

Notes from Skyline Co-Production Session, 24/10/2022

This was a recorded conversation in which Andi and Mike, two members of Leeds Skyline HIV support service, discussed their experiences of intimate healthcare and responded to some of the objects selected for the Private Parts exhibition. Part of this document is the live notes taken during the conversation, but the more relevant parts have been listened back to and Mike and Andi's contributions have been transcribed in full (the interjections from staff members have been minimised).

Present:

Andi (them/them), Skyline

Mike (he/him), Skyline

Ross Horsley, Volunteer Coordinator, Thackray Museum

Mary Stones, freelance curator working one day a week on the Private Parts exhibition

Amelia Silver, Curating for Change Curatorial Fellow, Thackray Museum

Natascha Allen-Smith, Collections Access Assistant, Thackray Museum

Sex education at school (original session notes)

Andi: Mine's very quick. [Laughs.] Nothing.... There was nothing about what sex was, but there was a little bit about condoms, but that was in a mixed class, and that was, what, ten minutes? ... It was delivered by someone from the sexual health clinic... we were 15 or 16 at this point, so we'd had a bit in Biology, but more rabbits.... There was nothing about sex, there was nothing about pleasure... It was all about heterosexual sex. It was definitely not about STIs, it was about pregnancy.

Mike: Ours was segregated, guys and gals. All the boys went into the main hall one morning... and there was a projector screen there; they gave us a talk about love, and then they showed us a film about rabbits. [Check wording.] It was maybe something to do with the headmaster being a Baptist leader... even though the school wasn't religious, or wasn't supposed to be. You basically found out for yourself.

Andi: I guess we were on the tail end – my grandparents would have been brought up by the Victorians.

Andi: My parents didn't talk about anything – they didn't tell us about sex.

General intimate examinations and the stigma around HIV (checked against the recording)

Andi: I remember the first time I went to – not Sunny Bank Mills, Sunny Bank - what was it called? The STI... where Sexual Health used to be at the edge of the LGI? ... I remember the first time I went, they were very gruffity with you when you went to make an appointment that you should be ashamed that you're there. It was all that kind of attitude towards you, and everybody would sit there staring at the floor, and it was all really uncomfortable. It was all separated, men's and women's.

Mike: It was horrible.

Andi: You know, you ignore it for ages, and you thought 'I need to go and see somebody', and it is mortifying! ... You need to get it sorted, so you have to just brace yourself and get on with it. And then things have changed massively – you know, I think there was – probably around some of the HIV and AIDS stuff kind of changed the way that medical care was given, and people realising that, you know, STIs and sort of safe sex and stuff was a big thing, wasn't it, within the whole HIV story, so they realised they need to change their attitude in how they were dealing with, you know, having sex and getting an STI isn't a bad thing; it's just pros and cons, innit.

Mike: [The new location on the top floor of the Merrion Centre] is welcoming to walk in. There's isn't much else up there.

Mary: Do you think attitude is the main thing that's changed now, not so much the design of the building?

Mike: Definitely.

Andi: They had to change it, didn't they?

Mike: They did have to change it. Plus you used to feel ashamed walking to the old building, 'cause everyone knew that that's what was in that building, so you'd be looking round before you ran for the door [(mimes being furtive)].

Andi: I think there's definitely some of that trickle-down, isn't there, from people receiving better sex education and more kind of conversations about sex and those kind of things.... It improves how people now respond... it's just kind of normalising it rather than being this kind of behind closed doors thing.

Andi: Originally, in the sexual health clinic, all the HIV care was integrated within it, wasn't it? And then in – I can't remember when it was – 2016, 2015-ish? – they separated when they moved to the Merrion Centre, and HIV care is now done at the Brotherton Wing of the LGI. And people at the Brotherton were horrified that they were going to separate it, 'cause they'd rather, if one of their neighbours saw them, that they [thought they had] gonorrhoea rather than HIV.... So, yeah, people found it really hard to deal with when they first separated it so it was a standalone clinic on its own – when it was in Sexual Health, they didn't care that their neighbours thought they were there for something else.

Mary: Do you feel that attitudes and stigma etc surrounding HIV and AIDS has changed now as well?

Andi: It's still really bad... it's not changed, unfortunately. Andrew was saying – one of the guys who came [to a Skyline session] the other week, he's based in York... A nurse in York Hospital – this was like two or three weeks ago – had written on the door that this patient was HIV positive... on the outside of the door, where people were passing.... So yeah, things have changed in terms of treatment, massively, and they're still progressing, and there's lots of advancements in that. But then you come across that in a hospital!

Andi: And we had a case with one of our clients – it was a custody case with one of her children... but the social worker was citing a transmission risk to the child because she was incontinent of urine, so [the social worker was claiming] she could catch it from her urine. And this was evidence she'd put in a court case. There's all these areas of people where you think "You're educated... you should know a bit more!" But they clearly don't....

Andi: On my medical records when I was getting treatment in Middlesbrough, it had 'Infected' stamped in red – a bold red stamp on every page, just in case one would fall out and they didn't

realise [laughs]! And that was only five years ago. And even now when we give blood it says 'Infected', doesn't it, even though you're undetectable and you can't pass it on.... Hence why I'm saying the stigma is still very real.

Andi: Even last year, there was a guy, and he needed some surgery, and the surgeon was asking him how he'd got infected and asking him all these really really inappropriate questions.

Mary: There was a time where the media was very much fanning the flames of stigma around HIV.

Andi: It still does.... They still use that very inflammatory language around HIV-positive people, which kind of keeps it in that 'There's something you should be scared of' kind of this. So... they quite often use that very homophobic, prejudicial language.

Mike: And you can't get life insurance if you're HIV positive, even if you're undetectable, still. 'Cause I use to work in mortgages and protection, so they'd keep saying 'Oh, you know, renew your life insurance' – no. I just don't go any further with it. And when I was diagnosed in 2017, I rang them up and said "I've just been diagnosed" 'cause they can't cancel your life insurance if you've already got it – 'cause it was protecting me mortgage. But I rang them and told them and said "Is this covered?" "Only if you've got it through a blood transfusion." So I said "You mean through haemophilia?" They said yeah. So [they're implying that] I went out and caught it on purpose.... All that needs to change.... They wouldn't pay out because I didn't get it through a blood transfusion. As if accusing me that I've gone out and got it on purpose.... [From later in the session:] It's something I am going to look into as to whether I can fight that... It's like saying, "You've got a type of cancer; you've been out and got that yourself; you're not covered for that."

Andi: And not just in, you know, certain cohorts of people – within, you know, educated professionals is often the worst. Dentists... I've got so many stories with clients and their experiences of dentists – dentists putting on extra pairs of gloves when they carry out procedures, full hazmat suits and Wellies, everything... and you're like 'Did you not do HIV in your training?' You know?

Andi: I've had clients where I've had to say "Look, you have to believe the science." You know, he'd told all his – where he worked, he'd told them that if he cut himself he'd put a plaster on so he didn't kind of put them at risk, and I was like "You're undetectable! So you're at no risk to anybody, you know. So you need to start believing the science yourself."

Andi: I was at a conference in London a few months ago and they were talking about the whole U=U thing and whether it's a very... sort of cliquey thing. If you work in HIV services or you're HIV positive you're aware of it, but if you step aside of that and you go to somebody "I'm undetectable" and they go "What? What are you talking about?" ... How do you rephrase that as a new message?

Mike: I think they did a small snippet on the news a few months ago, didn't they – just one little bit about it. And that was it; it was forgotten, never mentioned ever again.

Andi: There's never been a massive [public awareness campaign about it].... Like there was the whole mailout to the entire country with the leaflets in the 90s and 80s, and there's never been a similar one going "Look", you know, so everybody's knowledge is stuck there.

Mike: People are still stuck here with the tombstones.

Andi: If people come in at like Amelia's age [26], they [the makers of information leaflets/posters] still go with the tombstones.

Andi: It [U=U] came about, didn't it, on the back of the partner studies, which were these extensive studies with – they did it with heterosexual couples and then gay couples. One [partner] would be positive and one would be negative, and the positive person would be undetectable, and they measured thousands and thousands and thousands of sex acts, and there was not one case of it being passed on. So that was where the whole... people on treatment can't pass it on and, you know, undetectable thing [came from]. That's, you know, a massive study, so how do you kind of collate that into something more... [widely visible].

Ross: [I was working in sexual health when the U=U literature started coming out, but I've only ever seen it aimed at a gay male audience... I have only ever seen it [with] sort of two men on the cover of a leaflet.

Andi: This year I remember... I think one of my colleagues had been talking to a client and mentioned U=U, and they'd been positive for eleven or twelve years and hadn't heard of it. So... I think sometimes the clinic assumes that message is out to everybody. [But] You know, clinicians come and go, people move around....

Mary: What message would you want to get out?

Andi: Just – I don't know.... Well, it's just that you can't pass it on, isn't it, if you're on treatment, so it's that, you know, risk... Life expectancy of somebody positive is the same as the general population if not slightly higher because of the regular medical checks you go through – you know, you go to the clinic twice a year.

Mike: Most of us tend to take care of ourselves a little bit more – I won't say a *whole* lot more [laughs], but a little bit more.

Andi: But you're having liver and kidney function done twice a year, and other tests as well, so you... have those conversations: "How you're doing?" "Well, I've noticed this..." you know... so our population is now living as long, if not longer, than the rest of the population.

Mike: I would say we're at more of an advantage of picking up other illnesses. That's what happened to me. When I first got me shoulder problem, they gave me steroid injection in me shoulder. It reacted with my meds. [This was] in the mid-October, so I went through all the symptoms, [and] then when I saw me specialist in the January I told her the symptoms – I said "I'm really lethargic, I've no energy whatsoever"... I told her I'd had the injection... I told her I'm having suicidal thoughts, permanent headache, and she said, "I'm just going to do a blood test, and I'll call you when I've got the results." ... It was a temporary version of Addison's disease. Basically, the reaction stopped me adrenal glands from functioning at all, so there was no adrenaline going around my system at all. But the thing is, I'd been having these symptoms and telling the nurses when I was admitted to hospital in the November for an internal bleed. And the other symptom was rapid weight loss – I lost a stone in hospital in a week... I think they thought it was the food! [Laughs]... I was begging them for paracetamol every four hours for headaches, and I was suffering insomnia – I was up at four in the morning walking round the ward. But it wasn't until I saw my specialist in the clinic in the January, and she picked up on it straight away and prescribed me steroids straight away.... I think that's probably an advantage where we get seen every six months, 'cause you can discuss what problems you have and they can make the right referrals for you.

Testicular prostheses and testicular cancer (checked against the recording)

Mike: They only do one size as well.

Mike: [About the silicone one]: That's the one I've got.... I wasn't given a choice. They just said, "This is what we can put in." I had all the questions when I had the operation – you know, "How're you going to get it?" I thought they were going to slit the scrotum, but no. No, it's all done like a – a scar, you know, like an appendix scar? ... They obviously had to extract the tumour, which was me right testicle from me testicle, which was then that size – just a bit smaller than a tennis ball. There was no testicle left; it was one huge tumour. And then they had to take away the pipes that go to it, etc, tie them all off and then put the new one in.... Yeah, it was all done in one go – I think I was down in the theatre about two and a half hours. Just a bit sore afterwards.

I first went to the doctors in the June, with just what felt like a swollen testicle. Just pain – there was no lumps or anything, it just felt slightly swollen and painful. He had a quick examine, which is embarrassing enough, you know, when you, you know, drop your pants every time for't doctors – and he said "Oh, it's a water infection; here's two weeks' worth o'tablets for a water infection." Took those; nothing – left it a month, went back, so that'll have been the end of July I went back, and said "Look, the testicle's a bit bigger now; those tablets haven't worked". "Oh, well I still think it's a water infection; here's three weeks of [unintelligible – flyer?] tablets." So three weeks religiously taking these tablets for a water infection; this time the testicle's still getting bigger, and then I left it till the... it was the middle of October, 'cause I thought "Maybe the tablets are taking time to work; maybe it's me." By the middle of October, I went, and that was when me testicle was like that size [mimes an orange] and it felt like I'd been permanently kicked in them, so that sick feeling in your stomach and down there, and I said, "Look, this is not a water infection." I wanted to say to him, "If you give any more of those tablets, I'm gonna ram them where the sun doesn't shine!", but I didn't. So he said, "I still don't think it's anything serious, but I'll make you an appointment to see – for an ultrasound." So I thought, "It's gonna be weeks, that." That was on the... Thursday, they rang me on the Friday, me ultrasound was on the Monday, I was back at the doctor's on the Thursday – he said, "I still don't think it's anything serious, but I'll make you an appointment at St James's to see someone in Oncology." I didn't have a clue what Oncology meant then. So I thought, "Oh, it's gonna be a few weeks" – they they rang me on the Saturday and said "Can you come in Monday morning at 10 o'clock?" So I was at St James's at 10 o'clock on the Monday morning, I saw the specialist, and the first thing he said to me was "I take it your doctor's told you what's wrong?" I said, "No, the doctor said it's nothing serious." He said, "Nothing serious?! You've got no right testicle left. It's one big tumour." He said, "Have you driven here today?" I said yes. He said, "Take your car home, pack a bag, catch a taxi back; we're admitting you today and operating on you in the morning." ... Because it'd been going on for like, four, five months.

Mary: God, that's a lot to take in in one go.

Mike: Yeah. My parents were on holiday, so I couldn't phone them, and I lived on me own in a flat in Garforth, so I just literally packed a bag, caught a taxi back, into the hospital... so they operated on the Tuesday [and] I was discharged on the Wednesday evening and rang me aunty and uncle and said, "Look... can you come and pick me up and take me back to me flat" ... And then, because it had happened [for] so long, they wanted to do treatment for the lymph node here, just above – the first lymph node above – because they thought it might have spread. So between the operation in November and starting radiotherapy on the day before Christmas Eve, I had to go the Infirmary to, er, 'wank on demand' to store sperm because of the radiotherapy, even though I said "I'm gay, I've no plans for anything" - they said, "You might change your mind on planning to have children." So I had to do two sessions of that, which was *the worst experience of my whole life*. Down a really quiet corridor, in a room, with just a straight sex magazine, and you could hear everyone walking past and

conversations [laughs], and I had to perform! So that was two sessions of that, and then of course I had radiotherapy for two weeks every day over Christmas and New Year at Cookridge Hospital.... And now I'm still going [(seemingly meaning alive rather than still having radiotherapy)]. I mean, they were fantastic.

Mike: I deal with every trauma in my life with humour. That's how I get through it, so that's how I dealt with all that. And then after the radiotherapy... 'cause of course I worked straight after the operation and I worked right through my radiotherapy, and then I had to take two weeks off after me radiotherapy 'cause that's when it hits you. That's when I was literally wiped out, and I was a bar-restaurant manager then, so I just had to take two weeks off and get my system to do all the cellular work and all of that. But yeah... I was classed as clear after six years.... I promote testicular cancer everywhere I go. I speak to people about it, and I say to them, "I've got one real one and one that bounces."

[Possible acquisition if we don't have any: sperm specimen jar/tube? We can accompany it with Mike's whole story, assuming he's happy for us to do that, and the couple of sentences specifically about providing the sperm sample are a great label length. We don't seem to have any, at least none that are labelled as being for sperm/semen – there are two fairly modern single-use specimen jars (80.016 and 2020.0093). Latter is on display in Health Heroes, case 9.2.1 – check label. There's also a disposable specimen bottle with a plastic screw cap (737.917) and some specimen tubes (737.914, 617.001), but these look too narrow to be for sperm sample collection. They more closely resemble 97.001, which contains gall stones.]

Mike: I'm glad I've got that one [the firmer silicone prosthesis], because, er... we're not going to go into that [bursts out laughing].

Andi: I'd go for the other [more flexible saline] one.

Mike: It's too fragile.

Andi: That [the other] one's too hard!

Mike: It feels different when it's in you.

Mary: Is this offered to everyone?

Mike: I had to have a reason... why I wanted one. At the time, I was a keen swimmer; I mean, I used to swim for Leeds in me teens, so I was still a really keen swimmer, so when I went swimming I wore proper Speedos, not shorts, 'cause they cause drag. So they said, "What is your reason for wanting a prosthetic testicle?" I said 'Because when I'm swimming, I swim in Speedos, and I want to look like I've got meat and two veg, not meat and one veg – I want to look normal down below, same as a woman would be if she had prostheses breasts.' So they went, "That's a good enough reason." If I hadn't have asked, I wouldn't have been offered... No, it's not standard. It may be nowadays. But I know of so many – since I had the operation and had testicular cancer, I've met so many people who've had the operation but have just gone one [testicle], 'cause they were never offered.

Amelia: It would have to be a separate operation to go back in and...

Mike: Yeah, and I don't think the NHS would fund that.

Sex and Relationships

Mike: I remember, as soon as I came out when I were 21, they lowered it to 18.

Andi: I remember being 21 and I was seeing someone who was 18, which was illegal. I didn't, but I could have been arrested and put on the sex offenders register.

Andi: [At the time of Section 28], homophobia was allowed; it was respectable.

Sex and Relationships continued (this is from the end of the session, but has been pasted here to unite the theme)

Andi: Everyone gets pleasure from touching themselves down there. I did a project with Yorkshire Sculpture Park last summer... for a project called On Queer Ground, and there was this 78-year-old woman, and she told me that she and her friends used to touch each other when they were young girls. They didn't know what was going on, but they would just sit there giggling, knowing that they were giving/having pleasure – didn't necessarily think anything sexual.

Andi: Keeping it [discussions about sexual activities] hidden didn't serve anybody, did it? This was the approach, you know, and look where it got us! Whereas now, it needs to me – we try and normalise it and talk about it as much as you'd talk about your physical health. It's still one of the most regular conversations I have at work is people sharing [HIV positive] status when they're first diagnosed, or even further down the line with a new partner.

Andi: Yeah, you can then get the ignorant comments.

Mike: And you can get people who then go and broadcast it to everyone.

Andi: There are people who threaten to share someone's status as a controlling abuse thing.

Andi: As gay people or women, people are going to have assumptions about the kind of sex you're going to like, and it's never right.

Remaining objects (notes from original session)

Sounds (2005.0206)

Andi: It's that weird kind of crossover between the medical and the pleasure. There's a club in London called the Torture Garden, which is for people who like medical things.

Andi: People have been sticking things down themselves since time immemorial, haven't they? And different materials have different textures and sensations.

Andi: The same with speculums and those kind of anal dilators, where they've been coopted into that slightly more fetishistic side... Not every gay man is shoving those up their willies, or sticking stainless steel up their areseholes, but...

Lord Anal Dilator (737.1000):

Andi: That's a bit small for a lord! You can get way bigger.

Andi: Medical things have been appropriated, probably by doctors, who've been doing it with their mates or whatever, and then [it's filtered down/word has spread].

Mike: You'll have to do a search: The origin of the butt plug.

Andi: But it's how you talk about that, in't it? You do have medical and pleasure, and then people can clearly see the relationship between the two.

Andi: It's like looking at the law around S&M sex – lots of activities are still classed as illegal. [Operation Spanner is a case in point.]

Andi: We had a session [at Skyline] a few weeks ago about consent. Some of the older guys said 'If you go to a cruiser party (?), that's your consent; anyone can touch you', and it's like 'No!' There's all these differing views about consent.

Sigmoidoscope (100411):

Mike: I think I can work out how that works... That's probably from a film I've seen.

Mike (on seeing the wire): That's electro-stimulation. There's quite a few people who enjoy that internally.

Andi: If you look at some of the chastity devices that were probably – again.... I looked here some years ago at the historic medical catalogues, and a lot of them had anti-masturbation devices, because that was the root of all madness, wanking too much.

Mike: And that's a source of pleasure now.

Andi: There's a 'slave and master' thing where the 'master' decides when the 'slave' can take it off. They're that small that it's painful to get an erection when you're wearing it.

Prostate massager (2007.0088):

Amelia: This looks like a sex toy to me.

Mike: Definitely. There's a lot of toys out there.

Andi: There was a new string of sex shops set up in London [, possibly by Anita Roddick's daughter, which made toys which looked like exquisite decorative items]. You could put them on your mantelpiece.

[Amelia explains how she believes this would have worked.]

Mike: I don't think I'd mind! I find that very sexual.