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I: Okay, that's on. So the first question then, [REDACTED], is can you tell me more about the work that Cysters do and the sorts of things that you provide just in general?

R: Just in relation to period poverty related things?

I: It can be both, so like the wider stuff that you do and then the period poverty because they're linked, aren't they?

R: Yeah. So we initially started out as a group to support the patient voice around reproductive and mental wellbeing and one of the things that I really recognised as a person of colour that my voice was never really at the table when decisions were made about me. So I felt that decisions were made about ethnic communities being called a hard to reach community, et cetera, and those decisions were made about us but without us and I found that really strange, though this group essentially was to sort of tackle some of that.

But also on my journey with my own sort of issues having multiple health issues myself I felt that within my community there was a real lack of access to information.

I: Yeah.

R: So it's almost like an education poverty.

I: Yeah.

R: And I found that certain areas of Birmingham where I spoke to people, for example, those who went to faith schools or those who were living under the poverty line, they didn't have the same access to information the same way I did. And those that lived...for example, we've got many people within Cysters that have lived in their area all their life, parents have lived there, grandparents have lived there, everybody knows each other including the local GP, who is also a person of colour – so conversations around reproductive menstrual health weren't being had because of the stigma within these communities about what that conversation is. So it was almost a case of they couldn't access the same information because of the level of stigma and unconscious biases, and sort of internalised patriarchy and misogyny around reproductive wellbeing and how it's been sort of carried through generations of families and communities.

I: Yeah.

R: So I wanted to tackle some of this by talking about these issues and actually educating people from a really basic level on things like what is PCOS and what is a period – a lot of people that we did some work with two years ago, they didn't know what ovulation was and, you know, that's something that I think is really basic and you should know what it is with the education system alone.

I: Yeah, yeah.

R: So it's stuff like that – we've been trying to sort of get hold of those communities, because they're not hard to reach. If you don't identify with these communities you're never going to be able to reach them and that was the problem that I was finding, that the people that were going into these communities or writing about these communities or studying these communities were never people within those communities.

I: Yeah.

R: So we wanted to work as a grassroots community to support the community, if that makes sense.

I: Yeah.

R: With that, that's when I then came across things like period poverty because...in a sense of the physical products but actually poverty around education, like I said earlier. It was understanding was it period poverty; and for me it's not the literal sense of not having the products it's also the education around it. Even managing hygiene around having a period as well has been quite interesting because some people because of the lack of products would wear a pad for longer, not knowing about things like toxic shock syndrome, and things like that I felt was quite important that everyone should have the information because then they can make informed decisions on what sort of product they want to use, things like re-usable products. A lot of people within these communities didn't initially want to try these products because they felt they were dirty. Again, it comes down for me like a lack of education.

So what we've been trying to do is work in the community as community advocates, as patient advocates, to say actually these are other things that you should be doing instead or have you tried this – giving them the actual information so they can make powerful, informed decisions on how they want to manage their reproductive and menstrual wellbeing.

I: So how would you have like normally done that, so pre-COVID what sorts of things would you do?

R: So we've just done workshops within...we started off in places of worship but we did had problems with places of worship in that the subject matter has to be delivered really sensitively, and even then it's still quite a problem for a lot of people in the community.

So if I give you an example of say a [inaudible 00:05:01], they are usually run by males. Whilst the female members of the community which we call [inaudible 00:05:09] are really happy that we're there doing the work the males get very...they find the conversation very intrusive and have on a few occasions been like we don't want you here doing this. So that's

been quite difficult. What we've done is move to sort of neutral settings or community settings, so working with, for example, you've got community halls which are very within the community. We've also used places like, you know, the John Lewis hub which is unfortunately going to...

I: Yeah, close.

R: ...well, will have gone now...

I: Yeah.

R: ...to sort of create those safe spaces and put on something where people could attend freely. That's take a while to kick off, if I'm honest, because people had to develop a lot of trust in us as an organisation before they started coming to us, but if you look at the membership and the people that come to Cysters I'd say about eighty to ninety percent of them are those from black and ethnic minority backgrounds – and that's taken at least five years of work to get that trust built with these communities.

I: Yeah.

R: There's such a distrust with medical professionals based on years of medical gaslighting, so it's taken a long time to get us there. And corona has really pushed us back quite a lot, to be honest, because... The trust is still there but the people that would access us don't find the same benefit in doing this online, if I'm honest, because it's just not as real to them. And with that time with people face to face appeared to be so important and we're losing a lot of that at the minute.

I: Mm-hmm. So you've tried to move stuff online then?

R: Yeah, we have. We're doing a workshop...not a workshop, we're doing a project with Endo (UK) about marginalised groups and their sort of attitude and sort of their experiences with COVID and endometriosis. And we got a group of nine people in a room a couple of weeks ago and as much as it was really powerful... It was great; it was the first time you will have ever seen a room of people of colour talk about endometriosis because usually it's white females and it's never anyone else usually, apart from me unfortunately. And this is the first time that they've ever been able to talk about it outside of that space. But I had to do a lot of mental health check-ins with a lot of them afterwards because they found it quite triggering at the same time because they had to acknowledge medical gaslighting and things like that.

I: Yeah.

R: And those conversations for me have been really important to do in person - doing it online doesn't have the same effect. It doesn't have the same support level as, you know, in person, and I think peer to peer

support has been really crucial to that, sort of helping people through that trauma as well.

So we have been moving things online really slowly – I'm very conscious of it because I think it's really difficult for a lot of people and there are people that are getting missed because they don't have the same access to online, you know, aids. And Zoom fatigue is a real thing; you've been at work all day looking at a screen the last thing you want to do is then look at another screen and talk about feelings, et cetera – it's very emotionally time consuming for a lot of people.

I: So does that also apply to...? So you have volunteers, don't you, at Cysters - are they saying the same sorts of things or how are they finding it?

R: Yeah, yeah. So I mean we've done a few different projects but by the end of it I think people feel genuinely exhausted and that's what a few of them have felt. In the moment they feel great because they're talking about things but then, you know, as soon as it's done afterwards it's then... It's like a massive high and then you literally leave a cold, don't you, and that's it and you're back to whatever sort of world you're living in.

And I think a lot of the people that were in that particular chat room that day, they live on their own or they're single, so when they leave the room they physically are just on their own and I think when you've talked about something that's so traumatic to you and relative to you, then suddenly to be on your own is quite difficult, whereas when we were doing it in person when we would finish a session people would sort of either mingle around afterwards and have a chat with each other – a lot of people, because we were in John Lewis, would actually walk over to...I think it was called Pho, a little restaurant and get food and stuff.

I: Oh yeah, the Vietnamese one, yeah.

R: We don't have that interaction anymore at all.

I: So have you found then that that kind of community sense that goes with shared experiences, particularly if they're not very pleasant, that's what's been lacking, isn't it?

R: Yeah, definitely. I didn't realise how much we did rely on that and that is essentially what the community is; that informs everything we're talking about. Even if we have a quite simple peer to peer sort of meet-up which become a sort of giant chat that informs a lot of our work because you find themes that people are all talking about and that naturally starts to inform what we're going to do next, and we are struggling as an organisation what is the next thing because the theme very heavily at the moment is mental health. It's multi-faceted, mental health; it is such a big area anyway, but mental health and chronic pain is something that has always been overlooked anyway...

- I: Yeah, definitely.
- R: ...and I think that's becoming more prominent now. What COVID has done for us which has been quite useful is highlighted the health inequalities with people of colour, with people from LGBTQ backgrounds, and I think that has been...it's finding everything we've been chatting about for the last five years and someone's actually turned round and said actually that's true. And that's been quite validating for us as an organisation and it obviously filters through to our communities who have then slowly started to feel validated but also a little bit angry that it's taken so long for their voices to actually matter, if that makes sense.
- I: It certainly does make a lot of sense. Yeah, I think in the chronic illness world in general I think because everyone's now like, oh look, you know, the long term impact of COVID, you know, it's causing things like fatigue and pain and this, that and the other and it's like, yes, these are things that we have all the time.
- R: Yeah. I think one of the biggest things, right at the beginning, which was an annoyance for me and a lot of people in Cysters was the working from home because suddenly you had to work from home.
- I: Yes.
- R: But, I can tell you from personal experience and a lot of people in Cysters...a lot of them weren't allowed to work from home because apparently they weren't productive enough or they was no need to work from home and now suddenly everyone has to work from home.
- I: Yeah, couldn't be trusted, yeah.
- R: And I think that shift and that change in mindset should have been done for people who had chronic illnesses a long time ago instead of having to fight for it.
- I: Yeah, it should. And the thing that I'm worried about...I know we're going off-track now, the thing that I'm worried about is that when we do go back to whatever this new normal that people keep talking about is that people will be like, oh well, you don't need to work from home anymore now so you can come back into the office, and that will get lost again.
- R: Exactly, and I think we've got a real danger of doing that and I think we need to sort of almost safeguard those same people.
- I: Yeah, definitely. Anyway, back to the period poverty stuff. I did a talk for the Feminist [inaudible 00:13:11] Association on chronic illness in the pandemic and those were all the sorts of things that I was saying, like these are things that we've been talking about and that we need regardless of the pandemic.

- R: Yeah, it's not new information.
- I: No, no, but suddenly you're interested, yeah. So tell me then about the period poverty stuff – so what were you doing before lockdown and COVID?
- R: I started working with an organisation called the Handsworth Association of Schools, so I think they've got about thirty schools under them. Because Handsworth is quite a socially deprived area and every school under them again socially deprived. We attended a few of their teacher meetings with all the schools and period poverty was brought up as something that they were experiencing. Schools had their own mini food banks within the schools and we were topping them up with products and then using it as an opportunity to sort of talk about, you know, the PHE lessons and how we could contribute and support there, which is what we were doing beforehand. That slowed down obviously with all the things coming around schools getting support though from my knowledge the schools haven't really been taking up the offer of getting free products.
- I: Yeah.
- R: I have spoken to a few of the faith schools and they weren't actually aware themselves.
- I: Yeah, that's the big problem across the board with that scheme.
- R: I know.
- I: Yeah.
- R: So that's something that I've been sort of saying to them, you can go and do this. So a couple of the faith schools are now applying for things that they can get now.
- I: Good.
- R: But we were always predominantly schools, we never really ventured any further than that. We dropped off a few things to a few homeless organisations through the community settings we've got, so through [Nishcam and Midlands Langar Seva 0015:10] which are two Sikh based homeless organisations. And that's kind of where we were and then the pandemic hit and we then found our period poverty work suddenly become more popular for a number of reasons.
- Firstly at the beginning of the pandemic it was two people within Cysters actually took it upon themselves to send products to each other because certain areas were running out of products. I think this must have lasted about three weeks, if I'm honest – I couldn't give you direct timescales of that but what I know is was a couple of people had started to mention, oh,

our local area doesn't have this, and you were having people send products from their area to another so the other Cysters could have products. Because you'll realise with having things like PCOS or even fibroids your bleeding is much, much heavier.

I: Yeah.

R: We did have a lot of people arguing, using the group to sort of vent, because they'd been buying a lot of period products and then other people are saying to them that they're stockpiling. But actually when you have a chronic illness that affects reproductive and menstrual wellbeing, you're not stockpiling, that's normal.

I: Yeah, that's what you need, yeah.

R: That's a normal amount. So it was interesting. We did a small article on it actually about how people weren't stockpiling, it's actually a need for them.

I: Yeah.

R: So that was something we noticed at the beginning but that sort of calmed down and finished. But then we started getting foodbanks in our local area. And so what I did is I contacted all our local foodbanks and said do they need some support in this area with menstrual products and they all did. That has now expanded out to Tamworth and their foodbanks which was not something we were expecting. So now that is the biggest place that we're sending; we're literally dropping products off every month, and if it wasn't for Hey Girls we would really struggle, because we struggle a lot with donor fatigue anyway with period poverty products.

I: Yeah, yeah.

R: What we found before COVID was a lot of the organisations we've worked with corporate-wise, like the Chambers of Commerce, they'd get really excited for a month or so, we'd get loads of products but that would literally last about two months.

I: Yeah.

R: And then you have donor fatigue, because who wants to keep supplying you with products.

I: [Voices overlap 00:17:39], yeah, yeah.

R: But we have been so, so fortunate to work with Hey Girls and they've been sending literally...it's almost like a palate to my house and I've literally got a wall of products at the minute and I can't get through my door properly because I need to send them all out. So I'm heavily reliant on my volunteers here because I don't drive, and my partner's been doing

lots of driving around Birmingham to drop products off to different food banks. But that's where a lot of our energy is being sort of given to now. We haven't really had the time to do sort of education around periods generally. What we've been doing is a lot of work around actually getting the products into the food banks because that's where our energy has been taken up.

I: So when you say... So you're talking about...is it the whole of Birmingham or is it very specific areas?

R: It's not the whole of Birmingham, it's whoever contacts me, to be honest, but like geographically I couldn't tell you. That's why we were surprised when we had somebody from Tamworth getting in touch and now we're supplying four different places there.

I: Yeah.

R: I mean I could sit down and map it out for you but, to be honest, my biggest problem is, in all honestly, I don't have enough time to do this backend stuff, I just want to do the work, if that makes sense.

I: Yeah, yeah, yeah.

R: So I can...if you want me to spend some time doing that and I can come back to you with that if you want.

I: No, it's fine, it was just out of curiosity because it's like, you know, Birmingham is a huge area so to have the whole of Birmingham and then Tamworth as well is just like wow.

R: Yeah, it has been really eye-opening, if I'm honest.

I: Obviously I'm Birmingham based but you are pretty much the only provider that I'm aware of that does anything around products. I know there were a few Red Box projects but they closed down as soon as it was, oh, the schools can get free stuff.

R: Actually I think we are the only ones.

I: That's ridiculous, isn't it, for the whole of Birmingham.

R: And the problem I'm having massively at the minute – I know there are more organisations that need us, I know there is. I don't know where they are and I haven't got all the network resources to tap into every single one of them.

I: Yeah.

- R: We've been using all the resources we've got in terms of community but I know there are more people that would benefit and it's trying to get hold of people, where do they need, so we can set up.
- I: Yeah.
- R: So what we've done with some of the food banks here, rather than me coming monthly we go bi-monthly and that makes it easier on us because then my volunteers aren't driving around every two minutes, my partner isn't driving round every two minutes, I will learn to drive at some point to do this, but bi-monthly has made it a bit easier on us right now as well so we can do our other side of the work. Yeah, the biggest thing is we want to help; we want to know who they are so we can reach out to them and get products to them. It's just finding them.
- I: Yeah, yeah.
- R: And it's not a case of hard to reach it's just tapping into the right communities – and let's be honest no one really wants to say that this is a problem for them.
- I: No. That's [REDACTED] Bloody Good Period said exactly the same thing about it's not...the problem is that you don't know who you don't know.
- R: Yeah.
- I: Yeah.
- R: Yeah.
- I: And who has the answer for that because like you say if you don't know the person that knows...
- R: Yeah, [voices overlap 00:21:23] social media that actually...and this is where the pandemic really has hit us hard - I'm a very community person, I'm in the community, I work with the community and I've really struggled not being there. It's almost like I feel like I'm a bit of an imposter trying to work with this community when I'm not physically in it right now.
- I: Yeah.
- R: We're all just sat in our homes sending things out, so that's where we really struggle - because that's how we find out about other organisations through that power of community.
- I: Yeah, yeah. I don't really have any other questions to ask you. Obviously we're now back in another lockdown so I'm guessing that it's going to carry on, like you say, just focussing on the product drop-off and making sure that places that need them have got them. Is it mainly food banks that you're sending things to?

R: They're the ones that we've found a lot of people have reached out to us for and it's all been sort of poverty, food bank related.

I: Yeah.

R: And they've been pop up ones. They're not the normal, you know, ones that you've heard of or that are established, these are literally local ones that have popped up because of the divide because of the pandemic. We've literally got one literally down the road from me that like is an old converted...the pub's...you know, that pub's not going to come back, you know, after the economic downturn they've had so they've converted that space into a mini food bank and, you know, that's not something we ever expected to work with and that's what we've found...and that's where our community has slowly started coming back, little pop up ones that the community have done.

And things like Facebook groups have been so, so helpful for this and I'm probably going to send a message out a bit later trying to say to people do you know anybody, where can we be sending them to and getting people to share that because that's really important for us right now to make sure it gets to the right person.

I: Yeah. So are you quite reliant on social media at the moment then instead of your normal community?

R: Massively, massively. I can't think of anywhere... Like we've sort of appealed things like your TV, BBC things but, if I'm honest, it's not been really of any interest to people.

I: Mm, yeah.

R: So we're just heavily reliant on social media to get our message out there. I know there are a few community WhatsApp groups; I know that within the Sikh community we have a massive WhatsApp group of what we call [inaudible 00:23:57] which is basically volunteers in the community and messages get sent out from them to other WhatsApp groups, so that's been quite big for us. But then that's only limited to a south Asian Sikh community.

I: Yeah.

R: We've really struggled in every other one as well because we're not physically there and we're used to physically being there and having... It's a conversation piece as well, especially when I'm walking round with pads and saying hello, can I help you?

I: Would you like one?

R: We don't have that.

- I: Yeah.
- R: So that's us in a nutshell at the minute.
- I: So kind of going back to the chronic illness stuff, so when you've done the online sessions and the groups with women have they been saying anything about how being able to access healthcare has changed?
- R: Massively. So the work we're doing with Endo (UK) literally focusses on that at the moment.
- I: Yeah.
- R: I did a couple of talks with the [APB inaudible 00:25:03]. I don't find their webinars all that informative but I found it is a space for a person of colour to actually be saying it to them, even though I'm saying the same things I said five years ago it doesn't actually make a difference what I've said at the minute. It's a lack of communication and there's this one approach fits all sort of thing going on.
- I: Mm-hmm.
- R: But you've got to understand, most people from south Asian communities in particular live with their extended families, so we can't talk about these sorts of issues at home via a telephone appointment, it just does not work for us.
- I: Yeah.
- R: And I don't think that was even every taken into consideration. The first time I said it none of the GPs in that room had a clue. And this is the problem when you're not there to advocate for yourself or your community you get left out and a decision gets made for you and this is what the pandemic is highlighting.
- I: Yeah, yeah, yeah. So, yeah, and it applies to people that are in abusive relationships and just having that safe space as well.
- R: Yeah, the whole thing.
- I: Yeah. Yeah, that's something that's come out a couple of times when I've been talking to people. Like you say it's not just a poverty around products, it's the poverty around education suddenly has stopped and, you know, menstrual health isn't a priority anyway in terms of healthcare.
- R: No.
- I: And women's reproductive health just got totally deprioritised. Things like smear tests and just being able to, you know, get your contraception at

the beginning – I think that's slowly starting to improve but, you know, that comes into the overall thing around period poverty, doesn't it, it's not just people can't afford products, everything else gets taken away as well and that's been amplified.

R: Yeah, it's been really interesting because I've got a woman who is...I think she's in her sixth year of having the Mirena coil in and they haven't been able to take it out yet. And they've basically said to her unless she's trying for a baby it's not a priority.

I: Yeah.

R: Well, she wouldn't be trying for a baby; she actually identifies as LGBT, so they've kind of brushed her off as not important and I don't understand how that is acceptable. But another woman who originally is from Romania, and I really had to reach out and send an email on her behalf because she's been in so much pain – she's fainted in the office twice, because she works with me as well, because of the pain that her coil's been giving her, but they've said to her that she has to go back to Romania to have it removed.

I: What?

R: But that's bullshit, she doesn't. English isn't her first language and so they've brushed her off, and it wasn't until we intervened that she's actually got the medical care that she needed, otherwise they were just putting her on lots of pills.

I: So they were happy to give her lots of pills but not take out the coil?

R: Yeah. They wouldn't; they said that she would have to go back to her country of origin. Well, we're in the middle of a pandemic so she can't just hop on a plane, have it taken out and come back, it's literally impossible to do that at the minute. And it's things like that really concern me at the moment.

I: That's shocking, yeah. I mean I knew it was bad but that is bad.

R: Yeah, yeah. I was really shocked when I found out myself, to be honest, it's just...it's really highlighted that... If I'm honest, if you don't speak English as your first language it's almost like you haven't got a chance.

I: Yeah.

R: And that really concerns me and this really highlights why I think the work we're doing is so needed because we're still having problems around this.

I: Yes, you do amazing work.

R: Oh, thank you.

- I: And all of those awards that you've got at the bottom of your emails it's like she needs more and she needs money.
- R: But, you know, it sounds really silly but, you know, if it wasn't for some of these awards people still wouldn't have taken me seriously.
- I: Yeah, I know, I know.
- R: And I don't know what it is about awards...and I remember when I got my first one that's when a lot of people, especially on my side of the community, thought that the work I was doing was therefore worthy and real and authentic then because there was an award attached to it. So, yeah, that was interesting for me.
- I: Yeah, it's a title, isn't it? It's like having a title. Like if you have...likes of when I'm finally doctor...
- R: It's a [paperweight 00:30:00].
- I: Yeah, when I'm finally doctor it's like, well, then we'll see what happens when I go to the doctor's surgery and they see I'm a doctor.
- R: That's one of the reasons I was saying that I wanted to do some research like this because I wanted that whole title of a doctor because I can tell you now as a patient we are not given the same sort of platform or respect as well.
- I: Yeah.
- R: I've been in so many recent meetings where I've had to almost stop the meeting and turn round and say just because I'm a patient voice I do understand what you're talking about and I don't need to leave a meeting or be introduced later because you don't think I know what I'm talking about or I'm only here to give you my story and then leave.
- I: Yeah.
- R: I want to be involved in dismantling this structural oppression.
- I: Yeah.
- R: And they find that very difficult and it literally is a case of I don't have this title that they think makes me worthy of a conversation.
- I: Yeah, yeah.
- R: So it's been a very interesting journey.

I: Yeah. Yes, I find that as well. People get confused because I'm a research fellow but I haven't got a PhD yet and they're like, oh...

R: You wait until that's happened.

I: You can have research experience and not have a PhD.

R: Yeah. But it doesn't make it any different though. I mean if you become a doctor tomorrow really your work isn't any different.

I: No, no, no.

R: You're still doing the same work and you're still representing the same voices. It annoys me. It's elitism and classism.

I: Yeah, it annoys me as well.

R: Yeah.

I: Okay. Do you have anything else that you wanted to kind of add on top of what we've already talked about that you think is really important to highlight around period poverty?

R: I don't think there is. I'm going to have a look at geography and stuff when I get a chance and I'll send some stuff over to you just for you really. If there's anything that I come across then again I'll ping it over to you. But right now, no, I can't think of anything.

I: Yeah, that would be great, but don't feel like you have to.

R: No, well, to be fair I need to get on top of doing some of the backend type of work anyway.

I: Yeah, that would be really helpful because, as I said, it's such a huge area and you're literally the only person I know that does anything.

R: And that's not great.

I: No. But, like you say, there will be other people that are but you just don't know who they are.

R: Yeah. It's strength in numbers as well, isn't it?

I: Yeah. It's very frustrating. But thank you so much for your time. I'm going to switch off the recorder, she says.

R: No, thank you.

End of transcript