darkrooms, as... saunas, I think we even had some that were men who used saunas too, which were all the hard to reach groups within what was already seen as mainstream society as a hard-to-reach group.

I think one of the things for me that's worth saying is, although I was teaching community studies students about research methods, so I had a good understanding of the methods literature, I was also involved in setting up a Women's Studies degree at Manchester Poly. So I was also a feminist researcher, and a lot of the principles behind feminist research - thinking about who the research is for, who's going to benefit from the research, who's helping to define the people who are the subjects of that research, and people being subjects of research rather than being objects of research - all of those things were driving me in terms of how I thought about the methodology, and thinking about how the methodology could work for this group, this community that we were looking at there.

[00:10:06]

INTERVIEWER: Do you remember some of the questions, or what the questions were trying to... what data you were trying to generate, and why?

PARTICIPANT: Yeah. So at the time, the medical profession were interested in routes of transmission and a very medicalised model of HIV transmission and AIDS. They were interested in risky activities and things like that. But we went back, just as we went back to the basics in terms of designing a methodology, a sampling strategy, we went back to the basics in terms of, well, what does sex actually mean in its social context?

So we actually designed the questionnaire [so] the first questions weren't about sex at all. We were asking people about how they socialised, how often they use pubs and clubs and different venues, what kind of venues they used, which ones they used most often. And then about halfway through the questionnaire, when men had said that they would meet other men for sex, or sexual activity, we had a question in there that said, the last time you met someone new for sex, what did you do? And we got them to describe it in their own words.

Well this was totally different to how the medical profession would do it, which is very bounded categories of sex and sexual activity and what was risky behaviour and

what wasn't risky behaviour. I mean, there were papers written on, was this risky, was that not risky, all sorts, you know. Was oral sex risky? Under what circumstances was it risky, and how would you know, and how should we be targeting education and all that. Well that didn't really seem relevant in terms of how men thought about their own lifestyles and their own sexual activity and where they perceived there were risks.

So actually getting men to talk about it in a whole social context of a night out, or how they socialised during the week, was actually a really important part of how the questionnaire was constructed there. So that question about sex and sexual activity was very much contextualised in their lifestyle. So it wasn't really the sort of threatening question you might get if you were under the spotlight in a medical practitioner's office.

From that we were able to... I mean... people would describe things, you know, the last time I had sex with someone new, "well it was the full works". And then we'd ask if condoms had been used, or if they'd taken any measures for it to be safe. And we got information there, but we could kind of categorise risk according to a much broader model of, some men were quite clearly risk-averse, and other men would think, well I need to manage risk in this context, if I'm having sex with someone new, but I don't need to manage risk with my regular partner. And this was opening up whole areas that we kind of intuitively knew needed to be the focus of a study, but we didn't have data that would actually support that people weren't going round- you know, risk wasn't a uniform thing. Men individually weren't either risky or not risky, they were managing risk depending on the context of where they were. So, as I say, this very back to basics questionnaire opened up all sorts of avenues of evidence and enquiry for us.

[00:13:48]

INTERVIEWER: Could you say just a little bit more about how this was, in a way, a departure, that it was a new kind of research, especially in a health setting?

PARTICIPANT: Yeah... What I used to do, because I used to talk- I mean, later on in my career I'd talk to doctors and members of the medical profession about how we came to understand this, and in fact... I mean, I still use this approach in terms of patient's experience of health. The medical model, you know, of course it's valuable, and it's really important if you're looking at a disease model, you've got to know whether someone's got a disease or not got a disease, so you need categories and so on. There was so much fear around. I mean, HIV and AIDS was only discussed in terms of it being a disease that would kill you. It was never discussed in terms of, it being a disease that would kill you. It was never discussed in terms of, well this is something that actually, you might need to think about in terms of your social lives, in terms of how you think about risk and how you might want to manage that risk in your own lives.

So we were very much thinking about it, or looking at it, through the lens of the people who the knowledge was actually going to be about, and who the knowledge could actually benefit. Sometimes when I talk about this type of research say with doctors, I'd start off by saying, alright, I want you as a doctor to describe in medical

terms, a kiss. And you can see them kind of laugh and joke. And I said, no, seriously, tell me what a kiss is in medical terms. And it's quite funny because they do then get into the physiological kind of definition of what a kiss actually is, and then they start questioning each other and saying ah no, but you need to include this, or that. And it gets quite amusing to them, and then they get this ah-ha moment, and think, oh actually, yeah, people aren't just diseases, there's a whole body and a whole person attached to that, and then that person's also connected to other people. And they realise that just isolating something down to what in this case was medical routes of transmission, so, you know, was saliva a route of transmission, and if so, under what context, or you know, sperm. It's kind of like, everything has to actually be put into the context of what it meant to someone's lifestyle.

[00:16:22]

INTERVIEWER: You've mentioned that you were interested in not only people who identified as gay, but the broader category of MSM, men who have sex with men. Could you tell me a little bit about that distinction, from a research perspective? Because MSM was something, I guess, that, in a way came out of health promotion efforts and we still use it today. Could you just say anything about why that made a difference to your research?

PARTICIPANT: Well, I suppose, the sense of community was very much around, at that time, what was clearly – although to define it would be difficult – but there was clearly something that was called a gay community at that time. So men who would call themselves gay and who would identify with other men who were gay. But there were venues that were being used, not just by gay men, but by also men who would perhaps be in straight relationships or not identify as gay at all, who would use the same venues, as a way of having sexual contact with other men. So we knew that if we defined the research just around men who called themselves gay, we'd be missing out men who didn't define themselves as gay, but who nevertheless had contact, who wanted contact, with other men. So the MSM thing was a really important part... and again, that influenced the language that we used in the questionnaire. So the title of study was always, Men Who Have Sex with Men in the North West. And we focused in on around where men who would have sex with men might meet and congregate, because the one thing that we did know is that we weren't interested in men who might want sex with men but who never met any other men. So it was very much around venues that men could meet. Which is again how we defined the study.

We focused on Manchester because there were various venues within the confines of the city centre. But we also knew there were places in Oldham, where men could meet other men for sex. And we went out, I think in the end I think we went out to Lancaster and also Blackpool, to administer the questionnaires too, or to make sure they were available in venues there. So what we actually ended up with was quite a sophisticated network of where men would go.

So I think one of the important findings of the research was that men would often socialise, or meet men for sex, actually some distance from where they lived. Because they didn't want to bump into their neighbour. So we knew that men would

travel quite a long way, say to Manchester City Centre, or to Blackpool, because it was a more anonymous place for them to meet.

And a lot of that, I suppose, HGM would know intuitively, but we were actually beginning to develop quite a massive database around that kind of movement, really. We had data that would say, for example, we know that on a Friday night in Manchester, there will be at least 30 men from Bury who are potentially engaging in risky activity - certainly who could benefit from having a safe sex pack. So why doesn't Bury health authority start paying for safe sex packs in Manchester? So it comes down to... But of course we had to have the data to show Bury that actually, you know, your money is well spent here. So that was all behind the politics of... there was always money attached to the kind of, where we were going with this.

[00:20:29]

INTERVIEWER: And how did... I know you mentioned earlier on when we were just chatting, when you took this research to the people who did pull the strings in terms of the funding of health services in Greater Manchester. How did they respond to your research?

PARTICIPANT: Well it's kind of interesting really, because at the time, the literature on hard to reach groups and marginalised groups had very much come out of research into poverty, so that people who were often the objects of research never had any cultural capital or political clout. But it was, even in those days, there were men within the gay community who were actually quite well-connected in terms of the medical profession, the social work profession, so knew how these big policy-making bodies actually worked. So I think that's one of the big successes, and that was one of the great things for me as an academic, because you know, as an academic you don't have any obvious connections with policy-makers. But HGM did.

And I remember, it was a Wednesday afternoon or something, the movers and shakers in the health authorities were all meeting at Gateway House near Piccadilly in Manchester. And we'd been given an hour of their time to go in and present the findings of our research, so we kind of, you know, nudging each other and saying, right, we have to be smart, I'm going to wear a jacket. And I remember Paul and Gerard saying, I wonder if we should wear ties or not? And we were laughing away, that kind of thing.

And we went in, and it was just quite obvious really, it was a really sunny afternoon and the sun was streaming in through the window, and it was quite clear to them that they didn't know quite what to expect from us, so I introduced myself as a lecturer from Manchester Poly, and began talking about the study in very social science ways, and in a way that was very credible. Then we talked a little bit about how we did it, so we started with our assumptions and premises and so on. Then on how we did it, and they were saying things like, oh, but if one of your interviewees was a finalist in Mr Gay UK, and men were choosing to be part of the study, surely that means all your findings are biased? And we just said, what do you mean by biased? Because actually what we're trying to do is build up a really sizeable sample here. If we can get men queueing up to take part in a study- you know, show me another

study where you've actually had people queueing to take part in an otherwise dry, scientific survey. And they grumbled a little bit.

But I think the big thing for us was that by the time we started to report the research, our community sample had grown up to be over 1000 men. So there was nothing like it of its kind, and I think we heard in the wider circle that at the time that we did the study, it was actually the largest study of its kind in Europe. So however we did it, we had statistical material there, and we had data that no one else could match. We just said, find us some better data if you want to refute our findings, but we don't think you can. So they had to take it seriously, because methodologically it was OK, and the sample size was unrivalled. There was nothing to touch it. So they had to listen.

And that's really where I could leave it with HGM. And you know, they could use it. I think Paul was saying that they used it as part of their campaigning work for a good few years after that, because it was just such a valuable piece of data. Interestingly, we actually got some money to do some further analysis of it, because suddenly it was like, everyone was going, this is an interesting data set. So it became a very robust piece of work, and had quite a lot of status behind it really.

[00:24:51]

INTERVIEWER: Great. You mentioned the importance of language and the language that you used in the survey. I was wondering if you could say a little bit more about that... and obviously how that then connects with people being subjects rather than objects of the research.

PARTICIPANT: Yes. The language was very much about us not falling into- I mean, we had a big discussion about, were we going to use the medical model of sexual activity, or medical models of sexual activity and sexual risk and all that? And we just thought, in terms of the first principles where we were coming from, well, no, we weren't. We didn't want to get people to look at a whole load of different types of sexual behaviour and to tick the box that applied to them. What we wanted to do was understand what that sexual behaviour meant to them and how they described it. We were interested in things like condom use, but at the same time, we knew that in terms of the range of sexual activity, that condom use wasn't going to be appropriate or necessary, so we didn't want to push people into describing their experience and their behaviours in terms of how we thought they ought to be able to describe them. We wanted them to self-define as much as possible really.

[00:26:32]

INTERVIEWER: Did that pose a challenge in terms of an analysis or then collating the data?

PARTICIPANT: Yeah, we all sat round, I remember we all sat round I think in the offices of HGM where we had literally piles of these colour-coded questionnaires. And we were looking at either what the researcher had written or what the man himself had written about his sexual behaviour. And then we started to say, well, we can put all that lot over there. [coughs and sips water]

Yeah, so we sat in the offices at HGM with these piles of colour-coded questionnaires; so I think purple ones had gone out to one type of venue, and yellow ones had come from somewhere else. And we had this question in the middle, last time you had sex with someone new, what did you do? And then we had a supplementary question where we could begin to attach some type of risk factor to that. And we just literally went through them, and read them out, and thought, well, OK, that sounds really quite high risk, so we'll put that in one pile. And looking at [another] and saying, that doesn't sound risky at all, so we'll put that [over there]. And so we could kind of get them into two piles of, risky [and] probably not risky, in terms of HIV transmission. And then we had to subcategorise in between, the kind of things that are maybe risky.

But in the end that's all that mattered really. Because the purpose of the study was to get funding for safe sex packs. So what we were saying was, if anyone's going to have something that's potentially risky, they need a safe sex pack. If they're not going to do anything that's risky at all, there's no harm in letting them have a safe sex pack, but you know, we don't need to say, someone's done something and they're definitely going to get HIV, that's not really what we were about. It was actually, someone's done something that could incur a risk; if they've got a safe sex pack, they can then choose whether they identify that risk themselves, and whether they do something to manage it. But without the safe sex pack, you're taking that choice away from them. So that was what it was about really.

The medical model was very much about *proving* whether something was risky or not. You know, proving that unprotected sex was risky, or... you know. At the time it was like, was a cut risky? Was a cut risky in that context but not in that context? Was kissing risky? And it was kind of like, there was mass hysteria about it. But if you broke it down to the reality of people's lives, it was actually giving people an opportunity to think about risk themselves. And even just the visibility of safe sex packs around gay venues, or venues that men who have sex with men might use, was actually saying, this is available if you want it, it's free, take one, take two, you know, of these packs, and use them if you want to. So it was never about being prescriptive, like, you've got to stop doing this, which is what a lot of the literature and the adverts were about, you know, the idea of a gravestone falling over and all that. It was actually about, OK, you're in this venue, this could happen, here's something that might help you manage the risks associated with what you might want to do with someone else this afternoon or this evening.

[00:30:20]

INTERVIEWER: And it sounds like then, that HGM were able to use that quite successfully then to mobilise more resources. Is that your impression of...?

PARTICIPANT: That was... I mean that was the great thing about it, was that... I mean, I wasn't a member of HGM, I was an academic. So they had their agenda for what they wanted to do as an organisation, as a voluntary group, and the kind of audiences that they wanted to take it to. And their audiences were policy-makers but of course it was also for the gay community, it was for men who had sex with men. I was really pleased as an academic, because I thought, wow, I'm doing a piece of

research that's both academically robust *and* it's going to be useful. But for me it was also useful, because it helped me to think about how I wanted to do research in the future, and my approach to research was very much about that kind of, not using a model where people were objects of research, but the research should be participatory, it should be working with groups and individuals so that groups and individuals can actually benefit.

So I was taking the research, you know, and it kind of became the cornerstone really of my academic career. I was taking it to Women's Studies conferences and writing about the ways that feminism had influenced the way I was thinking about research. But also, how you could do feminist research with gay men. Or you could do feminist research with men, and take those principles forwards in that way. So in time I worked with people with mental health problems and got them involved in designing research and administering research, and again, getting them to define the language that was used in the study of a community gym for people with mental health problems.

I talked about this particular research with HGM as recently as last month on the Isle of Wight, because I'm now a member of the governing body of the Clinical Commissioning Group on the Isle of Wight, the CCG. And my area of responsibility as a lay member on the governing body is for public and patient involvement. And I said, well I've been doing public and patient involvement since before it got called that. I've seen it work from quite early on in my career, and once you've seen it work you just don't do it any other way, because it's kind of like – if it's not going to work for the people who are meant to benefit from the research study or from a service, why do it at all? So it continues to have currency for me in terms of what I do these days.

[00:33:13]

INTERVIEWER: Great. You mentioned that you took the research to women's conferences and that specifically it came from your own interest in feminist perspectives. Could you say a bit more about that, and how, in a way, as a woman, doing this kind of research, how that... or maybe it didn't, but if you could say how that was maybe unusual at the time, or how that was received, and what that feminist understanding is for you, in terms of your approach?

PARTICIPANT: Yeah, well I suppose I'd moved to Manchester because I'd identified it as being a big urban population where there was a growing and visible lesbian population. I would at that time have defined myself as a lesbian feminist, and I was as much involved in the women's movement as I was the lesbian movement. There wasn't an awful lot of overlap and connection, at that point, [in the] late 1980s, maybe even to an extent into the 1990s, between lesbians and gay men. There weren't... I mean, later on I became a member of Manchester Lesbian and Gay Chorus, which was 50/50 lesbians and gay men or so, well, 50/50 men and women by the end. At that time, they were very separate communities. There was also quite a lot of antagonism between lesbians and gay men, so I can remember going into certain venues in what's now the Gay Village, where women were muscled off the dancefloor if we went in as a group of women, and told we weren't wanted there. Women didn't have their own venues, we tended to sort of get the last Friday of the

month in a room above a pub. I'd say the lesbian community invented popup venues long before anyone invented a popup cafe, that was how you socialised as a lesbian.

But at the same time, obviously, around that time there was section 28, where we suddenly got lesbians and gay men united against the antagonism towards the miners and the miners' strike and supporting the miners. So there were points of connection, but there were also points where we didn't necessarily have a lot in common as well.

[00:36:06]

INTERVIEWER: OK. And so how did that then feel for you, bringing a feminist standpoint to something that might be considered just the concern of gay men, in a sense, or... Do you see what I'm saying?

PARTICIPANT: I don't think I would ever have said to Healthy Gay Manchester, I don't think I'd ever said, look, let's do this as a piece of feminist research. Feminist research was influencing how I thought about research, and those were ideas around research that I thought were really exciting and really interesting. From Healthy Gay Manchester's point of view, it was like, urgh, no, we want it to be as mainstream and academically robust as it could be. But for me, the principles are that the research should be with the community that you're trying to benefit, and for the community that you're trying to benefit, and by the community. So it's very much a participatory angle for me. And you know, ideas around participatory research were floating around at the time too, so... there was kind of like, feminist participatory research. But participatory research had come much more from a different kind of root. Anyway, I got really interested in the ideas, and I edited certain books about it as well, and went to international conferences and... A lot of the ideas now have become very very mainstream. So you can't get a research grant in health anymore, unless you can show user participation. So if you contrast that to what these doctors said at the time when we gave them the first results, and said, oh no, your research is contaminated because you've got members of the community actually doing the research. Well, now, if you haven't got members of the community involved in the research and having a view on the research, you can't get research grants anyway. So it has, over thirty odd years, actually become quite a mainstream way of thinking about research.

[00:38:23]

INTERVIEWER: Could you say a little bit at a more personal level, about when you first heard of this thing, which was maybe called HIV, maybe called GRID, or whatever the term was being used – but personally, when did you first hear of, or were aware of this epidemic?

PARTICIPANT: I think... for me, as I say... my experience in Manchester was being on the editorial collective of the women's liberation newsletter, which shows where my political origins were really. And there's no doubt, at that time, there was a stream of women's liberation and a stream of feminism, particularly lesbian feminism, that just didn't have anything to do with men at all. So I would say that our political interests at the time weren't necessarily that much interested in what was happening

around HIV and AIDS. I think feminists were interested, became interested, because of the risk to sex workers; female sex workers were clearly a vulnerable group there. But gay men socialised differently to women, didn't have a lot in common, and as I say, there was a sort of antagonism really. So for me it was more of a backdrop, to my political interests and my social activity in Manchester at the time.

But at the same time, it was kind of important. It was so big, you know, in terms of, you know, there were mainstream media campaigns. But I was probably as influenced by mainstream media campaigns as I was [by] what the gay men's community was doing about it as well. So in some ways, getting involved with HGM really brought it home, because it forced me to think about it, and it forced me to think about it in terms of the connection between the community I was in and the gay men's community, and also the connections there in terms of the politics behind this as being a pandemic. But at the time, going back, everyone said, we're all going to die of AIDS, kind of thing, it was going to wipe out the entire planet, the way that it was talked about at that time.

[00:41:12]

INTERVIEWER: You mentioned the Don't Die of Ignorance campaign, the gravestone. Could you say a little bit more about the political atmosphere at the time? I mean, the time before and maybe leading up to when you first got involved with HGM?

PARTICIPANT: Yeah. The Don't Die of Ignorance was very much about focusing on individuals, but there was also a whole dialogue around deserving and undeserving victims. So I was interested politically, or I was kind of worried politically, how sex workers were seen as perhaps deserving victims because they were promiscuous. But also that translated to how some men who have sex with men were promiscuous. So they were kind of bringing it on themselves, and all that kind of stuff. Well, you know, just instinctively, that can't seem right, from having a social analysis of any of this, that it just didn't seem right that, in terms of how the tabloids talked about it and in terms of how the media got hold of it... I mean, that stuff made me really really angry, that it was this disease, this illness, that in itself the understanding of the illness was based on a lot of prejudice and misunderstanding, they hadn't really got the research around drugs and prevention and all that kind of stuff. But then actually using it as a way of stigmatising groups in society who are already vulnerable. Well that kind of, in a sense, motivated me to think, well actually this is really something that no one can ignore, even if you're not in a "risk" group, kind of thing, and what does "risk group" mean anyway, you know. So I was interested in it from the idea of how certain groups had been scapegoated and that. Part of being a social scientist, you know, you never take things at face value. It's kind of like, this isn't right, kind of thing.

[00:43:31]

INTERVIEWER: How do you think attitudes have changed, or not changed, and how do you see your research or your role in that, to an extent... how have things changed up until the present day?

PARTICIPANT: Well as I say, for me, in terms of research, given I'd had such a really positive experience of doing research in a way that was... important research, because it was an important topic, it was meaningful, because it could actually help influence policy-makers and it was applied – that shaped the type of research that I wanted to do. So I then spent the next thirty years doing that sort of research. As I say, sometimes I'd be working with people who are mental health users, people with learning disabilities. We did work around community safety. But it was always doing research that was with, or for, or by, or ideally all three of those criteria, for the groups that had actually... you know, so that the groups that the research was about would actually benefit from that research.

So through my career, I went from Manchester Poly, went to Lancaster University, where we got quite a big grant to do a community study of sexuality, safe spaces. So we did a study of violent sexuality and space. Again, trained researchers from the community to go round and do questionnaires in safe spaces, and try to understand how safe spaces work. From Lancaster I went on to the University of Bolton, where quite soon I set up my own research centre, and was working with practitioners across health and social care, where people were doing projects, you know as professionals, we're doing projects, and bringing them together to talk about how their research could be used and implemented. So as I say, for me it was the starting point of quite a good career really. I got invited over to conferences in Australia and San Francisco, Canada, you know, to talk about this approach to research. People were interested, and certainly as I say, now, I wouldn't say it's become mainstream, but I think mainstream research can't ignore the participants of research in the way that in the past people were just the objects, they were just the chemical elements that you needed to study that phenomena. Whereas now, it's like, well actually if it's not going to work for the people that the research is about, it's probably not that good as a piece of research really. So this whole idea of user involvement, public and patient participation, service user involvement, all comes from those ideas really that we were beginning to hammer out in the 1980s and 1990s.

[00:46:41]

INTERVIEWER: OK. Maybe this is something that you might come across in your current role here on the Isle of Wight. In terms of the kinds of... obviously technologies have changed in terms of, obviously there's condom and lube distribution, but there's also improvements in testing, and now we've got PrEP – well hopefully soon have PrEP – and PEP, and so there's all these... and treatment as prevention as well, so kind of undetectable viral loads. There's obviously been quite a lot of changes over the past couple of decades. I'm not sure how much of that you're... but how would you see, today, the position that we're in, in terms of thinking about some of the questions you were asking back then with your research?

PARTICIPANT: I think... I mean obviously, sexual health is such a major part now of public health. I can remember quite early on in my career, there was a big study of sexual health, sexual activity. And one of the researchers there was told quite early on, you know, if you want your career to develop, you'll ignore sex because it doesn't really go anywhere. It was seen as a bit quirky. Whereas now, as I say, you can't imagine public health without sexual health being a really major part in all of that.

And sexual health across the whole population. So not just around sexual minority groups, but actually sexual health is something that affects everybody.

So you know, that's certainly changed, and it probably is the case now that you could make a fairly decent career out of being interested in sex and sexual health. I think it was seen as a bit exotic, or... there were probably quite a lot of Victorian values around, you know, and it's within living memory that... you know, people aren't embarrassed to talk about sex and sexual activity anymore. Whereas before it was a taboo subject. And certainly men having sex with men was a taboo subject within a really taboo arena.

[00:49:32]

INTERVIEWER: OK. Just one more question on that. Through a lot of the interviews that I've been doing, and this may or may not be relevant, but a lot of people who've been involved in outreach work around safety sex and sexual health awareness, have commented on the relationship between mental health and sexual health, in the sense of people... I don't want to fall into the language of risk, but maybe the ways in which people do or don't manage their sexual health may be related to where they're at in terms of mental health as well. Was that something you were aware of in your research, or did that come through, or...?

PARTICIPANT: I think probably only anecdotally. And not something that would have come out of the formal research that I was involved with. But certainly at the time we were doing the study, we were learning things as we went along, and, you know, there was that feeling about, within all of that, that there were people who were vulnerable, and they may well have been vulnerable because of reasons of mental health, and not just vulnerable because they didn't have a job, or, you know, they were young, or what have you. So I think it was probably something that was there that we'd be aware of, but we probably even at that time quite see the connections, you know.

[00:51:25]

[Interviewer switches over battery on radio mic.]

[00:51:40]

INTERVIEWER: I was just going to ask you if there's anything else you wanted to talk about that we haven't covered.

PARTICIPANT: I don't think so, we've covered quite a lot of ground, haven't we?

[00:51:54]

INTERVIEWER: We have, yeah. How are you doing, are you OK?

PARTICIPANT: I'm OK, yeah, I'm fine year. I think the fire's going out, thank goodness.

[00:52:04]

INTERVIEWER: It's quite warm, isn't it?

[Interview continues adjusting mic.]

PARTICIPANT: I think what I might want to say is... [coughs and takes a break]

I don't know quite how to articulate it, but it's that thing around how it was also the impetus for looking at... you know, the gay community were seriously victimised, there's no getting away from it, during the 1980s, as you say, with clause 28 and everything else that was going on around then. And the idea... so it wasn't just section 28, it was about raids on clubs and so on, it was around what we now call hate crimes not being reported, or if they were reported, not being dealt with by the police, not taken seriously.

So I think what was quite interesting really was how, by becoming active in research, we could then go on and actually do research around issues that were of real importance, not just around sexual health, but around community safety, that were of real importance to the lesbian and gay community. You know, bullying in schools. I'm not saying one led to another, but it was part of a social movement of research in some ways, that meant we could see the importance of getting good evidence. And once we'd begun to get good evidence, we could start to influence arguments that were taking place at a policy level. That's all been part of a momentum, and we've, you know, very much moved away from anecdotal evidence to actually saying, well let's do this in a proper, robust way.

But at the same time with all of that, it's like, because the research that's been done is with and for the lesbian and gay community, it's like, we've not turned ourselves into victims in any of this. So part of creating a new vocabulary was not just about doing research on potential victims of HIV and AIDS, but was actually changing the way that we spoke about things, to say, well if there are these risks around, how can we help people, how can we empower people to manage risk? How can we empower people with information? How can we empower people with condoms and lube, and things that are actually going to help them to manage risk? So it's actually turning things round on its head really, and not just prescribing people are victims in all of that. So how can we talk about, not that people are vulnerable out on the streets, but how can we think about making streets safer for people? And thinking much more about perpetrators of crime, and turning them into the problem, rather than as lesbians or gay men – in those days we were the problem. We were the hard to reach group, we were vulnerable. Actually it's the people who are perpetrating crimes, or not providing services for us as a community, we were invisible. Research has done an awful lot to make us visible, really. Not the only thing of course, but it's played an important role there.

[00:56:19]

INTERVIEWER: Great. Well, we're close to the end of the interview now. Is there anything you'd like to add, or anything you'd like to say about your life today on the Isle of Wight, or something? It's up to you.

PARTICIPANT: I think I'd say about that research, really, is that I feel very proud of being part of it, and I'm glad that it's... for me, it's part of my history and part of my biography, both personally and professionally. So that's something that I'll always feel very proud of really. And yeah, I think that's, for me, something I'm really glad I've been involved with, and has provided a lot of food for the way that my career developed over the last couple of decades really.

[00:57:19] End of transcript.