Transcript Michelle Croston

Robert Yeah. So just for the tape it's Robert um from George House Trust and

Michelle Michelle Croston from Manchester University Foundation Trust.

Robert And we're at Stockport.

Michelle. We're at Stockport Choices Clinic

Robert. Brilliant. Just adjusting the um recording levels. So that's brilliant, we should be OK with that.

Michelle Ok

Robert So um. Michelle, tell me a bit about yourself. Are you originally from Manchester?

Michelle Yeah, so I'm Manchester born and bred. I grew up in um. Just outside of Manchester when I was younger, we moved to Glossop
p for a while,

Robert Erm

Michelle. But then we moved back to Manchester, probably my Late teens, yes

Robert. And what was that like, being in the countryside and then moving into the city?

Michelle Yeah, it was really different, so obviously in, in Glossop, it was um a very small town um where everybody knew the business, everybody's business, and obviously being part, in a bigger town, it was, it was kind of um it was more vibrant but more anonymous as well, which was kind of different.

Robert. So did you go to secondary school here in Manchester?

Michelle. No, so I went to secondary school in Glossop and then I went to um. University in Sheffield, but then came back home.

Robert. And what did you study in Sheffield?

Michelle. Nursing.

Robert. Ah, what made you want to go into nursing?

Michelle So all my life I've enjoyed looking after people. So when I was doing my options, there were choices, I, there was like two paths really. I could have gone into law. Or into nursing, but I just really enjoyed looking after people a little bit more than I did. Um, I know in law you get to stand up for injustice, um, but it just felt I liked the interpersonal stuff. I liked to

care and I like people, but and I know you get to do that in law, but it's just something drew me into nurse.

Robert. Is it something in your home life where you saw people looking after one another that made you think, oh, I want to be a nurse.
Michelle. Yeah, I think it was more like my grandma and granddad was a huge influence on me. So they, they fostered young kids, you know, back in the day where,

Robert Wow

Michelle where you did that, but you didn't get an income from that.

Robert Yeah

Michelle. So that, you know, so growing up we had. Like, um, you know, the, the plaster tables

Robert Yes

Michelle. Just filled they'd go up and we'd have like different kids coming around and I just saw how much of a difference my gran made in different people's lives. I thought, yeah.

Robert. So she was a really important person to you?

Michelle Massive, massively important. Yeah.

Robert Is she still with us or?

Michelle No, she, she passed, um, a couple of years, probably about 7 years back now yeah.

Robert So when you started your nursing course, what was that like, cos it was it straight to university and nursing at whilst you're doing uni.

Michelle. Yeah, so I had a time, so I worked at Tesco's while I was doing my A Levels, and then I needed, I wanted to get some experience cause I think sometimes we think, definitely I would encourage anybody who was thinking of a career in nursing to get some experience because there is the things that you see on the TV.

Robert Yeah.

Michelle And then the actual reality of what nursing was like. So I did some support work at Manchester Royal Infirmary at the time, you know, like some hands on care work, and I think that's where I kind of, that would probably be 97, 98 time.

Robert Right

Michelle. And that was probably the first time I ever came in contact with somebody living with HIV. So it was kind of something. That I'd become aware of prior to starting my um training and

kind of looking back now, that was a really kind of significant part of my journey into nursing as well.

Robert. So because we first became aware of um HIV in the, the mid to late 80s, was, did that take any part in your nursing course? Were you made aware of HIV?

Michelle Not really, to be honest with you, we had um. Just kind of casting my mind back. Maybe one lecture, if that. So probably the time I was doing my nursing course was just on the cusp of treatment. So definitely when I was training, it was more around the nurses role being around palliation.

Robert Yeah

Michelle. Around supporting people to die well

Robert Yeah

Michelle Rather than kind of living well as we think about now.

Robert Yeah, because that was obviously the, that's what it was like at the time, wasn't it?

Michelle Yeah, that was the driving force around. um, we didn't really talk about testing, you know, I can, I can think about. Maybe some of the wards during my training, so I worked in gynae and there was people having terminations, but we never thought about testing it was never a conversation we seemed to have,

Robert Yeah

Michelle. Really.

Robert And when did you first decide that you wanted to work within a HIV environment?

Michelle Yeah, it was probably quite early on in, in my training. I want, to be honest with you, I wanted to work in infectious diseases and tropical medicine,

Robert Yeah

Michelle And that was kind of my sort of, um, motivating kind of desire. So, as I mentioned, I'd had experience when I was, um, like a support worker. So that was, um, 18 year old me.

Robert Yeah

Michelle. At the time there was something called MRSA, which is like a a a bug that um it was resistant

Robert Yeah

Michelle  Um kind of antibiotic bug. And part of the nursing role was around kind of making sure that didn't spread, so we had to kind of go to great lengths to wash people in like this, this like lotion thing and wards were closed down and it was kind of highly kind of spreadable. And then I remember kind of being on this ward, and there was a side room and there was a young kind of guy in there and he had, it was the first time I'd ever come across somebody who'd, like, self-harmed because bear in mind I said I grew up in a small village

Robert  Yeah

Michelle  And he was street homeless. It was marks of self-harm, um, and at the time, like any good nursing, um, support worker had a comb. So I used to go in and like lend him a comb, and we'd have a chat, and I just loved the stories he'd tell me because this was somebody who had a similar-ish age to me, but had a very different life, and I just couldn't understand why he was hurting himself, basically, and, you know, we, we shared stories and then Towards the end of the shift, the sister who I kind of looked up to and I thought, oh, when I'm a nurse, I'm just gonna be like you because you're just amazing. She kind of pulled me to one side and said, um, I'd leave thingy alone if I was you. I can't remember his name, bless him. John for, for, for,
Robert  Yeah

Michelle  I'd leave John alone if I was you. So I was like, what, why, um, thinking, oh God, instantly I'm gonna get in trouble.

Robert. Yeah

Michelle.  I've spent too much time chatting. So she said, oh, we think he's got HIV AIDS, and I was like. I honestly didn't really know what that meant.

Robert.  Mmmm

Michelle  I remember kind of seeing like AIDS don't die of ignorance, and I kind of thought.

Robert.  Oh, the advert,

Michelle Yeah

Robert  The public health film

Michelle  Yeah the public health

Robert  Yeah.

Michelle  I'm thinking, oh God, don't die of ignorance. That's me. I'm going to die of ignorance. I don't know what I did, honestly, I didn't know what it meant, so I was like, oh right, OK. Left the ward and instantly thought, oh gosh, I don't, I know, I knew enough so my frame of reference was this MRSA

Robert.  Yeah

Michelle. Thinking oh my God. John's been using my comb. What happens if I give Burt in bed 5 MR erm Aids because he's like my comb.

Robert. Yeah

Michelle I just generally really kind of shocked. So I went to the library at the time. So this was back before the internet was a thing.

Robert Yeah

Michelle So I spent hours after the shift in the library thinking about, OK, what is this HIV? What is this AIDS? Cause I was literally scared to death by I. I kind of

Robert Mmmmm

Michelle Passed it on on around this world like the MRSA. So I got myself, um, I spent probably a lot of money printing stuff out for this ward sister I like, and and kind of really it was the first, it was the first time I'd kind of Become interested in infectious diseases or, you know, anything other than, you know, like your cancers

Robert Yeah

Michelle Or anything like that.

Robert. So you were finding the information out not just for yourself, but you were going to pass this on to

Michelle yeah to the to my colleague and I wanted to reassure this like I can't remember his name, but I just wanted to let him know that it was, you know, it's going to be giving him some information. And I remember going back onto the ward and the ward sister was just not interested, absolutely not interested. And I just remember thinking, but, but it's fact, these are in black and white.

Robert Yeah

Michelle Um, but yeah, so that was the first time that I kind of became aware of sort of HIV but also the stigma that came with that, and also how terrified he was and how worried he was about, cause I, I tried to obviously spend time with him, and he was convinced he was like, I don't want to give you HIV or AIDS I I was like and I and I was like, well, Surely I would have got it by now if, you know, because we both didn't,

Robert Yeah yeah

Michelle didn't know, so I think that kind of sparks my passion to probably learn more about different ill at the time different illnesses and different diseases and then obviously that transpired when I went to um kind of um. Like the infectious diseases ward.

Robert And what was it like starting work in infectious diseases?

Michelle Yeah, so I think it was at the time, so I was only like, looking back now, I was what, 19, 20, if that, um, and at the time on the ward, we had a lot of young, young males on the ward. Um, because it, because it was on the cusp of treatment, so there was some

Robert  which hospital was this?

Michelle That was at North Manchester,

Robert. Yeah

Michelle  The infectious Disease and Tropical Medicine ward. So there was a lot of young people, sort of very similar ages to myself,

Robert.  Mmmmm

Michelle  kind of, excuse me, being diagnosed, but then or being very unwell, and it just felt like a really Sad time, but also a really privileged time, um, cause we were supporting lots of people through really tricky times in their life. We saw a lot of death, but we also saw a lot of joy, um, as well. So it was quite a, a dark time when I initially started.

Robert. How did you cope with seeing people pass away?

Michelle.  So, I think, you know, back then, like now, there's lots of stuff and I've kind of done some work around kind of this idea of secondary trauma and, you know, looking after yourself better. But I think knowing what we did at the time is we used to just go out and dance, and so then we'd go, we'd just go out and dance. We would finish our shift and we would head to the village

Robert. Yeah

Michelle  And we would just dance because actually we were out, we were together and we were dancing and When you're dancing, you don't have to talk, but it does actually do something for you,

Robert. Mmmmm

Michelle  The music, being around people. So, yeah, so that's how we copes as a team, we just used to dance, go and dance. And sometimes on the ward, um, cause it was like isolation cubicles, and sometimes I remember one particular shift, we'd had quite a few deaths of young people, and it felt, it felt a bit overwhelming.

Robert. Mmmmmm

Michelle  So we just cracked the radio up really loudly and just danced because we, we just didn't know what else to do.

Robert. Were there many people who um were in their own room and didn't have people visiting them?

Michelle. Lots, lots of people at the time and I remember. One particular man who who'd been diagnosed and his, his family had found out and like, you know, disowned him

Robert. Mmmm

Michelle And he was really lonely and really sad and Just depressed and didn't really want to take treatment because he'd lost essentially what he thought was everything.

Robert Mmmmm

Michelle So we used to take it in like shifts to go and have our dinner with him. The reason why we took it in shift is, is because obviously we had other jobs to do,

Robert Yeah yeah

Michelle But we used to just go and eat, eat with him because he wasn't eating. So we'd go and have our packed lunch with him and then eventually he'd say, what are you doing, you lot? So, well, we, you know, eating's a social thing,

Robert. Yeah

Michelle. So and then eventually he did start to eat up a little bit, yeah.

Robert Wow Well, I can imagine that would may lifted his spirits.

Michelle Yeah, yeah, cos like what we used to just kind of go and I have a brew with him and have a chat to him and. Yeah, and then eventually he did start to eat and drink a bit more than.

Robert And what was it like, um, Seeing friends and family come in and have to deal with the um the trauma of seeing their loved ones passing away in front of them. How, how did you cope with that?

Michelle I think that's always really, really hard when you're around somebody's grief like that. Um, I also think it's a huge privilege to support somebody to kind of leave this world as well, and, and be trusted to care for their loved ones as well. Um, I think at the time, you know, we went to so many funerals, it just It became too much, um, and I remember, I think it was probably at least every other week we were attending a funeral and, and as, as this team, we felt that was really important that we would want to go, um, and sometimes there was just us there cause families didn't show up.

Robert Yeah.

Michelle. Um, but then it did get too much because we were just like, this is, you know, it felt like every, every day off we was it was at a funeral

Robert Were there any funerals that you went to that were just like out of this world, you just thought, oh wow, this, what a way to go?

Michelle Yeah, there was a few that were like, you know, the invites was like, do not wear black. I like wear colour. Um, and yeah, they were the ones that I think, you know what, this is how I want to go out, this is

Robert. Yeah

Michelle How I want to be celebrated.

Robert. People who had a colorful life, therefore they're gonna have a colourful funeral

Michelle. Absolutely

Robert. And make a real marker.

Michelle. Yeah. Yeah, they were probably the ones that we thought, yeah, and, and probably the reason why I didn't mention it then is because it didn't feel like a funeral.

Robert. Yeah

Michelle. It didn't feel sad. It felt like a celebration, it felt like yeah

Robert. Did you ever feel um working on the infectious diseases unit, um, even though we now know that HIV is a virus, not an infectious disease, um that. There was something was happening within the um LGBT community in terms of not just not just putting up with the way that people were being treated or the stigma. Did you ever get a feeling that there was something going on?

Michelle. Definitely there was lots of I think that's what kind of attracted me to specialize in HIV care, if I'm honest with you. That kind of activism, that kind of, you know, um. This is, we're a community, we're standing together, we're not gonna accept poor care, we're not gonna accept no treatment. It felt quite um an edgy place to be as well,

Robert. |Yeah

Michelle You know, like, yeah, this is, these are my people, this is where I want to be Yeah

Robert Um, would you ever have considered yourself, um, to be a HIV activist with some of the work that you've done?

Michelle I, I think, I think so, yeah, definitely. Because like, looking, looking back now, I think I mentioned at the start, my other career choice was law, wasn't it?

Robert Yeah yeah

Michelle I always, I don't like injustice, and I think, you know, I think nurses inherently are activists in their own way. Um, and I think, yeah, definitely some of the work we've done has, has helped, kind of say, the care needs to be better and it needs to be different yeah

Robert And that first example you gave of when he met that young man um who was HIV positive, um, and in those days he would have been told, you know, you have AIDS and you're gonna die. You went to the library and try to find out as much information as you possibly can. Do you think that was the trigger to start in terms of you're not dealing with injustice within the health system?

Michelle Yeah, definitely, I guess for me that was initially it started out probably quite fear based oh God, what for done, and then in that moment I thought, actually, no, I, you know, I don't want people. To feel like that. They deserve people to know what they're dealing with. If they come into hospital, then they have the right for the person treating them to know what this this is about. So yeah, I think it was my, my first thing that I actually know people need to be treated with humanity, dignity and respect, and part of that is knowledge.

Robert. What was it like, um, being in that environment when the first lots of drugs started?

Michelle. Yeah, I mean, drug rounds at the time were just horrendous if I'm honest with you. It felt like we'd, we'd say to people, you know, have you had your, like, I think it was like. A kind of apple or pineapple juice, have you had your pineapple juice? Have we got the drugs out of the fridge? And sometimes it felt like I'd be saying, Robert, have, have you stood on your head today? Take your tablets stood on your head or, yeah, and then some of the unbearable side effects as well.

Robert. Yeah

Michelle. because I, as I mentioned, I'd come into HIV care to care for dying people. So I'd done lots of extra study around symptom management. But actually the symptom management was around side effects management and supporting people. To take drugs that made them feel really sick, that gave them crippling diarrhoea. So in one hand, I was handing them literally a pot of a pot of pills. Sometimes watching people swallow those with, um, like really bad, um, kind of like Candida

Robert Thrush

Michelle thrush and stuff was, was hard. Um, but yeah, but then also on, on the opposite side, you'd go into a room and somebody would have like, um, Age-related dementia, they'd be really like, you wouldn't, you would think right next stop for you love is a nursing home,

Robert. Yeah

Michelle. And we'd have conversations about that. Give them treatment, and they'd be like dancing down the ward like a couple of months later

Robert. Yeah

Michelle. This kind of Lazarus effects and you know, if you, if you're reading about that you think surely not, I would be exactly the same that I've not seen it with my own eyes, this kind of people literally going from nursing home to disco in.

Robert Laughing

Michelle  Couple of months it was, yeah, amazing to see.

Robert.  Do you think that there's some link in your experience between those people that were disowned and isolated and had given up the will to live as against those that were surrounded by people who supported them and. Do you think they responded better to the early medication than those that were left on their own?

Michelle  Yeah, 100%. I, and I feel that's where, you know, like places like George House Trust came in massively. When families left or left people or disowned them, they got this, the pseudo family from. You know, doctors, nurses, George House Trust, they try to provide that wraparound service, and I always know that people, from my own experience, when they're diagnosed and connected, even now, they do better with that support. It's just more powerful, really powerful, yea definitely

Robert.  So we went through AZT and Septrine , etc. and Vallacyclovir remember was given straight away because of the the conceived link between HIV and the the herpes virus. Then when the protease inhibitors came in and you talked a bit about side effects then as well, um, what was it like? For the individuals having started this treatment, did everybody think, oh this is gonna fix me and I'm gonna be fine?

Michelle.  Yeah, I, I, I think so. So I went to um. I think it was the launch of Saquinavir, and it was at on Granada, and we were, I was there and I was like, oh my God, this is like the, the drug. I mean, we don't give it now, do we?

Robert No no

Michelle  So. But at the time, it was like, um, drink this battery acid and it, you know, there was a lot of hope built into medicines and, you know, at the time it was the best available and and they paved the way and I think people. I did think that this was gonna be OK, but then it was that trade-off between side effects

Robert. Yeah.

Michelle  as well.

Robert  I mean it was difficult, wasn't it? I mean, you, it wasn't unknown to be on 32 tablets a day when you were you starting those early treatments.

Michelle Absolutely

Robert.  And you're there trying to encourage somebody to take them. What's that like as a, as a care provider, as a nurse?

Michelle. It is, yeah. I mean, I remember kind of helping people with their pillboxes and just literally constantly dishing out tablets and like you say, a handful of tablets, thinking about, um, when people aren't eating as well.

Robert. Yeah

Michelle. And they've got to swallow these tablets that are quite toxic. And there is that empathy to think, do you know what, I don't, I don't blame you for not wanting to take these

Robert Yeah.

Michelle.  Because I don't want to take them. You know, I remember one lady um lifting her dough set box out. And I was just like, oh my God, this is like overwhelming, absolutely overwhelming. So it is tough to try and encourage people to, to take medicines, especially if they are battling side effects or actually have lost the will to live as well. So some people did make active choices not to take treatment. And for me that was something that really sparked my career and maybe some of the work that I've done cos I couldn't, I couldn't understand it, especially. When I'd watched people kind of fight for treatment and died when they didn't have access

Robert Yeah.

Michelle  To treatment and then for somebody to choose not to really kind of mess with my head for a while, um, so I kind of did a lot of work around how best to support them with the choices that they're making.

Robert  It's difficult to imagine now, isn't it, in 2024, but back then in the early 90s, that people were being encouraged to take medication as a named patient because these drugs weren't licensed at the time, were they? Um and yet now when we look at how far we've come, it's amazing, isn't it?

Michelle. 100% I mean, yeah, absolutely. So I always think like, we, we could be in sat like this in the consultation room having a chat and I'm they're saying to you, oh, what you like with, you know, have you ever taken tablets? You know, for some people, these were young people who may never as much as swallowed a paracetamol, you know, and actually swallowing tablets is a thing, you know, it's a skill, isn't it? You know, what you like at

Robert. Yeah

Michelle. Swallowing tablets and then pull out a horse pill I was just like, could you, could you try that? Um, and I remember people saying to me, oh, not very good with tablets. Do you have any injections? And they're like,

Robert No

Michelle No, no. And they used to say, maybe one day with that faint, not in my lifetime thing in my, in my mind. To now thinking about we've got injections, we may have an injection coming in for twice a year and it feels sci-fiy to me,

Robert Yeah

Michelle You know, from back like you say to those 30, 30 pills in your hand yeah.

Robert So I want to get into some of the specific HIV um work that you did, cos, um, can you tell me what um lipodystrophy and lipoatrophy is and how you got involved in working with patients at North Manchester?

Michelle. Yeah, of course. So when I joined North Manchester as a specialist nurse, we, we had a research trial. So one of the side effects to the antiretroviral older antiretroviral. Um, therapy was like facial wasting where the um, the tissue in your face would kind of go, um, and that for some people were quite stigmatizing and a sign that they, they felt that the world could see that they were living with HIV erm and one of the treatments was something called New Fill where we basically filled in the parts of the cheek, um, to help with that. And I remember I was the adhearance's nurse at the time and my colleague.

Robert. Can you just say what an adherence nurse is?

Michelle Oh yeah sorry, yeah, so adherence nurse at the time was basically what you were saying, Robert, around supporting people to take really complicated treatment regimes, so encouraging people to take tablets when they didn't really want to take tablets, finding out ways to help motivate them to take treatment, and also looking at different side effects and different combinations that may be helpful, um, to them. Essentially, it was a lot of psychosocial support rather than 95% of the time, it was never about the tablets. It was always about something else that was stopping people to take treatment. So I remember I was in the office and that's what I was doing, um, and one of the, the research nurses came in and said she was leaving, but she had this new fill clinic, and would I consider doing that? I was like, oh, what, what does that involve? So she said, injecting facial filler and I was like into people's faces, you know, obviously the clue is in the

Robert Yeah

Michelle. title in it. So she was like, yeah, um, do you want do you want to come and watch? And I was like,

Robert Well, at that time that was one of the, that was quite. Revolutionary, wasn't it? There was only a small cohort of patients who received the treatment at the time.

Michelle  Yeah definitely, there was London that was the big treatment and we had a clinic at North Manchester and I think regionally, I think we were the, the largest, I think there was some private, but there wasn't anything. NHS wise. So it was a clinic that we were all very keen not to go because somebody, you know, needed to step up and do that. And I remember thinking, oh, I don't want it to go. I see the benefits in it, but I was like lowkey, really nervous if I am honest with you because I thought, this is a big thing. This is the girl that doesn't really wear makeup. I was supposed to be injecting people's faces, but I just saw the, the transformationary difference in people. So people would come in, really concerned about the way the face looks, you know, that kind of sinking and hollowness in people's faces and, you know, people would be coming in, hiding themselves in the polo neck jumper, or, you know, they'd say that they'd, um, not been out because they were scared people would be able to identify themselves.

Robert  Ermm

Michelle  Then as a result of the, the way they looked, and then they would, would do the treatment or this clinic I watch you do the treatment and you could literally see their entire soul light up when they looked in the mirror and you know, then they'd they'd go out and it was really kind of transformational for people. I remember one lady in particular who was really depressed, she would come in with a like polo neck when we first started, you know, treatment. She was saying she'd not had her hair done in years, she, why bother, look at my face, look at me, look at the state of me. So over a period of time with the treatment, she went from feeling like that to having a makeover in Chanel, and

Robert  Wow

Michelle  She was just, she was, I was just like, well, are you, what have you done with her? So, so although it's a, a physical treatment, psychologically has a huge benefit.

Robert.  And I suppose that would help people stay in employment,

Michelle Absolutely

Robert  Lead happy lives, um, feel good about themselves.

Michelle  Absolute massive impact on mental health and also in, in kind of relationships as well, connections with others and they're feeling good about themselves and wanting to go to work, and also just connecting with friends as well, you know, wanting to, to be visible outside of kind of their home as well.

Robert You talked about, you've talked about two women in this um discussion that we've had. From your experience, what's it been like for women who are living with HIV going through um the treatment?

Michelle  I, I think for women, um, it's a different story, isn't it? Um, there is often different layers of complexity

Robert  Um

Michelle. for women being diagnosed with HIV. So I've supported a huge number of women, and I feel like. Because their voices are often silent, they're often not included, and obviously that's changing now in 2024. But back in, back in the day, they weren't included in research trials. So all the data we had of how drugs would work were in men. So when we were starting women on treatment, we were kind of watching and waiting to see what would happen for them, how this would affect their facil fertility, and also, Some desires of women to have children. I remember one woman saying to me, you know, I'd always dreamed of having a child, but that's not gonna be possible for me. Um, and we kind of unpacked that and they're concerned about, well, will I be alive long enough to, to look after my child and You know, concerns about um vertical transmission, lots of other worries about kind of what it's like living as a woman and then obviously aging as a woman as well, and what does that mean alongside living with HIV. As well. And gender-based violence as a result of the diagnosis, which has been mass like, really harrowing stories of the violence women have been exposed to and their status has been revealed as well, and some of the, um, ways in which people feel they have to live in order to protect their kind of diagnosis from from getting out as well.

Robert I mean there's still some elements of that now, isn't there in 2024, particularly for,

Michelle  yeah unfortunately yeah

Robert.  So with the um specialism that you worked on at North Manchester and obviously you were still um not just doing that clinic every day, you were doing other work as well. That part of your career, what did you decide, you went on to, to start doing more studying.

Michelle Yeah, so, um, we'd, we'd done, so North Manchester is a really big, um, HIV centre with over 2000 patients at the time. And part of that, there was a national HIV nurses Association, and I got invited to speak at this conference. Now I am a really proud Northern Robert

Robert Yeah you are.

Michelle  Totally Proud

Robert  Quite right too

Michelle.  100 percent and I was at this conference and there were nurses standing up, sharing best practice, and I was sat there thinking, we do that in the north. We do that in the north. Um, so every time I kind of became like a little bit of an echo. Like we do that and I was just so proud, so I ended up, um. Joining the HIV National HIV Nurses Association, but also I wanted to learn how to do research properly. So it became, um, it became really important to me to think about this quality of life of people living with HIV. At the time there was advances in medicine

Robert  Hmmm

Michelle. and we've just talked about stigma, but actually those advances were very slow if existent, because all the focus tended to go in to getting back lotions and potions and pills.

Robert. Yeah

Michelle.  But I was really concerned about the psychosocial

Robert  Hmmm

Michelle.  Aspects of of life. But I wanted to learn how to do research properly. So I did go back to university to do a PhD to be able to

Robert  You, you did a PhD.

Michelle I did.

Robert.  So you're now Doctor Michelle?

Michelle.  I am yes.

Robert  Fantastic, congratulations.

Michelle Thank you.

Robert  That's no mean feat, Michelle.

Michelle I know exactly

Robert. and working full time and

Michelle  Absolutely and yeah, yeah, and then I became the chair of the National HIV Nurses Association as well.

Robert. So that first group that you went to, that you,

Michelle. Yeah

Robert.  That first meeting you then became the chair that organization

Michell.  Yeah

Robert  Wow.

Michell Yeah, and all because I couldn't bear that the North wasn't represented. I just kept saying at every meeting, we do that in the north, and I kept thinking somebody's gotta do that.

Robert.  Wow.

Michelle Yeah

Robert  Um, so what was your PhD about?

Michelle.  So my PhD looked at how we provide psychological support for people living with HIV. So how nurses can connect with people to create um better outcomes for people and provide that psychological support.

Robert.  And are there any golden nuggets from your um study that you would if you were meeting a newly qualified nurse today that you would share with them?

Michelle  I think the main thing I've learned is, I know it sounds really corny when I say this, but put the person first. I know in healthcare, we have an agenda, that's, you know, why we're there. We, there's certain things that we need to know, but actually, always start with what the person wants to know first, and then building your stuff around that, cause you get to a different place and often to a, to a better place because it's about the person and not our agenda.

Robert. Um, so did, so after you did your, your PhD, what did you do then once you'd, you'd become, you got your doctorate?

Michelle.  So did lots of different things, worked in academia for a while.

Robert. What was that like working in academia?

Michelle. That was good. I did like it. It was about shaping um kind of the next generation of nurses, making sure HIV care was interweaved in with. In a very generic curriculum. So again,

Robert. Ermmm

Michelle  thinking about when we talked about my nursing career, and there wasn't much HIV on there. So trying to make sure that there were examples of people living with HIV, but also updating people of where we are today. So I enjoyed that, but I did love HIV nursing, so I

Robert.  So did you miss the hands on?

Michelle.  I'm totally, I love chatting to people. I love supporting people, so I decided to come. Back.

Robert.  So you left academia and you came back into the NHS.

Michelle  I did yeah.

Robert. and what role did you take on when you came back?

Michelle A specialist nurse in HIV care.

Robert. Wow. And in this role are you able to implement not just things from your experience but from your, from your studying, from your academia and your experience?

Michelle. Yeah, definitely, I I feel like. I had the time of my life when I worked in North Manchester at 20 years and it was amazing. I had that break and I've come back, but I feel like I've come back differently.

Robert. So you work in a sexual health clinic

Michelle sexual health clinic um the north and the central Manchester, which is again slightly different, um, as well, but I feel like I've come back different with a lot more experience and a lot more. Able to put some of the theory, some of the research that I've developed over the years into practice more practically, and also some of the skills that I gained. We're just looking at our aging cohorts now and thinking about actually how do we shape care moving forward, um, for people. Also still links with the National HIV Nurses Association. We've just developed a model of care, HIV nursing, person centred model of care.

Robert. Wow.

Michelle So that'll help shape the. Nurses coming forward, developed lots of, um, at the time there was no, um, national training for nurses working in HIV care. So you would qualify as a nurse and then it'd be like experience, um, and kind of in-house training. So part of my role was to develop some, um, national accredited training to make sure that nurses was a standard of education to provide care, um, for people living with HIV. So that's embedded within the model of care as well.

Robert. And do you ever bump into any of your previous patients that you used to treat at North Manchester?

Michelle. Occasionally, yeah, and I love it. I love it. Um, and again, I'm always like, little, little wave and yeah, but it's, and it is really nice. I, um. To think about the journey that we've walked alongside, so I was thinking about a mum that I saw, so I used to do the family clinic at North Manchester. And I, I saw Mom here. I was like, oh, you know, I gave her a big hug and we're talking what, well, her son's like 25 now.

Robert. Wow.

Michelle. Um, and I was like, gosh, I remember looking after him when he was like 5

Robert. Yeah.

Michelle. and I hold him in my mind, he's like this, but now he's a grown man

Robert. Mmmmm

Michelle. with children, and you just think, gosh, yeah, what a, it's just such a privilege to see that.

Robert.  Wow. And what's it like, particularly for women now who are diagnosed HIV positive in terms of treatment and care.

MIchelle. So in terms of treatment, um, treatment is really good. So, um, with effective treatment, the U equals U message applies. So if you're undetectable in treatment, you can't pass the infection on. Um, also, um, what we're seeing a lot of now is back in the day, I think you remember me talking about women feeling unable to have children

Robert. Yes

Michelle  because of life expectancy. It's nice now that we're seeing life expectancy is good, um, so we're seeing women have, um, Multiple pregnancies, um, which is great, unfortunately

Robert. And no transmissions

Michelle.  No transmission no transmission and um also, I think we're seeing women so at the time we used to see women who were newly diagnosed in pregnancy. But now we're seeing women kind of going on to to pregnancies, you know,

Robert Planned pregnancy

Michelle. and to planned pregnancy, that's it. Um, I think there is still a lot of late diagnosis for women,

Robert. um

Michelle. and that worries me because I think they're they're kind of sicker when they come to us. There is still a lot of stigma that we're trying. To work on. I'm currently working on a project, um, trying to seek funding to look at the untold stories of women.

Robert. Yeah

Michelle  Um, I'm gonna call it her story, rewriting

Robert.  Fabulous

Michelle.  rewriting the history of women living with HIV because I think it's really powerful that that voice is kind of out there.

Robert. I mean, as a volunteer at George House Trust as a peer mentor, I've received training in terms of HIV and the menopause,

Michelle.  Yeah

Robert.  and that seems like a big untold story, and I think there's a lot of research still needs to to go into how women can be supported. Do you experience that in your day to day work?

Michelle.  Absolutely. I I feel like as a woman aging as well. Who's heading into that chapter in my life

Robert. Never.

Michelle thank you, love you. Um, I think it's the worst secret we've ever kept. I think it's the worst, you know, everybody will pass through it, people have different experiences. But I think there is still a lot of work to do, um, in the general public, um, but also in, in HIV as well. And also there is that, um, cultural aspect as well of people not wanting to identify that they're going through the. menopause

Robert. Yeah.

Michelle. or perimenopausal because of the stigma that would come with that. And also some societal perception of that women are only good for in the childbearing years.

Robert.  Yeah

Michelle.  So I think there is a lot of work, sorry, a lot of work and research that needs to to go into that still.

Robert.  I can imagine you as an individual would um challenge and take on.

Michelle. Yeah

Robert.  Anyone who has any um misconceptions about anyone with HIV or particularly women, um, if you, if someone was listening to this um was interested in volunteering. With people with HIV, what would you say to them?

Michelle.  I would say do it, absolutely do it. Go to your nearest HIV charity and um ask how you can be of service, cos it's one of the best things I've done with my life. Um, I can't believe the amount of joy that it, that comes with supporting people. Um, and I think it's, it's just I can't begin to put into words the area, it's. Yeah, it's fun, it's exciting, it's rewarding, it's challenging, but actually the joy is, is. Amazing.

Robert.  And that privilege that you get.

Michelle  Exactly, and being part of somebody's story, walking alongside people and making a change that really makes, makes a difference for people. I think because I've worked in HIV care for such a long time, I, I'm sometimes. Forget just how stigmatizing the condition can be for people, um. But yeah, its.

Robert. We first met was it about nearly must be about 30 years ago. Looking ahead, what do you think the next 30 years would look like for someone who um is either receiving treatment or do you think HIV will still be around? Will it be on the agenda?

Michelle.  Yeah, so we've got some really big global targets, haven't we? So, um, to end HIV transmission in 20 by 2030 onwards transmission. Now, as I keep saying, this is on my watch.

Robert.  Yeah

Michelle. Yeah  so I've got another six years to think about what I can do to try and move towards that. I'd like to believe we get to that point. I really, really do. But we still have people living with HIV even if we reach that global goal. So I think care would probably look very different as a healthcare service as we move forward. I'd like to think we fast forward into a sci-fi era where it's an injection if people want. or a tablet that isn't massive once a year, blood tests are done quicker and easier, but I'm hoping that society is different in the next, I just can't wait 30 years for societies to be different, maybe in the next 5 years.

Robert.  What do you think we can do to bring about that change?

Michelle. I think it's making HIV visible, promoting the U equals U message, challenging those mis misperceptions. I think sometimes I know I'm guilty of speaking in an echo chamber. So I think you, you mentioned we met each other about 30 years ago.

Robert. Yeah

Michelle. So over those 30 years, I've weeded out the people in my life that don't share my values. So

Robert. yes, I can relate to that.

Michelle.  Yeah, so I'm kind of surrounded by wonderful people. So actually I sometimes speak in an echo chamber about how HIV is now and the undetectable information, so it's kind of, I need to start spreading. The words of people who wouldn't know or don't know, so maybe the next generation of nurses, medics, you know, um, teenagers, we just need to kind of think it'll be a generational shift. As well.

Robert. So just coming back to here and now, cos you're in this role within um MFT do you um. Ever work with people in the the general um STI setting who may just come along for um STI tests and you would talk to them about PREP or PEP.

Michelle  Yeah, so we do some outreach clinics as well, so we've we've done one we just um coming out of the back of World Aids day, so we do outreach clinics, and it really surprised me, so we had a few um. Heterosexuals, but also a few young gay men who came in before um we call them peace of mind screenings, and one of the questions we ask is, do you know about prep, do you know about PEP? And they didn't know about that. So we spent some time explaining that in a way that was empowering and supportive rather than kind of a fear-based approach, um, and to support people to make health choices around their sex life that they can enjoy

Robert. Yeah

Michelle.  their sex life, rather than it being a, a fear-based approach like the old ad campaigns that we've had.

Robert.  So just before we finish, are you involved in any other initiatives or projects that we've not talked about today?

Michelle. So I was part of the, the, I was a clinical and academic on the Our Stories told by Us project, um, which celebrates, um, the African contribution to HIV pandemic,

Robert. Huhu

Michelle Erm 00, I, I forgot that I have a podcast.

Robert.  You have a podcast. Tell us about your podcast.

Michelle  Yeah, so I have a podcast called HIV Matters where we're in the 5th series, now we're just going into our 5th series, where we talk to different people, either living with HIV, working in the area, just to think about quality of life and how we can improve the quality of life. Um, we've reached over 6000 listeners.

Robert. Wow

Michelle  Yeah, and, um, the podcast continues to grow.

Robert  Fantastic.

Michelle And also, I'm a patron of a charity in Sierra Leone. So the patron in Sierra Leone for HIV care in 2024 isn't particularly that great. So, the charity or um the NGO is trying to get access to testing and treating and a sustainable. supply of antiretroviral therapy, uh, in a political context

Robert. Ummm

Michelle.  of a country that's been decimated by Ebola, civil war, and COVID. So it's a really challenging environment to work, but also. A place of where we're hoping to do some good work.

Robert.  And how do you um switch off when you've clicked the computer off and you're ready to go home? How do you chill out?

Michelle. So I've got a really bad yoga addiction, so. So, yeah, I still like to dance. I dance a lot. Um, and I do a lot of yoga, but I'm fortunate I've got really good friends who work in this area as well, so I touch base with them as well if I need some support. And I think over the years, what I've learned, Robert, is younger me didn't know about self-care, didn't know about, it's OK. Not to be OK if that makes sense

Robert. Yeah

Michelle.  I have a better threshold now of seeking support when I'm not OK. I don't see that as a weakness. um I see that as a as a as a positive really.

Robert. Michelle, I just want to thank you on behalf of um George House Trust and the, probably thousands of people that you've met, whether it be in a clinical setting, um, or in your other work, just to acknowledge what an amazing, amazing woman you are and the impact you've had on people's lives, and thank you for sharing your story with us. Thank you so much for asking me, it's been an absolute honour and privilege, thank you.