

Strength, Resilience, And Healthcare

Speakers: Micha Frazer-Carroll (MFC); Effie (E) - SWARM; Bakita Kasadha (BK) - Global Network of Young People Living with HIV; Pippa Grenfell (PG); Ember (E); Dana (D) - Action of Trans Health.

In May 2019 SWARM hosted a three day festival involving panel discussions across a wide range of topics that impact on sex workers, and that connect and intersect with sex worker rights organising and broader struggles for justice.

This recording is from that festival.

00:00:00 MFC Thank you everyone for being here. My name is Micha Frazer-Carroll. I use she/her pronouns, and I am the Opinions Editor of a magazine called *Gal Dem*, which is run by women and non-binary people of colour. But I was also the Welfare and Rights Officer at Cambridge University last year and worked on a project that basically lobbied the university counselling service to create more culturally competent mental health support. So that's sort of my relationship to the topic that we're going to talk about today. So this panel is on strength, resilience and healthcare. So, we're going to talk about ways that we can create more radical and liberated healthcare and what that might look like and how we get there. So, I think if we could go around and say our names, pronouns, and then a bit about what we do. Shall we start with you?

00:00:52 E Hi, I'm Effie, and I'm the representative for SWARM on the panel. I'm also a therapist, very recently qualified/just qualifying now. So, for the past couple of years I have been working in some LGBT counselling services and services dealing with long-term mental health conditions. And I think that's all I need to say.

00:01:25 B Hello everyone, my name is Bakita Kasadha. I am an HIV activist, so I hold different roles both nationally and internationally, including the chair of the

DECRIMINALISED FUTURES

Strength, Resilience, And Healthcare

Global Network of Young People Living with HIV. I'm also a woman living with HIV, so I'm going to be speaking on that experience, both professionally and personally.

00:01:49 PG Thanks. Hi, my name is Pippa Grenfell. I use she/her pronouns. I'm a researcher at the London School of Hygiene and Tropical Medicine. I'm a sociologist; I've spent about the last eleven and a half years doing research together with sex workers looking particularly at how legal, political, social and economic environments shape their health rights and wellbeing.

00:02:14 EM Hey, I'm Ember. They/them pronouns. I'm a trans healthcare activist and healthcare advocate for trans people. And I also have a lot of experience navigating healthcare as a disabled and trans and intersex person. So, fun.

00:02:35 D I'm Dana. I use she/her pronouns. I'm a full-time sex worker and activist. Before I was a sex worker, I was a builder. I don't have a particularly academic background, but I've been working on like, activism and contributing to different campaigns since the bedroom tax rolled around. We're both from a group, grassroots group, called Action of Trans Health, which is currently in a rebuild stage as we've been addressing a few systemic problems with the group, and soon we'll be opening up and yeah, doing some more trans healthcare activism.

00:03:18 MFC So, firstly we're going to start really broad, I think, and talk about... I think we're going to start talking about, just generally what the healthcare landscape looks like for different marginalized people in relation to your experiences and areas of work. So, what does it look like?

00:03:42 E I'm going to start partly because I feel like people are struggling to hear a little bit, so I'm maybe going to suggest we talk properly into the microphone. Is that okay? Are people struggling to hear a bit? Yeah. So the healthcare landscape. In terms of therapy and counselling, it's a bit depressing. Things are not great. The levels of funding, both in the NHS and in the third sector are quite worrying. It does differ from area to area, but what's available is increasingly limited in terms of the type of therapy, the length of therapy, and there's a real problem as well around choosing the practitioner that you work with. It's often not even something that people... you know, it's just not an option at all. So I think that... there is a real need

DECRIMINALISED FUTURES

Strength, Resilience, And Healthcare

to consider what's available and to try and work on that. I do have some ideas. Maybe we'll come to think about what can be done later, but in general the landscape is a bit worrying. And I think in particular for sex workers and the other communities we tend to belong to, because not very many of us experience being a sex worker as being the only axis of oppression that we're on. Many of us have trauma. There's a lot of trauma in the community. And the types of therapies that are available when there's something available within the NHS tend to be brief, tend to be CBT-type interventions that are not always appropriate to trauma. And I think it's important to think about what kind of spaces and services we need to recover and to heal from those things we've experienced. And I think that it's a... it is a problem that more medium- to long-term therapies that are more relational have really shrunk/begun to disappear completely from some areas because... you know, being in a therapeutic relationship where you can, yeah, build up some trust with someone in order to open up and begin those really difficult processes is, is really important, I think.

00:05:58 B So, thinking from a position from HIV, access to treatment and both prevention, HIV is a health condition that disproportionately affects people who are already marginalised, whether income status, gender, sexuality, class; there are so many intersections there. So for, in healthcare broadly, interactions with healthcare systems can be quite traumatic. They can be very difficult, because of, like you're saying, we have so many different overlapping identities; we don't just come into a space with one identity, right? And what I have found, and a lot of the things that myself and my peers campaign against and campaign for, are things around changing the language about what is and isn't accessible, "hard to reach"—and killing the term "hard to reach" is a hill that I'm prepared to die on because it doesn't really hold institutions to account and how they are hard to access. So, I tend to typically refer to healthcare institutions as "hard to access," as with other institutions as well. So I think there's a bit, with the healthcare landscape of, as well as individual and behavioural change, also them looking at their own behavioural change and how they treat patients, whether they're already known to them or they're trying to encourage patients to access their healthcare services. And also, at times, can be quite a paternalistic landscape. So there's the assumption that the professional, the doctor, whoever it is, the medical professional, has the knowledge to educate but can't also receive education. And that there's—my last point—would be that there's a

kind of divide that the person with the lived experience, whatever that might be, doesn't also necessarily have skills as well, but they're just that lived experience. So that's what I find often with the healthcare sector, so it's important to have those patient advocacies, and important to have peer-researcher roles where people with the lived experience are also seen as experts and having a skillset as well.

00:08:10 PG Thanks. Yeah, I would just really echo that in terms of, you know, what we're learning in terms of sex workers' experiences in specialist health services, in terms of... in terms of stigma, in terms of discrimination, in terms of the, that power relationship between providers, between people receiving services, but also between, you know, people like me, academics. You know, we're doing research on these issues and we get so much power and platform to shape health agendas and we have to think really critically about that, and we have to work collaboratively with sex workers. We have to be insisting that the research that we do and the services that we advocate for are in full collaboration with sex workers; that sex workers are leading that agenda. And part of that is looking at what we turn our attention to. So, the massive cuts to services that we're seeing in terms of sex worker support services, in terms of much broader health and support services in a context of massive austerity, in a context of an unabated hostile immigration environment which is affecting the kind of services that people can get. It's affecting the police enforcement that we know is really, really intense, and again, unabated, and that's massively affecting the kind of health services that people can get access to. We did an international review that we published last year of all the studies that had looked at how criminalisation and policing affect sex workers health and access to services, and it's what sex workers have been saying for years, that, you know, criminalisation enforcement harms health, harms safety, harms access to all the kind of services that we're advocating for. So, I think it's this combination of ensuring that we're advocating against these incredibly harmful policies as well as advocating for the services that are needed and recognising that sex workers have been doing that forever, and it's time for academics and practitioners to catch up.

00:10:41 EM So we were talking about, like, what we'd answer this question with, and it pretty much echoes both of your points of this very prescriptive paternalistic attitude from doctors. It seems like... I mean, the way that the people who have, who end up being in positions of power in the healthcare system tend to be a very small

group of homogenous people. And the way that that... attitude of prescriptive care, which leads to so much need being ignored, also compounds when, like, you're not white and straight and cis, and that's an issue. With specifically with trans healthcare, there's a total lack of understanding of what trans seems to be, which is not this singular term. Like, it's this... umbrella term for a massive variation of different expressions and needs, and that prescriptive attitude wants—well, the healthcare system at the minute—wants to describe this singular pathway which is not meeting a lot of people's actual wants or needs. So, it's a lack of dialogue just leading to a massive wait time list that is horrendous for trans people's mental health. I mean, there is a [chuckling] lot to talk about with like, being trans and trying to access healthcare. With the wait times, if you're trying to... trying to like, take care of yourself and go to mental health services, there's a lack of education around what trans needs are there. If you're suffering from a... like, God help you if you have anything else, like, going on, if you have any mental health conditions or disorders or anything like that. There's so much gatekeeping. There's so much... yeah. I feel like it's been said.

00:12:57 D I think fundamentally services for trans and intersex people are based on a medicalised idea. They treat it entirely as a mental health condition and there's—or, in terms of intersex people, a physical health condition—which has nothing to do with their identity, and that's fundamentally wrong in terms of how we exist. And so, there's just a fundamental lack of respect for consent, which underpins the entire system of how healthcare is provided for us.

00:13:37 MFC And just to note, we don't all have to go in order. If anyone wants to jump in just grab the mic off of me. The next thing I wanted to talk about is obviously when we look at all the problems that manifest in different ways structurally throughout healthcare systems, how do things like kindness, community support, care more broadly, how do they fill those gaps? Anyone have thoughts?

00:14:06 D In terms of trans and intersex healthcare, community has to take up... like, has to take a huge role in providing support and healthcare for us, which we frankly don't have the capacity to do. There's so many things we do: we support each other through mental health problems that we don't have the skills to do so; we share self-medication resources, medication itself, healthcare advocacy services,

fundraisers. So often you'll see surgery or self-medication fundraisers for individuals who aren't able to access it on the NHS or can't wait because the waiting lists are years and years. This is not support that we should be providing. This is not something that we've been trained to do. This is not something that we're being paid to do. And yeah, so many people fall through the gaps of healthcare.

00:15:20 E Yeah, I would, I'd really echo that. It's not something we should be doing, and it indicates that we've been let down, really, when that's happening. At the same time, I feel as if... we want to keep advocating and campaigning and pressuring for the stuff we need and we also want to try and keep people alive and do what we can. I feel like a lot of us in the community have supported people, particularly as regards mental health, through crisis. A lot of people have been through crisis themselves. And that shouldn't happen that way. But we do have experiences and knowledge, and I feel like a lot of that doesn't end up being documented or shared, and it would actually probably be quite helpful, and I wonder what structures we can create so that, not in moments of crisis but afterwards, we can kind of talk about what worked and what didn't and what people need in moments of crisis. Because the capacity in our communities is often very low for very good reason; we're very stretched and if we didn't have to reinvent the wheel each time that might be really helpful. And on top of that, there's an incredible amount of knowledge, particularly in the trans community, about medications, how to do stuff with very limited resources. I think there's also a lot of information and knowledge about mental health and how to manage it and medications and different treatments, and again that could be shared. And obviously there are examples of that out there. I think we could do a bit more of that. We could... acknowledge, yeah, that difficult experiences also leave us with a knowledge base. And in terms of practically navigating mental health services and therapeutic services, I think there are times when it's really hard to get through, when you feel like you've hit a brick wall. I mean, there's the classic thing of, "You're not ill enough for this service—sorry now you're too ill for this service," which is just an incredible thing to come up against. In my experience, it's important not to underestimate the power of just having someone with you. Reaching out to a friend and having them sit next to you while you're in the doctor's office and say, "I don't really feel this is good enough. I'm quite worried about my friend actually." And I mean to just kind of, yeah, work with the situation. Develop a healthy sense of entitlement; you're entitled to healthcare, and if one

doctor won't give it to you, go see a different GP in the surgery and be like, "This is what's happened and what do you think?" And I do think there's... obviously you want to... I don't know if it's in our interest to get too angry at people in those moments, but to ask them to document things like refusals. "So you won't refer me to this service? Okay. I'm sure you have a rationale for that, and I'd like you to put it down."

00:18:22 B In terms of—I completely agree in terms of like, self-advocacy. But also, there's this thing about reaching a point of confidence to be able to self-advocate in a space like that, especially if you're in pain, if you've gone to the doctors, you're already distracted by your pain then you have to like, self-advocate to be taken seriously, and so on and so forth. I think in terms of community support and kindness, it's been fundamental for me and my own personal journey as a Black woman living with HIV, and even being able to like, be open about my HIV status, because not many of us feel that we're able to be and that we're safe enough to be. So I would say that, in terms of peer support, it's been *incredible* just having spaces where other HIV positive people are together, understanding how to navigate healthcare systems, like, tools for self-advocacy as well, that as like, you were saying earlier on, it's incredibly emotionally... a lot. It's a lot. It's a lot. [Chuckles] That's it! That it's a lot. So, I think it's about also, I found really helpful, going into organised network spaces as well as a one-to-one and friendship group, because it can be quite difficult on a one-to-one friendship group, but in networked organised spaces, a lot of the time there's more of an approach to make sure that the person who is hearing is also being supported. Like, as a peer mentor, they're also having the support of other people and being able to share what they've heard for their own self-care as well as looking after other people's self-care.

00:20:16 PG Thanks, yeah, I would just really echo those points and build on this idea of knowledge and how that's recognised and how that's valued, especially as we see health services increasingly having to measure success in terms of these very narrow metrics, and also the fact that we very rarely properly document the extent to which, you know, communities and peer groups are having to pick up so much of the slack in terms of what's not available. So, we need to be ensuring that that is properly documented in ways that are trauma-informed, that are respectful, that are collaborative, and, you know, that people who have the capacity to get

access to resources for things like participatory research, for things like collaborative health services, that can support community-led programmes. We have to be doing that, and we have to be thinking creatively about ways that we can work together to support that.

00:21:35 B Yeah, and I think as well it's the sharing the knowledge so that we can support each other and then also push against certain... the way in which certain institutions can sometimes behave. Because what can happen when funding is reduced and services are withdrawn is that we fill the gap because we love each other. Like, we're, in our different communities, we want to support each other, we love each other, and there's nothing wrong with that. I do it all the time, so I'm hoping that there's nothing wrong with that. But then the risk that can also happen is that, it will be like, "Oh look, they can manage themselves. They don't need this support." So I feel like it's a two-way thing. Maybe it's more than two-ways but I can only think of two-ways right now, in that we're looking after and supporting each other whilst also, you know the tools that you're talking about in terms of also knowing, those of you who are comfortable to also push against, when you feel safe enough to and well enough to, push against certain systems and practices so that they can't just say, "Oh look, you marginalised group over there, you are looking after yourselves. Let's withdraw this and withdraw that," and it just keeps... especially within the current climate, with the current government, that's how things typically tend to go.

00:22:50 MFC And I might also add making sure that those groups aren't always invisible as well. Like, I know at university we had a group called FLY which was for women and non-binary people of colour, and they would talk about experiences of racism within university, but there would also be themed forums. And the uni just weren't really aware that this was something that was happening, and also that a lot of people went, as a result of the fact that they didn't think that there was competent mental health support within the uni, a lot of students would say, "I would never go and see a counsellor at the counselling service because I've experienced racism within that setting," and that kind of thing. So, I, as part of the project, interviewed people from FLY, that group, and tried to kind of bring that information to the university and make it more visible. I think that can be really important. I also wanted to talk about looking towards the future and thinking about what—because it's quite

theoretical sometimes the way that we talk about it—like, what would a radical liberated vision of healthcare actually look like, and how would that function?

00:23:59 EM I guess this sort of crosses into this but also is a point on the last point. One of the projects Action for Trans Health did at the end of last year through to this year was we've been trying to, in answer to the GRA, especially since the GRA consultation—does everyone know what that was? The Gender Recognition Act public consultation, which has now been scrapped. There's not going to be any changes. It was very quietly dropped after all of that. We actually put together our own survey to try and collect information on trans experiences in trans healthcare by trans people to try and like... yeah, solidify a quantifiable, evidential, demonstrable experience of what we're going through, to try and present this to government apparatus as much as we're pretty anti-state [chuckles] in our group. It seemed to be like a good holding pattern, kind of like, action, to try and talk to this organisation. What we found out was that the Department of Health don't—it's unnavigable by their own staff. They don't know how to make changes in the NHS, the way it operates, themselves, and that's the government branch that runs it and oversees it. Like... [chuckles] it's very disheartening. But yeah. I just wanted to reference that project because that seemed relevant.

00:25:50 D We've spoken lots about how to create healthcare services for trans people in an ideal setting. For a group that is like... we have medical needs, but they're very much—there's a huge intersection with social identity and... so... I want to see clinics that are led primarily by trans people who are not necessarily medical experts but can provide support, the wealth of our own experience, and reinforce the importance of informed consent, of respect for the patient. Just allowing ourselves to exist in the way that we choose to, not the way that the kind of current healthcare system forces people to behave. Like, in order to get healthcare in the current system, a lot of trans people will lie their arses off pretending to be someone they're not in order to convince medical professionals to, like, give us hormones or surgery, and that shouldn't be required. And in our radical ideal setting, that would not exist. You just, you go in and you ask for what you need. And so, these services can provide that, and can provide referrals to surgery, no questions asked. And provide access to therapists who are skilled and who are trans and can actually treat the trauma that so many of us have. Yeah.

00:27:56 E Yeah, thinking about the future going forward. So we had a workshop yesterday that was sex workers talking about their experiences of therapy, of accessing mental health services, what some of the barriers were to them accessing it or, once they're there, using it in a way that's actually helpful in getting what they need from that service. And as well as all the stuff that you probably would imagine came up, the financial barrier and being able to actually get into services, even when we were talking about private practitioners, although there are a handful of really great people in London who we know are sex-worker friendly, there aren't enough people. A lot of therapists end up seeing quite a lot of people in the same community. That's just a necessary thing, but it's not really ideal in terms of the separation. You'd like maybe to go to a therapist who isn't seeing all your mates. And so, when the information for this panel was actually sent to me, some of it kind of got me thinking and I started to wonder, is there any reason why we couldn't have a network of sex worker-friendly therapists? We have—there's some great people already out there practicing. There's also, like a real, there's a good crop of people qualifying now and just about to qualify, recently qualified, and there maybe aren't an awful lot of people who are former sex workers or current sex workers alongside their therapy practice, but there are definitely are some of us. I feel as if those of us in that position could work with trusted allies who are practitioners and that we could do, you know, peer supervision, where those people who have no lived experience of sex work but are committed to learning from sex workers could really up their competency around working with sex workers, and we could create a network. And we could think about offering things on a sliding scale; we could think about... I mean, I'm like, "We could get funding!" I know nothing about how to get funding, so if anyone is like, a fundraising genius, I want to maybe talk to you. But I feel like we could try and find a way to fund a couple of free places and just think about like... even that would be so much better than the current situation we have. Another where maybe talking about our kind of radical, liberated healthcare future. Maybe I'm just... I'm just so kind of immersed in the really difficult reality of the situation with therapies and counselling and mental health at the moment that I'm just like, "Wow, imagine that!" We could have a, you know, a handful of people and maybe there'd be a few free places and that's kind of... that feels like dreaming big at the moment, which is quite sad but that's where I'm at. But I am hopeful. I don't know if it sounds like it, but I am.

00:30:49 B I think for me it would be a focus on quality of life. So all of the... whatever the service is, that the focus is on quality of life. There is—which is a very abstract term, I guess, but I guess I just think, thinking from an HIV perspective specifically, there's a lot of focus on numbers as with, I'm sure, other medicalised conditions, but HIV is the world that I know. So, it will be your virus load, it will be the cells that count your immune system, and then it doesn't—and if those are both good, whatever 'good' is, agreed between you and your doctor, then you're good to go. And some doctors are really, go beyond that. There's a lot of benefit of being in London. I'm a Londoner. You wouldn't necessarily get the same healthcare access across the UK and beyond the UK. But actually having a focus on quality of life. So, the numbers are right, but how's my mental health? Do I have a job? Do I have somewhere to sleep? How's my quality of life overall? Am I happy, actually, because I think it goes beyond having a house and a job. Am I happy? Quality of life. And thinking big, maybe. But I completely hear you. Like, what does it actually look like? Because I see the numbers now and I talk to my peers now and it's hard for a lot of people. But yeah, that's what I would say.

00:32:11 PG Thanks. What you just said there, Bakita, really reminded me of something I was reading recently about structural competency, and we talked a bit about cultural competency in services. I think there's a move in some of the US to think structurally, so ensure that healthcare providers have structural competency, understand what people's lives are like, not just the metrics of the narrow area that they may be working in. And I think a big part of that is what everyone's been talking about which is ensuring that the central involvement of communities in designing, delivering, getting to evaluate the services that are there for their communities, and that's, you know, in collaboration with the services that are there. So, there are examples in the HIV sector where there are third sector organisations and people come from those organisations and work collaboratively in clinical settings. And I'm sure there are lots of issues with that as well, but I don't think we see that very much in terms of sex work services, where sex workers can be in positions where they're getting paid but have the freedom to deliver and influence and shape those services and also offer the kind of peer support in collaboration with other services that are there. And of course, we see lots of amazing examples of sex worker led groups developing services themselves and working collaboratively to find networks with other trusted providers, but we also know, you know, from what everyone's said, the

onus that that puts on communities and the burnout that can come with that. And I think we just need to be looking really carefully at how, you know, that work can be properly recognised and remunerated.

00:34:10 MFC When we talk about what the ideal radical liberated version of healthcare would look like, sometimes it's hard to think about what we actually do and how we build towards that. Does anyone have thoughts on how we can build towards that future? It's a huge question [chuckles].

00:34:30 B I do, yeah. So I'm going to drop some names right now because I think they're amazing, including the t-shirt that I'm currently sporting. So there are certain... for me, the steps to get there, it's about self-organising, and doing so in a really kind of bold and a really clear way that recognises the overlapping identities of different people. So there's a group called BlackOut and they support Black queer men in the UK—I believe it's the UK, Mark will kill me if it goes beyond the UK!—and also PrEPster. So they're really about ensuring that people who are most vulnerable to acquiring HIV know about PrEP which is a drug that can considerably reduce the likelihood of HIV transmission if you take this drug. There are currently trials happening, so look into that. And when—the word 'trial' is very misleading because it's not trialling whether or not the drug is effective. It's trialling how... how people would sign up to use the drug. That's what the trial is; the demand for the drug, not if it's effective. And I think that might have confused—like, made people think, "Oh it's not... it's not safe yet." So just that, sorry, as an aside. And then also, so there's PrEPster, there's BlackOut, there's also Decolonizing Contraception. So they are a group that is all about making sure that Black and brown people understand the history and the presence of sexual and reproductive health, pleasure and wellbeing. So, it's not just the numbers, do you have this condition or that condition, but actually sexual health in its fullest, being empowered. And I feel like they are being bold. They're taking information and they're tailoring it in a way that better serves communities while also recognising the context, the structural context, but then also what can be done on an individual and community level to navigate these spaces better and to not just feel like recipients of information but to also feel emboldened to pass on that information as well.

DECRIMINALISED FUTURES

Strength, Resilience, And Healthcare

00:36:55 EM I think whatever the, like, the work that will change this will look like, I really, really loved what you were saying about like, the value of community, and like, it's like a necessary, vital part of this. And looking for what is going to make you happy as well, and quality of life. So I think I'm a big fan of the way Act Up worked in New York and the way that they encouraged everyone around them to look to the people around them that are like, immediately next to them and pull them close, and develop those relationships and spend time together. It's difficult with restricted access to capital and physical spaces. Like, queer spaces are disappearing. Just places that are [chuckles] affordable to gather socially are getting rarer and rarer. But yeah, if... it's difficult. I don't know how to overcome that. Capital is... [chuckles] it feels like the only answer is like, full scale revolution, which I'm not against. [laughs][Audience laughs] Yeah! Let's burn it all down! Yeah! Yeah, I think in spaces that are grassroots, one of the things... one of the things that is a thing is like, schisms and differences that haven't been fully addressed in more leftist progressive spaces. And it's, they're all very vital conversations, I feel like, that are still happening. I feel like there needs to be more explicit invitation from people who aren't necessarily... I'm going to reference myself now, like I'm not particularly, in the grand scale of things, trans, like I'm not having the best life but like... if I'm getting involved in activism and community building, I should be actively, explicitly calling out if I'm part of a group to people who are having a worse time than me, people who are migrants or people of colour, and saying, "Yeah, let's get together," and really into seeing, in a group that I'm part of, Black and brown people having conversations that I'm not a part of, because that kind of thing needs to happen more. Like, it needs to be explicit that people who are somewhat benefiting a little bit more than others are acknowledging that? Yeah, because I get the exhaustion. Like, we're all exhausted. But just like, offering, just being explicit in the offering of like, let's really try and come together and be as acknowledging as possible and still look for that happiness that we can try and create in the spaces that we have together before going out and facing external issues caused by a small group of very, very rich people. So, yeah.

00:40:26 D Another way, I think, of building the radical healthcare future that we want to see is empowering the groups and communities that already are trying to provide the services that should be provided for us, like empowering them financially and legally to actually do what they're trying to do more effectively and to be paid for that labour. And yeah, I think we already have a really good idea of what we want to

see and we're doing our best to create it. You'll have organisations which try and distribute medication for self-medicators. Why not let them actually distribute medication legitimately? That sort of thing.

00:41:25 PG I just, yeah, sort of building on what you were saying, Bakita, about the work that organisations like PrEPster have done and what we can learn from that, and I think, you know, they've worked really, really hard to get a seat at the table in terms of the research that's happening, in terms of the policy that's happening, in terms of supporting the legal challenge that the National AIDS Trust took to the NHS and said, "You have to provide PrEP. This is not an argument." And they won that case. And it's really, really difficult because it depends on getting access to those spaces. I think those of us who do have access to those spaces in whatever small way need to be fighting really hard and insisting that sex workers and people from other communities get access to the spaces where decisions are made over what services get funded, what research happens. And it's not easy but we need to be working together to find ways to do that.

[Chat off mic]

00:42:34 B Just going off of what everyone else is saying as well, I think in terms of ways to get there in... internally within our different communities, however we're defining that, to understand that our bodies may remain the same, but they, depending on the space we're in, what that actually means tangibly is very different. And so, making sure that we—so say for example, in certain spaces, yes, I am a black woman, those are definitely my 'things' that make life a little bit harder, but then in other spaces as well, I'm a cis woman, I'm a fluent English speaker. And understanding what that brings, I have certain capital, education-wise, profession-wise. So understanding that, and like you're saying, using that to negotiate certain spaces, bringing conversations, bringing other people into the spaces as well. So, when thinking internally, actually, we do need to check our privilege as well as when we're telling other people to check theirs. And then thinking externally on like, the research side of things, I really, like I implore you to get involved in research as participants if you think the research is worth it. Because I was in the, sitting in in the panel just before this one and they were talking about how some research for sex workers is incredibly harmful, so if that is the case then of course, you make your

decisions and your better judgement based on your experiences, but where you feel that the research is trying to investigate something that is of use, the way that research informs policy and laws and a lot of our marginalised voices are not being considered, and then policies are being made and then services are being created that don't think about us, and then we get called 'hard to reach' but they never spoke to us to design services that would work for us. And it's this whole cycle. That's why we're going to burn the term 'hard to reach' and we're going to burn a few other things as well, but we're going to start with 'hard to reach'. [Audience chuckles] But yeah, so those were the two things based on what you were all saying just now.

00:44:49 MFC Amazing. Thank you so much for that. So now we're going to open up to questions from the audience. Does anyone have a question? Yeah. How should we do it? [Response off mic] Thank you. [Laughs] [long pause]

00:45:21 Q1 On? Yeah, it's on. [Chuckles] Thank you, that was wonderful. It's not actually a question, it's just a recommendation. When a few of you have been talking about community and care webs and caring for each other within the community, and for everyone here, there's a really, really great book by Leah Lakshmi Piepzna-Samarasinha, where she sort of gives a toolkit of how we can care for each other and how we can practice the best care for each other. It's specifically—so she's American. It specifically centres black, Indigenous, people of colour and how they can look after each other when they're disabled and when you're burning out. Yeah, and it's a really positive book, and it's like a little utopia. So....

00:46:09 ?? [off mic] What's it called?

00:46:10 Q1 It's—I've got it on me. Let me get it. God, I'm like a publicist. [chuckles] It is called... *Care Work: Dreaming Disability Justice*. It's very good.

00:46:26 MFC Amazing. Thank you so much. Any other questions? Yeah?

00:46:39 Q2 Hey, so I was at the panel yesterday about therapy and stuff, and I guess what I took away from that is that therapists—and like, I'm going to be careful with my words because I don't want to offend any therapists in the room—but you are a tool of state oppression, and that sounds dramatic, but when I engage in

therapy, it's about me finding meaningful work, and that's not what I think is meaningful work. What they mean is I'm engaging with capitalism. So, I'm paying my taxes and I'm paying a good amount of taxes. And I guess, like, how can we move mental health, or I guess health just in general, away from this idea of creating a good little capitalist that, that doesn't question the therapist when you don't call out that someone's just called you a whore, or how—you know like, you're not seen... you know, I'm seen as problematic and aggressive because I say, "Hey, like, no you're not allowed to ignore me. I'm important." Yeah, so like, how can we envision, create that world where we're just not producing more robots that are acceptable?

00:48:00 E Yeah, I mean I agree. I think therapists and counsellors have a responsibility to think about what they are being encouraged to think of as the desirable outcomes of the work. I think we've seen increasingly a turn to, "what is the minimum amount of care we can give this person and get them back to work, no matter how miserable they are when they're back." I think... that... yeah. I've forgotten what I was going to say now! Maybe come back to me in a moment because there was something else on the tip of my tongue and now it's disappeared.

00:48:48 MFC Anyone else? I have a thought. I think grounding in understanding of the social model of disability, which is a model that basically unpacks the idea that disability and illness are kind of the fault of the person, or the person is the thing that's not right and, rather, acknowledging that structures are built in a certain way to privilege and advantage certain bodies. And I think grounding in the social model, even with, say things like, people who hear voices or people who experience hallucinations, often those things will be seen as inherently negative or symptoms that need to be eradicated partly because they don't play into capitalist ideas of who makes a good worker and who is fit for work. And so, I think therapists, often, who know about the social model, specifically with that example, I think—hearing voices—often will instead look at the content of say, what someone's voices are saying, or whether it actually causes them distress. And maybe there's a way of getting rid of the distress rather than getting rid of the symptom. So, I feel like, yeah, everyone should know about the social model to be a good therapist. Any other thoughts on that question? No? Yeah?

00:50:08 EM There is a group that I'm aware of called Psychologists for Social Change. And this isn't so much of an endorsement of that group because it's... it's anti-austerity. That's what the group formed around. Protesting and campaigning against austerity, which is great. If there's anyone in the room who is a therapist or a psychologist, I would—who has capacity and has anti-state feelings, I would encourage you to go to the group because it could do with more anti-state members. Other than that, yeah.

00:50:48 E Yeah, I've just remembered what I was going to say. The title of this panel got me thinking about the term 'resilience,' because I thought, well, what is that? Do we want it? Because it sort of means to bounce back quickly from crisis or difficulty, to sort of remain perhaps unchanged, undented. And when I think about therapeutic work I feel as if what is lacking is space to have a breakdown, to acknowledge what has happened to you. To move the conversation from, "What is wrong with this person?" to, "What has happened to this person?" And to, you know, give us what is really lacking at the moment which is that space to, before we move to our potential post-traumatic growth, to grieve for what trauma does to us, to think about trauma as loss, as something that we have to engage with the effects of before we move on. And I feel like there is a lot of social and economic and practical pressure to jump straight from what has happened to you to survivor status, without the space to acknowledge what the real impact has been. And yeah, to grieve that. To grieve the fact that we, we do change, and sometimes we find enormous strength and growth on the other side of that. But to jump straight there? I'm not sure that works. But I think people... yeah, we need to think maybe about resilience and whether we shore people up to continue enduring intolerable situations and to think about why we'd be doing that. And yeah, there are some really good organisations, small organisations, but an increasing number of therapists and counsellors thinking about how they are used by the state to try and get people back to work or to get people to tolerate intolerable conditions, and what it means to be doing that. And I mean, don't.

00:52:55 MFC I love that you were like, "I forgot," and then came out with like, the most eloquent, amazing... [laughs].

00:52:59 ?? [inaudible]

00:53:02 MFC Any other questions? We've got some time, so... Yeah?

00:53:22 Q1 Hi again. I just had a question about finding community. Because you know, for people who have lots of problems and they might not have good friends or family or anything already in their lives, does anyone have any recommendations for how to find community groups and support groups and activist groups?

00:53:50 D I guess I can speak about how I found my own community. Social media is a big thing. I don't necessarily find much community on social media itself, but finding physical groups and activist groups via social media is probably the only way I've really found them. That and going to university, I guess. That really changed my life [chuckles] and that's certainly not something that everyone can do. I think we also need to do a lot of work to reach out to people who are marginalized and don't have access to the community. Because we do a lot of work to solve the problems within our community but that's not reaching everyone. Yeah.

00:54:45 B So how I found support groups and activist spaces was through my doctor in relation to like, HIV specifically; it was her that recommended certain things to do and places to go. And then also online, definitely. And then a lot of art spaces. Because I'm very artistic, and there have been a lot of spaces where I've found a lot of comfort and support, when I didn't necessarily know that that was going to happen, I just wanted to hear really good poetry, but it ended up becoming way more, so those are—that's where I've kind of gone to.

00:55:31 PG Just to echo the point you were making about people who may not have access to community networks. So we're doing some research at the moment called the East London Project. We're looking at how criminalization enforcement affects sex workers health, safety, access to services. And we're meeting a lot of people who, migrants in particular, who are experiencing a lot of oppression in many different ways, from police, but also really isolated from networks. And, you know, the researchers that we're working with who are part of community groups, community groups are doing amazing work to try and connect people up, and that's just something I wanted to say.

00:56:18 MFC Any other questions? Yeah.

00:56:26 Q3 It's something that Ember just said that made me think about what you said about abolishing 'hard to reach', or like not using it any more, that not being a thing. And I was wondering how you envision that all of these organisations and structures and communities can work together with research and with all of these kind of tools to change policy and to think on a larger scale? To think about outside of London, for example, because London is bubble, from what I've read and from what I've heard. I'm not from London. But yeah, how do you think about, going forward, making these services and making community and toolkits and things like that available on the larger scale, like, beyond London?

00:57:15 B Yep. So, I would say one of the first things is that skillset and ability needs to be, how we view it and how we define it needs to be broader. That people with lived experiences—community organisers, third sector—they are—and we know this, I'm telling you something you already know—but it's not a given in different spaces that those are skillsets in their own rights, right? So, there's that element of it. I think also there is, I would like to see more peer researchers. I do another thing, I probably won't name who they are, but I'm a peer researcher. So, it's about data sharing online, HIV positive people data sharing online, and it's specifically a UK project. And just little things of like academia and researchers in the traditional sense using peer researchers, in paid capacities—none of this free business, right? None of this free business when you're getting paid ridiculous amounts of money and you want me to basically do the same thing that you're doing for free. Nah. I am getting paid in this role. That's why I can say that so confidently. And then also actually listening to the peer researcher. Because there is this model, this participation model, about actually, are you being used in a tokenistic way or is it actually partnership? So, I think an element of it is that communities and third sector actually understanding that participation model so you can say, like, the next time somebody asks you to come along and say something or do something, actually where does that sit? Am I just being used as like, window dressing, sort of thing, or am I actually being used in a sort of partnership? But then listening to the peer researcher who— or whichever community groups that you've got in, in whichever ways. Like, simple things, to learn simple things and complex things, like don't hold it at that time of day, no one can come; childcare. But sometimes it completely... do you know what I

mean? But actually, if you're listening to people you will know, actually this is a very poor group of people so if you want them to participate in research, pay for their travel. Like, it's not a given. Because you don't have to think about your travel costs, doesn't mean everybody in this world doesn't have to. They might be foregoing lunch to come and participate in your research that may or may not benefit them in five years' time. What would you do? What would you do? So just little things like that. [off mic] I don't know. Sorry I felt like I got very loud and very emotional [inaudible 00:59:48].

00:59:50 PG Yeah, I passionately agree with you over remuneration in terms of money but also in terms of what people get from taking part in research, but also being part of participatory research teams. I think as academics we have a massive responsibility to be hearing participatory researchers, but also making sure that they get a stake in decision-making. So that's going back to when we first start talking about research projects that are going to be happening, and working together, making sure that's properly remunerated. So it's not just, "This is what I want to find out, can you help me do it and make my life easier?" It's, "What does the community need to know?" And working together to kind of, you know, recognise where the overlap is and how that can be done most effectively.

01:00:53 ?? [inaudible]

01:00:56 MFC Any other thoughts?

01:01:03 Em I'd add to that, alongside the academic stuff, conferences. Like, conferences like this. And I think it was last year or the year before, when ATH when actually like, a lot more into... like, the structure of the group has kind of like fallen apart a bit, mainly due to burnout and a lot of other things. But conferences for this group that was—like, ATH was divided into chapters that were location-based, and conference, I think a biannual meetup of all the groups really helped keep it together while that was still kind of happening, like, in real-life meetups. Looking for bridge people as well? By bridge people I mean people who have community in more than one space, physically, like people who have moved from the North down to here but still have that community in other cities. It costs and not everyone can do it, but like,

travel and in real life, meet up, like physical socialising is really integral; it keeps things together.

01:02:17 MFC Any other questions? Yeah?

01:02:26 Q4 Sorry this is a bit kind of a—oop, okay—this is kind of a half thought through question, but one of the things that kind of, is sort of a big issue in healthcare is chronic illness and illnesses that are maybe disputed by—which sounds basically like I'm talking about bullshit—but illness that are basically either seen as being, can only be treated through like, therapy, but actually also have a physical component. So these are things like Myalgic Encephalomyelitis or Chronic Fatigue Syndrome, some kinds of EDS, like lots of other illnesses that fall into the semi-auto-immune group that a lot of sex workers seem to have, and that kind of thing. And I'm just wondering what we can do more to help people who are—or like, fight for health justice for people who don't really have access to healthcare at the moment who fall into that group? Yeah. I don't know. It's kind of a half thought through question, sorry.

01:03:25 D I'm a sex worker; I have EDS and all that sort of thing. It's such a struggle to get healthcare. I've had to educate my own doctors about my various health conditions, try and convince them that EDS exists in some cases. I... yeah. I really wish I knew better how to fix these things, but certainly one of the things we can do is fund advocacy services. Like, in a very kind of simple way—not enacting structural changes to the healthcare system—advocates can help individuals access better healthcare. Better education for doctors is definitely something we could do with.

01:04:28 E So this is a half thought through answer to the half thought through question. I mean, from a therapy, counselling point of view, I think... I mean, when we talk about the idea of illness that maybe have a somatic component or that are psychological or origin, I don't understand why we would in any way separate that from the physical? Because if somebody would like to show me, you know, something psychological that doesn't arise from something in the physical world, I'd be happy to see that. I think there is probably some work to be done among therapists to think about how they approach people who are sent to them, and how they work with symptoms that appear not to have an explanation where we don't

have the knowledge-base we need to identify what's going on, or... I mean... I mean Ehlers-Danlos is not even something that's contested, or like...? You know, obviously there's lots of doctors who have never heard of it, don't know what you're talking about, but it's just... it's mind-blowing, because it's not even controversial, really, among rheumatologists. So it's clear there's loads of education work to do, not just among therapists, but among GPs and other practitioners in other fields. And that can be really simple. Like, I've personally been using a psychiatric service and had a doctor there see that I had Ehlers-Danlos on my record, and just say to me, "I understand that's a condition that can be really disabling and can have a really big impact." He made no other remarks about it, but just that was incredibly validating. And I think to get across to doctors and therapists and other people just to be like, you know... "You seem like you're having a shit time. You know, I understand you're in a lot of pain." And just to sort of give you that acknowledgement and that validation in those moments can be... can be something. It can be a start. And so, I think, yeah. Work to be done. I'm not sure quite how we go about it, but something to maybe keep talking about. And I'm glad you've brought it here, because I think if we keep it on the agenda and in the conversation, maybe we'll start to make the links we need to... yeah, get that out there a bit more. I don't know if that really answers your question, but....

01:06:42 D Can I just say in response to, "EDS is not something that's contested but still people have so many issues with it," some of the most common things I've heard is doctors just say, "Well, EDS is really rare," which I'm not convinced of, actually, "so therefore, you must have a mental health condition, or you must have fibromyalgia or something like that," and refuse to actually treat the issues that people are having.

01:07:08 E And it's sort of like... I mean obviously that is deeply annoying and not accurate, but like, it shouldn't even really matter. If you're experiencing all those symptoms it doesn't really matter where it's coming from. You should still be offered different treatments from different angles and it should be a case of, it doesn't really matter where this is coming from, we'll try all the different things we have available to us until something works. You know? So, blah.

01:07:36 PG This is maybe a bit kind of broad and theoretical, but I think a bit thing for me, I suppose, working in a university which is all supposed to be about public health and 1946, WHO defined 'health' as being about kind of full physical, mental, social wellbeing, not just the absence of infection, infirmity, disease. And so often we see in the kind of research we hear about, particularly in relation to sex work, everything being bannered under sexual health, the same in teaching programmes in health. And I think we need to massively be challenging that, and making sure that that carries through in the questions we ask, the teaching we get involved in. And for me the best way that's happened has been working with sex workers through the research and teaching that we do and doing it collaboratively. So I think fighting those conversations, and when we hear these kind of stereotypical views with a narrow view of health, just challenging it as much as we can.

01:08:41 MFC Any other questions? Yeah.

01:08:46 Q5 You, a few of you said some really nice things touching on how, like, in the communities that we exist in, there we pick up the pieces and make up the gaps because we love each other, and then often, like, the services that should be covering the needs of the people are like, "Well, they've got it covered, that's fine." And then on the flipside, often, in the gaps in funding, sometimes there is funding available, but how do you navigate whether or not—like, how do you work out for yourselves if those funders are good options to go down because they won't end up exploiting you or won't end up harvesting your data for their own purposes, or using, "We align ourselves with sex workers, therefore you should..." and then like, getting more funding from themselves more broadly. How... what are good ways of filtering through getting resources to prevent them from actually damaging your community?

01:09:57 D I wish I knew the answer to that question. [Audience chuckles]

01:10:05 B It's such a good question, it's such a good question. I would say... I think—okay, so, a couple of things, because I'm trying to secure some funding for something. I would say it's about understanding the organisation that's providing the funding. Like, even things like looking at their values, what they've funded before; it could even be a case of actually checking in with other recipients of funding to see what that relationship was like, as well, for them. And then I would also say

understanding how much... oh I don't know how to say it in a politically correct way... how much influence they would want to have over your work as you're doing it. Because of course you need to report back; they've given you money. Like, you need to explain what you've done with the money. But how hands on they're planning to be and how ethical. Whatever your values are, do they complement that of the donor? Because the money will be nice to have but you'll have a hellish few months, few years if there is that tension there. Yeah, I think that's all I'd say.

01:11:26 PG Thanks, yeah, I would echo that, absolutely. Like, hearing from organisations and collaborations where people have had good experiences, finding out strategic ways to get access to resources through partnerships that are going to be beneficial. Sometimes you can get funding from research bodies that are also about supporting programmes, so if you find people that you trust and that have good working relationships, that can be one way. It's getting harder and harder. What I would really like to see is sex workers on funding boards making decisions about funding that goes to sex workers, which, you know we see examples in certain cases with the Malmö Cash Fund 01:12:15, I think, in the US, and then sex worker-led funds like the Red Umbrella fund. So, finding ways that we can be advocating for that in research funding as much as in funding activism and services.

01:12:33 MFC Any other questions? We've got time for a couple more. Yeah?

01:12:44 Q6 Hello. I've never spoken into a microphone before. I was just thinking a bit about healthcare workers. I myself have worked as a healthcare worker in the past, and thinking about how there is this—we know there is this back and forth between healthcare workers and people who are working as sex workers, and also the fact that we've talked a lot today about doctors and therapists who are relatively privileged health workers, but actually the majority are nurses or non-qualified nursing staff. They're often migrant workers, they're often on zero hours contracts, they're often having to commute large distances because they can't afford to live in London, to work twelve-hour days, double the caseloads they're supposed to have. Like, it's a kind of... I mean that's my experience of being a health worker. And I wonder in some ways if there's anything happening to build kind of... because they also struggle with their mental health, they're often women of colour, people of colour, migrants, whatever. So, I suppose I'm thinking about whether anything is

done to build solidarity between the communities who are receiving healthcare and the communities providing it who seem to be, a lot of the time, maybe from the same communities? And yeah, I just was wondering if anyone had anything to say about that.

01:14:01 EM So this is something we've been thinking about. At the minute, Action for Trans Health isn't actively campaigning. We're doing internal review stuff. But as soon as we open back up one of the goals that we have is to try and build solidarity with union groups that are trying to get better conditions for nurses and also campaigning for more money for the NHS. It's like, a lot of the issues that like, marginalized people face in healthcare are issues that are more widespread; it's just like it's felt more in marginalized communities. And it feels like there's a lot of scope for a lot of good solidarity work. But we'd also want to hopefully see some kind of mutual return of respect as well. So when we start engaging, it would be nice to... yeah. Yeah, we're hopeful that that kind of good solidarity work can happen. We're just positioning ourselves to actually do it right.

01:15:08 MFC Any other questions? Yeah? Maybe?

01:15:15 ?? [inaudible]

01:15:16 MFC Yeah, yeah two is fine.

01:15:20 Q2 So I guess like we've had a couple of discussions about funding and applications for funding and basically users having to basically beg for money, but this money is here. The money that Britain stole from the rest of the world hasn't disappeared. Like, the money that like, bailed out the banks, we still have that money, or they still have that money, and it's like how can we empower people not to like, write to organisations begging and hoping these people will treat us ethically. How can we say to the NHS, how can we say to the government, "Hang on a minute, if you can renew Trident, why can't you renew this therapeutic community that has a massive impact on people's lives?" You know, how can... I don't know, that's, I only experience mental health care. Yeah, I guess that's... like, how can we empower ourselves to take back this power and this money that is ours? Like, you know, it

doesn't belong to the government; it doesn't belong to the banks; it belongs to us.
And we are begging for our own money!

01:16:38 MFC Huge questions.

01:16:44 B I would first start by saying, in part, I don't know. I would be like, in part I don't know. I think it's also about... but I would also say, it's about finding support—am I going to use the word 'allies'? I don't know, I don't know how I feel about that word—I guess finding allies who are in positions where they can have certain conversations. There are certain spaces I can't access. Like, I can't access them. Or I find it harder to get into them. So, but finding people who are empathetic, who are in certain positions where they can sometimes have the conversations on our behalf? It is also about self-advocacy, and then sometimes there are some people that I know in groups that I know that don't even—and it's kind of going back to your question as well—don't even apply for funding. They try—it's about the crowdfunding, it's about raising money to have that full agency over funding as opposed to having to keep going back to, you know, big business and the governments and the banks that you were saying. But I think your question is very important. It's a very important one.

01:18:02 D I honestly wish I knew the answer to that. Maybe a revolution?
[Audience laughs]

01:18:09 MFC And then do we have one more question here?

01:18:11 ?? [off mic] Yeah!

01:18:12 Q7? So something that isn't specific to sex worker community groups, but... the—what do you think about the ethics of having clients anonymously and with no strings attached be integral funders of sex worker peer-led groups, and having the money coming from customers, clients who frankly, they're not allies, they're clients, but they are those people in positions that have access to much larger sums of money and different spaces. Any ideas about colluding [chuckles] colluding with clients for enhanced resources?

DECRIMINALISED FUTURES

Strength, Resilience, And Healthcare

01:19:00 E I mean, if they're not going to limit what you do with it, then, I mean, take it, I reckon. I think there are—that maybe introduces particular power dynamics for those individual sex workers maybe who are seeing those clients. I think that can be a thing to think about before accepting donations. But a lot of them have, like, shocking amounts of disposable income. I really feel like we should skim off as much of that as we can, especially if we can put it into our own movements. And I—a lot of them... I mean, why are they giving those donations? A lot of the time they're not really that interested in the stuff we're doing but they'd like us to think they're nice. And I'm kind of like, sure. So whenever those people kind of, you know, want to get involved, I'm like, "Ah, there is—I can think of an excellent way you can get involved. You can give us your money and you can go away." And I would just roll with that.

01:19:57 MFC Any other thoughts?

01:20:01 EM Yeah, exactly that. [Audience laughs]

01:20:02 MFC Pretty much sums it up. Any final questions? No? Okay then I think we'll finish a tiny bit early which gives everyone a chance to have a rest break. Can we have a massive round of applause for the panellists?

[End of recording]

*Thanks to Academic Audio Transcription for the transcribed audio –
hello@academicaudiotranscription.com.*