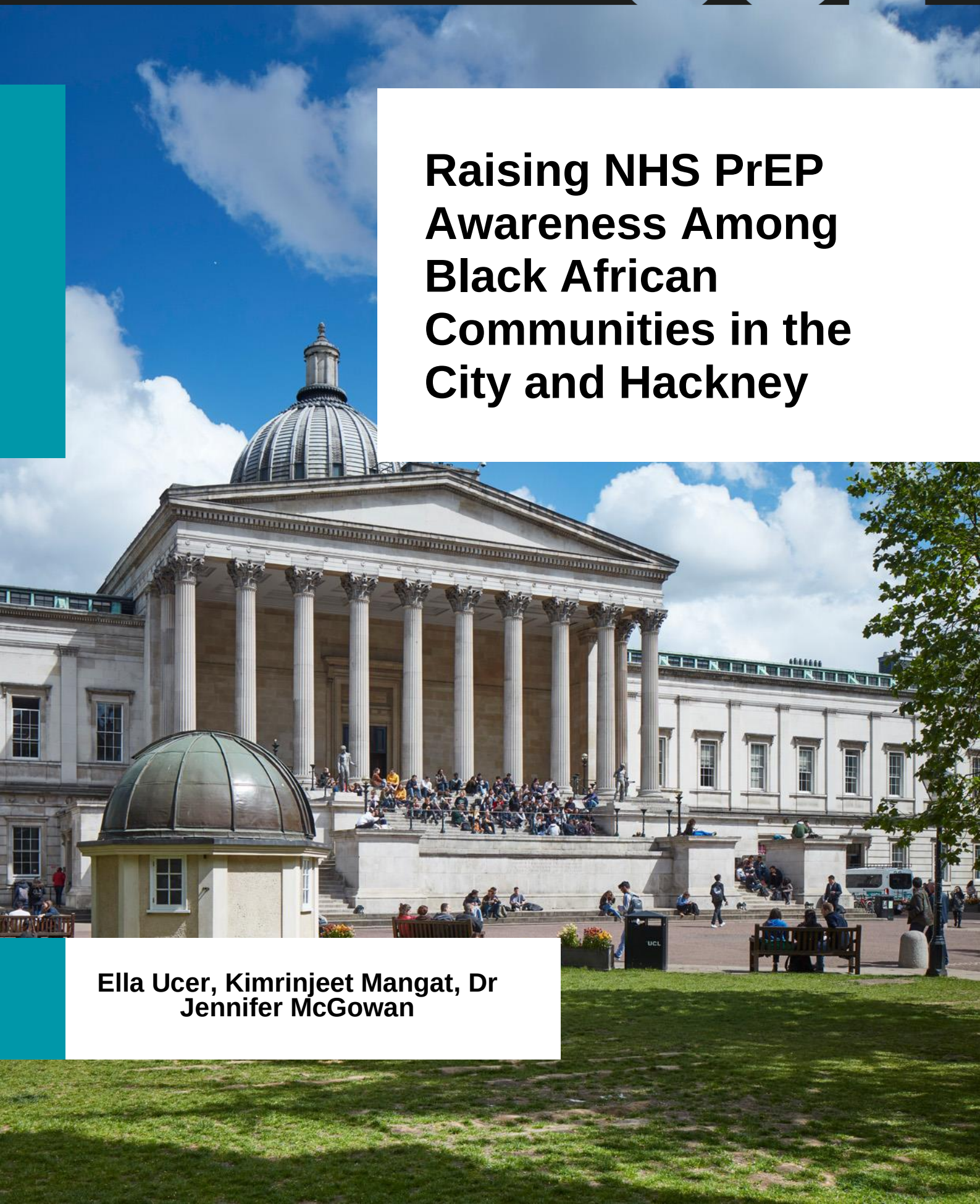
Psychology and Language Sciences

Raising NHS PrEP Awareness Among Black African Communities in the City and Hackney



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Abstract

Pre-exposure prophylaxis (PrEP) is a biomedical human immunodeficiency virus (HIV) prevention strategy that involves the use of HIV antiretroviral medications by HIV-negative people to reduce infection risk. In spite of its potential, the uptake of PrEP both in the United Kingdom (UK) and worldwide has been limited, with disparities emerging across lines of race, ethnicity, socioeconomic status, geography, age, and self-identity. Following men who have sex with men (MSM), the UK's BA population currently faces the second-highest levels of HIV risk, yet awareness of PrEP within the community remains low and research on the subject is limited. The present study aimed to address this gap by asking how to raise awareness of PrEP within London's BA community appropriately and effectively. To this end, a focus group was conducted featuring two members of the BA community, both working in the domain of sexual health. Seven questions focused on various aspects of raising PrEP awareness guided the discussion. Four main themes were identified: taboos and stigma; medical mistrust; local engagement; and the diversity of the BA community. The effects of stigma on healthcare workers' ability to discuss PrEP were considered for the first time in a UK-based sample, as were the consequences of widespread medical mistrust. Key considerations pertaining to community engagement were contemplated, and participants discussed the importance of catering to numerous segments of the BA population. These results provide a first step towards increasing PrEP awareness within the BA community and ultimately remedying some of the HIV-related health inequalities experienced by this population.

Introduction

PrEP for HIV Prevention

Pre-exposure prophylaxis (PrEP) is a biomedical human immunodeficiency virus (HIV) prevention strategy that involves the use of HIV antiretroviral medications by HIV-negative people to reduce infection risk (Collier et al., 2017). It has been proven safe and effective in various populations including young women, men who have sex with men (MSM), serodiscordant couples (where one partner is infected and the other is not), and injecting drug users (Mahase, 2021). When taken daily, as directed, PrEP's effectiveness approaches 100% (Chou et al., 2019; Rutstein et al., 2020) and evidence from the UK PROUD study has reported a reduction of 86% in new infections among MSM provided with PrEP in England (PROUD, 2015). As a result, the United Kingdom (UK) National Institute for Health and Care Excellence (NICE) has recommended that PrEP be offered to all individuals at "high risk" of acquiring HIV (Mahase, 2021), and as of October 2020, PrEP has been available freely on the NHS to anyone in this category.

Unfortunately, the uptake of PrEP both in the UK and worldwide has been limited. Only a fraction of people who could benefit from PrEP currently have a prescription (Calabrese, 2020), and troubling disparities have emerged across lines of race, ethnicity, socioeconomic status, geography, age, and self-identity (Bavinton & Grulich, 2021). In the UK and other western high-income countries, uptake is typically the highest among MSM with connections to urban gay communities and lower among minority ethnic groups, migrants, and non-gay-identifying MSM (Annequin et al., 2017; Grulich et al., 2018). Efforts are needed to ensure that existing health inequalities are not exacerbated by unequal access to and awareness of PrEP.

According to Public Health England's (PHE) 2016 report, second to White MSM, the population facing the highest levels of HIV burden in the UK is the Black African (BA) community (Kirwan et al., 2016), with 38 out of 1000 BA individuals estimated to be living with HIV (HIV Commission, 2021). Despite making up only 2% of the UK resident population (Office for National Statistics, 2012), BA heterosexual adults were reported to constitute 39% of

new heterosexual-related HIV diagnoses in 2016, and 13.0% of new diagnoses overall (Brown et al., 2018). PrEP could signify a step towards remedying these health disparities around HIV. However, awareness of it within the BA community remains low (Di Giuseppe et al., 2019).

Knowing about PrEP is a necessary precursor to its uptake (Kelley et al., 2015; Parsons et al., 2017), and research has shown that learning about PrEP's ability to reduce HIV risk often leads to increased interest and willingness to start (Koechlin et al., 2017). Collier and colleagues' (2017) study featuring Black and Latina women in the Bronx, NY, for example, found that focus group participants who had not previously heard of the medication were eager to learn more once they did, and asked many follow-up questions. A similar observation was made by Rice and colleagues (2019) in their focus group involving mostly Black Americans from Birmingham, Alabama. Participants highlighted the need for more readily available information on PrEP and its benefits within their communities, and an inadequate understanding of PrEP was said to constitute the greatest barrier to its uptake. Before PrEP can be put to use to reduce the unequal HIV burden borne by members of the BA community in the UK, it will thus be necessary to increase awareness of it.

Barriers to Increasing PrEP Awareness

Though there have been few UK studies on the topic of PrEP awareness, especially within the BA community, several barriers have been identified worldwide that are applicable. HIV- and PrEP-related stigma, for example, have consistently been shown to reduce interest among persons at high risk of contracting HIV (Calabrese, 2020). In Rice and colleagues' (2019) study, participants explained how cultural norms and community level stigma could act to prevent conversations about PrEP from taking place among families, peers, and healthcare settings. Interviews conducted by Rogers and colleagues (2019) with African American MSM living in the Jackson, Mississippi revealed how people were hesitant to access medical services related to PrEP given that "everybody [knew] everybody" in their city. Being seen at the clinic, or having clinicians talk about patients to friends and family, were highlighted as risks. Research by Witzel and colleagues (2018) on the qualities valued by Black MSM living in London in a potential PrEP service supported this finding, with many participants mentioning that their interest

would largely depend on the extent to which accessing such a service would make them vulnerable to HIV stigma and homophobia. Confidentiality was emphasised as a key concern. Stigma thus prevents people from seeking out information and blocks conversations that could otherwise increase community knowledge.

Uneducated or unwelcoming clinicians can also thwart the successful communication of information. Participants in Collier and colleagues' (2017) study who had previously heard of PrEP reported struggling with finding providers willing to prescribe it, mainly due to misconceptions that the drug was for MSM only. Rogers and colleagues' (2019) sample echoed this finding, with participants explaining how medical providers and pharmacists were often unaware of PrEP and its function, rendering them unable to provide basic information. Given existing fears of stigma, it is also important for staff to act in an empathetic and professional manner (Bavinton & Grulich, 2021). Participants in Witzel and colleagues' (2018) study noted how the absence of such an approach would likely prevent people from asking questions about PrEP, stopping them from finding out what they need to know.

Medical mistrust within the BA community may also turn people away or lead them to believe false information, thwarting efforts to raise awareness. In the United States (US), centuries of systemic medical mistreatment have resulted in greater scepticism on the part of Black Americans towards HIV-related medical innovations (Corbie-Smith et al., 1999; Thomas & Quinn, 1991; Washington, 2006) and an increased likelihood to endorse conspiracy theories around HIV and PrEP (Eaton et al., 2017; Westergaard et al., 2014). Indeed, one study involving Black MSM from the cities of Jackson, Mississippi and Boston, Massachusetts reported how participants described aversion to medical care within Black communities and doubts about the effectiveness of PrEP (Cahill et al., 2017). Some participants even expressed concerns that PrEP would increase their risk of HIV infection and noted their wish to see someone using PrEP for an extended period of time (e.g. 1-10 years) before considering taking it themselves (Cahill et al., 2017). In the UK, mistrust of the medical profession has been documented among HIV-positive Africans and is thought to impede willingness to access healthcare (Erwin & Peters, 1999). Whether this could manifest as a barrier to seeking out information about PrEP in the UK, as well as in the US, has not yet been investigated. However, it is clear that medical mistrust and misinformation are significant causes for concern.

Research in the UK

A clear caveat to applying the findings discussed thus far within the UK's BA communities is that most of the studies were conducted in the US, and the

one conducted in London featured MSM only. Though HIV stigma is also present in the UK, and there is a similar precedent for medical mistrust, experiences between the two countries are far from identical and transferability cannot be assumed. Furthermore, the concerns of MSM and heterosexuals may differ on a number of points.

In a review of the literature, only three studies were identified explicitly considering the challenges involved in raising PrEP awareness among heterosexual BAs in the UK (Di Giuseppe et al., 2019; Nakasone et al., 2020; Young & Valiotis, 2020). The first, conducted by Di Giuseppe, Kasoka and Dunkley (2019), split a sample of 18 BA women living in East London and Hertfordshire into focus groups to discuss the barriers and facilitators to PrEP uptake in their communities. Results confirmed generally low levels of PrEP awareness and hesitation to access healthcare, as identified in US samples. Participants described feeling stigmatised in healthcare settings and consequently doubted whether providers would have the competence enough to promote PrEP effectively. The importance of developing specific educational programs to raise HIV awareness was discussed, and participants emphasised how PrEP-related information should be spread at a community level, e.g. in religious settings or at festivals.

Nakasone and colleagues' (2020) research involved 32 in-depth semi-structured interviews with BA or Black Caribbean women in London and Glasgow, with similar conclusions. Though the majority of participants displayed good HIV knowledge, very few had known about PrEP before the study. In line with Collier and colleagues' (2017) findings, once participants did learn about PrEP, they were enthusiastic. Community-level stigma was viewed by almost all women as an obstacle to attending sexual health clinics, with participants fearing being seen and judged by members of the community. This finding echoes that of Rogers and colleagues (2019), indicating that concerns about gossip, perhaps unsurprisingly, is a universal deterrent. Experiences of racism within the NHS were also discussed, predominantly by the Glasgow sample, and dissuaded participants from bringing up PrEP to their clinicians.

Young & Valiotis's (2020) sample included both men and women and focused on the difficulties experienced by clinical and community practitioners in their attempts to increase HIV literacy and PrEP awareness in Scotland. Practitioners working with African communities highlighted the importance of HIV stigma as a barrier to people's willingness to engage with HIV-related information. Furthermore, they noted that the relatively low levels of self-perceived HIV risk within BA communities meant that any messaging campaigns promoting PrEP as suitable for those at "high risk" were likely to miss the mark.

Overall, the existing research indicates that awareness of PrEP within the BA community in the UK is low and the effects of stigma powerful. Not only does the fear of judgment appear to limit interest in PrEP, but it also prevents

conversations with professionals from taking place. This problem is exacerbated by BA people's experiences of stigmatisation and racism in healthcare settings, causing them to doubt whether clinicians could even offer the information they need were they to ask.

Yet, further research is warranted for a number of reasons. First, the novel and unique findings featured in each paper demonstrate how the subject has just begun to be explored, and much remains undiscovered. Given the paucity of the literature so far, additional research is likely to grant novel insights. Second, the three papers were published prior to PrEP's availability on the English NHS, and at the time when the focus groups and interviews were being conducted, participants in England would have been able to access it solely through the Impact Trial (Sullivan, 2019). The shift in PrEP provision to mainstream sexual health services may have affected people's perceptions and awareness levels, justifying more recent research. Finally, though the three papers covered issues related to raising awareness, only Young & Valiotis (2020) made it their primary focus; the others asked participants about the barriers and facilitators to PrEP uptake more generally. It is important to study awareness in and of itself, as knowing about PrEP is a necessary precursor to its uptake (Kelley et al., 2015; Parsons et al., 2017) and yet the evidence shows that very few people in the BA community have ever heard of it before. Research examining why the requisite information is not reaching everyone who could benefit, and how this situation could be remedied, is urgently needed.

The Present Study

The present study addresses the identified gaps in the literature by running a focus group featuring healthcare professionals from the BA community in London, in collaboration with the City of London Corporation & London Borough of Hackney Public Health Service. The aim is to obtain new data on the information about PrEP that is considered salient by members of the BA community in London, the barriers people face when attempting to access such information, and how information could be spread more successfully. The overarching research question guiding the focus group will be how to raise awareness of PrEP within London's BA community appropriately and effectively. This will constitute the first study on the subject involving members of the UK's BA community since PrEP was made routinely available on the NHS to individuals at high risk of contracting HIV. It will also be the first study to focus on raising awareness in particular, rather than the issues applying to

PrEP uptake in general. As discussed, awareness of PrEP is a precursor to its uptake, warranting further research in itself. Findings will be used to inform the actions of local authority sexual health commissioners and tailor future promotion efforts.

Methods

Positionality Statement

It is important to note at the outset that the author of this study is positioned as an outsider, not belonging to the BA community herself. She is Caucasian and has been living in London for the past five years as a university student, prior to which she lived in Spain and Turkey. She has no previous experience conducting cross-cultural research or in public health. These qualifiers may have produced blind spots affecting the analysis and interpretation of qualitative data.

Design

Data for this qualitative study was collected from a single focus group. This methodology was chosen due to it facilitating the exploration of collective experiences and decreasing researcher-participant power imbalances (Wilkinson, 1999). During focus groups, interactions between participants replace interactions with the interviewer, emphasising participant points of view (Morgan, 1988) and allowing them to develop the themes that matter most to them. Participants are able to describe experiences in their own words and it becomes harder for the researcher to impose her own agenda (Wilkinson, 1999). Given that the researcher is not a member of the BA community herself, maximising this shift in power and voice was considered especially favourable.

Participants

The sample consisted of two BA women with experience working in the fields of sexual and reproductive health in London. Their current roles involved working with young people (aged 5 to 19 years old) to deliver health and wellbeing education at schools and in youth settings within the community. Throughout the discussion, participants revealed themselves to be second-generation migrants, though they did not specify where in Africa their families were from.

Procedure

Recruitment took place via mass emails sent out to healthcare professionals and community liaisons with links to the City of London Corporation and

London Borough of Hackney Public Health Service. The inclusion criteria were that the participants themselves identified as BA, had experience working within the community, and were willing to contribute their insights on how to better tailor the promotion of PrEP. Interested participants got in touch via email and were provided with information sheets and consent forms to sign virtually. They were also assigned randomised participant IDs to use when joining the focus group. Participants' real names were not included in the transcript or at any stage of analysis.

The focus group was conducted online, using Zoom, and recorded. It lasted a total of one hour, and participants were compensated £20 for their time. Although participants joined using their randomised IDs, it quickly became apparent that they worked for the same organisation and knew each other. This potential limitation on anonymity had been made clear before their joining the study, and neither felt it to be a problem.

Ethical approval for the study was granted by the UCL Department of Psychology Ethics Committee.

Measure: Focus Group

To ensure that both participants had access to the same basic information before beginning, a brief educational message about PrEP was read aloud at the start of the focus group. This message was also emailed to the participants to be referenced at will. Though they were provided with the opportunity to ask follow-up questions, neither had any. A copy of the information participants were provided with can be found in Appendix A.

A total of 7 questions guided the discussion, focusing on various aspects of raising PrEP awareness. The first few questions used the information provided at the beginning of the focus group as a starting point. Their aim was to identify what PrEP-related information would be considered relevant to the community, what background information would be needed, and what would most motivate people to learn more. The next few questions focused on the barriers and facilitators people might face when attempting to learn more about PrEP, as well as the challenges involved in promoting it on the professionals' side. Overall, the questions were intended to elucidate various components of raising PrEP awareness, such that future practitioners might have a better understanding of what information to include in campaigns, what barriers to keep in mind, and what methods to use to spread information. The full set of questions included:

1. Was any of the information you heard surprising?

2. If we were to design marketing/educational materials featuring this information, which parts do you think would be helpful?
3. Do you think seeing this information could motivate people to learn more about PrEP?
4. Is there anything else you think people would need to know to better understand this information?
5. What challenges do you think people might face when trying to find out about PrEP?
6. What do you think would be the best way to reach people?
    a. Where?
    b. Via whom?
7. What do you think the main challenges are when it comes to raising awareness, especially given more sensitive subjects like this one?

Once developed, the questions were reviewed by one of the City and Hackney Public Health Team's BA community liaisons to ensure appropriateness prior to the focus group.

Analysis

The focus group transcript was generated automatically by Zoom and checked manually for errors. Inductive thematic analysis was used to analyse the data, taking a realist approach (Braun & Clarke, 2006); in other words, themes were generated based on the data itself, and not in accordance with existing theory. The analysis involved a number of steps. First, there was a process of familiarisation with the data, which involved reading through the transcript line by line, taking notes on initial impressions and marking any patterns that seemed to emerge. On a second read, preliminary codes were generated, which were then sorted into potential themes and subthemes. An example of how codes were generated from the transcript can be found in the excerpt presented in Appendix B. Data extracts assigned to each code were collated and the themes refined to represent the data as accurately as possible. Generating the themes was a recursive process involving many reads of the transcript. The last step was to finalise the themes and select representative extracts from the data, as presented in the next section.

Results

The analysis identified four main themes pertaining to the research question at hand, which asked how to raise awareness of PrEP within London's BA community appropriately and effectively. The themes identified included: taboos and stigma; medical mistrust; local engagement; and recognising diversity within the community. Participants identified the current barriers pertaining to each theme and put forward potential solutions.

Taboos and Stigma

In line with previous literature, issues of taboos and stigma were brought up on multiple occasions by both participants. Barriers appeared to be multi-layered, with both the public and professionals hesitant to bring up PrEP. On the side of the public, participants highlighted concerns shared by members of the BA community that enquiring about PrEP would single them out and expose them to stigma. In the words of one participant:

> "When we are discussing HIV, you do hear a lot of stigma that's already out there, so that it's a Black disease or it's a gay disease. And for a lot of the young people that I speak to, they don't want to talk about PrEP because they've never heard of it, but also, I don't think they're clear on their rights and also they're worried about judgment. I know one young person did say to me once like as a Black man, if I go and ask for PrEP they're gonna think I'm weird."

On the side of healthcare professionals, participants explained how the tendency to avoid taboos could prevent the necessary conversations from taking place. The difficulty of striking a balance between comfort and raising awareness was described:

> "Professionals might not have the tools to have the conversation, either. Because again, as professionals, sometimes you might shy away from discussions, because as [Participant 2] was saying earlier, you don't want to make it a taboo but you don't want to bring it up all the time and make it a focus and then you know, make it feel quite uncomfortable, so for some professionals I don't think they have the tools to have the conversation either."

Embedding conversations about PrEP into healthcare policy was put forward as a potential solution. One participant referred to the NHS's policy of Making

Every Contact Count (MECC), a behaviour change approach that attempts to incorporate the encouragement of healthy behaviours in every contact staff members have with individuals across the health, local authority and voluntary sectors (Making Every Contact Count, 2022):

> "I haven't worked in sexual health clinics for a while now, and things have changed since I was working in a clinic, but when you come into a sexual health clinic, the same way that we're all pushing Making Every Contact Count, when you are having conversations with anyone, are you having conversations about PrEP in there? Are you talking about that, are you talking about PEP, are you talking about PrEP? Like, maybe that needs to be embedded in policies as well."

When having such conversations, participants made clear the importance of professionals' own education and competence, reflecting concerns brought up in previous literature. Sensitivity and awareness were thought to be key to successful communication. As one participant noted:

> "It's just about- like any other conversation, are you sensitive to the issue, do you know what you're talking about, and if you don't know, do you know where to go to get that information?"

The role of considering stigma in PrEP-related messaging was also discussed. Stating its indication for people from African countries at "high-risk" of contracting HIV was thought to be off-putting and likely to evoke unwelcome feelings of vulnerability. Participants described how people would not want to identify themselves as belonging to a vulnerable category and could easily react by losing interest in PrEP:

> "For me the risk group is a massive thing, speaking as a professional and as a Black person. I don't want to see myself almost as a victim, or I don't want to see myself vulnerable, so for me that's a massive thing. Especially if you're someone who doesn't identify as that, but you do actually need access to PrEP, but you can't envision yourself in that vulnerable group, you're not gonna want to access PrEP."

A better approach was thought to be highlighting when to access PrEP, e.g. under what circumstances or at what stage, rather than painting identity itself as a risk factor. One participant compared this to the way in which condoms are promoted once individuals become sexually active:

> "The same one we do with like using condoms, for example, you start using condoms when you're having any sex… saying that you should be accessing PrEP if you are in one of these categories of vulnerable, maybe that's not the route you go down."

Medical Mistrust

Another key obstacle described by participants was the general suspicion felt on behalf of members of the BA community regarding new medications. The challenges of promoting information about PrEP were compared to the challenges faced when promoting the COVID-19 vaccine, for which similarly low levels of uptake among BAs had been observed:

> "I think you also have to think about specifically Black groups' access to healthcare, especially when you think about sexual healthcare. You know there's so much history there, history that people haven't forgotten, history that has been passed down, and you know about contraception that used to be tried and tested out on Black women, and being guinea pigs… There's a political and historical element to why I feel like Black groups don't access sexual health services and might not access something like PrEP because it's a relatively new drug as well, and especially within the Black community when it comes to accessing drugs that haven't been around for a long time there's always going to be that reluctance."

This medical mistrust was said to fuel conspiracy theories and increase misinformation around the COVID-19 vaccine, and participants warned against the same thing happening in the context of raising PrEP awareness:

> "We've been doing assemblies on the COVID vaccination and you hear young people talk about, you know, 'this isn't something for our community, they're trying to get rid of-'. There's all these conspiracy theories, you know, people are saying 'they're putting chips in your arms, they're doing this, they're doing that'… so I think there has to be consideration for the historical and political impacts faced by Black African communities."

When asked how to combat this issue in future promotional efforts, participants pointed out the importance of acknowledging people's suspicions and not minimising fears. Showing understanding of the historical background was thought to be critical:

> "I think it's about the way you give out information… it's about listening to people's concerns, validating it and not dismissing it."

Engaging Locally

Drawing on their experience within healthcare promotion, participants highlighted the importance of local engagement. Specifically, one participant mentioned a previous program's promotion of condom use using brief and

essential pieces of information offered in venues frequently accessed by the local BA community. It was suggested that a similar tactic could be employed to promote PrEP, with informative cards placed in spaces such as libraries and churches:

> "I'm just thinking about the "Come Correct" cards that we had – "Come Correct" was the old condom scheme – and it was like 10 bullet points of "need-to-know" information, and then at the bottom of the card it had your nearest place you could go to get condoms. I'm just thinking something like very small that can just be handed out, can be placed in spaces that are frequently accessed by the Black African community… Even like in libraries and stuff… Community walls, especially Community walls that are linked to churches… just like little cards that can be handed out."

Participants also highlighted the benefits of collaborating with community groups to host in-person educational events, as these provided people with the opportunity to ask questions and engage with healthcare professionals directly. This point came up in the context of promoting the COVID-19 vaccine but applies to PrEP as well:

> "I think tapping into community groups, as well, cause face to face events, they are helpful. I say that especially because just doing the COVID vaccine assemblies that we've been doing, there has been uptake following the session, because it's really a time to discuss these other issues, what it's all about, and just have any questions you want answered."

Local engagement was also listed as a priority due to the time constraints experienced within the BAME community in particular. Though the participants spoke on this issue by referencing the collection of PrEP from sexual health clinics, rather than in the context of raising awareness itself, the same considerations apply to planning accessible in-person events for PrEP promotion. One participant mentioned how clinic opening times were a concern, given that those in the BAME community were especially disinclined to take time off work:

> "Time. Time. Time is a big one […] There's that difference of knowing 'okay, I've got to head to the clinic, but the clinic closes at four, I finish up at five'. I guess it's a sacrifice, you know, you can always say you could be excused at work, but a lot of people in the BAME community don't like missing work or don't want to tell their employer they've got an appointment because they feel it may be against them in the future."

Distance was also highlighted as an obstacle and concern when planning BAME-specific educational events:

> "In my personal experience, Dean Street, central London, Soho, there was not an issue. It was always busy, people were happy to go in there, people knew where it was, we had little clinics, but again, it was open to everybody so mostly… if I'm honest mostly MSM men in that area who worked there went to that clinic. We did try do a BAME specific clinic but nobody from South London is going to trek all the way up there, do you know what I mean?"

At the same time, this point was contested by another participant who explained that anonymity could trump proximity for some people, particularly those in younger age groups, who preferred venues farther from home. As she put it:

> "Saying that, thinking about our younger age group… We have got young people that will travel to South London or West London just to get condoms because they don't want to be associated with the area, they do not want to go into their pharmacist… we do know that young people, for example, will travel, you know all over London just to get condoms and I wouldn't be surprised if they did that for prep as well."

Recognising Diversity

Participants made clear the importance of recognising diversity within the BA community when designing awareness-raising projects. Differential concerns were thought to apply with respect to a person's gender, faith, and age. The success of online versus offline advertisements and outreach attempts was thought to depend, for example, on the age group being targeted. When asked whether using the online medium could be beneficial, one participant replied:

> "That depends on the age group… If this is information for everyone of every age group, for some, well, online's great, and others online won't be so great."

Another participant noted how enticing younger people to take an interest in PrEP might be easier, as the taboos around HIV seemed to be reduced in this demographic:

> "You know younger people- Westernised people- what we call Gen Z, they are more equipped to testing, to accessing PrEP. There's not a

> taboo. Places like Hinge and Bumble, there's even like a section around your status, you know it's quite open, it's quite fluid."

On this point, the other participant disagreed, stating that taboos were present from a young age:

> "Working with young people aged 6 to 19, and up to 25 with additional needs, and doing sessions about STIs, and HIV is one that we do as a session on its own, and we already see those barriers in the Black community of why they won't access PrEP or PEP or even want to discuss HIV, so already starting to see those barriers form at such a young age as well."

Moreover, when one participant highlighted the importance of church within the BA community and explained how church events could constitute novel opportunities to host PrEP-related talks and Q&As, the other expanded this point to include all places of worship, stressing religious diversity in the community:

> "I agree, but I would definitely say more faith-based because other cultures and religions are in the BAME community.

Overall, it was evident that any efforts to spread information should not consider the BA community as a monolith, and that a multitude of differences might exist by age, gender, and religion. What works to raise awareness in one subset of the population may not necessarily do so in another.

Discussion

This study adds to the currently limited body of research on PrEP awareness within the UK's BA community. The research question of how to raise awareness within the BA community in London appropriately and effectively was answered by drawing on the experiences of two participants working with this population in the healthcare setting. The four dominant themes to emerge comprised taboos and stigma, medical mistrust, local engagement, and the diversity of the BA community. Some points confirmed findings from previous research, whereas others were entirely novel. The effects of stigma on healthcare workers' ability to discuss PrEP were considered for the first time in a UK-based sample, as were the consequences of widespread medical mistrust. Key considerations and ideas pertaining to community engagement were contemplated, and participants discussed the importance of recognising how different segments of the population might benefit from more tailored promotional efforts. Findings will now be discussed in the context of the existing literature along with implications for practice. Limitations of the study will be considered, followed by suggestions for future research and a summary of conclusions.

Taboos and Stigma

The first theme identified in the present sample indicated that in order to raise awareness of PrEP appropriately and effectively, healthcare professionals must overcome the manifold effects of taboos and stigma. According to Goffman (1963), stigma can be understood as a social practice that "marks" an attribute with negative value, and the bearer with a "spoiled identity". This reduces their status from a "whole and usual person" to a "tainted, discontinued one" (Goffman, 1963). Given the stigma surrounding PrEP, PrEP users may experience similar differentiation and devaluation as a consequence of its use, or even being seen asking about it (Calabrese, 2020). Indeed, previous research has shown how fear of judgment can prevent people from discussing PrEP within their communities and with healthcare workers. A desire to avoid being singled out and stigmatised thus constitutes a barrier to accessing information. The current study builds on this point by demonstrating how the issue persists in the present London-based sample.

Healthcare workers themselves were described as similarly affected by stigma, potentially preventing them from initiating the necessary discussions. This was a novel finding, as much of the research to date on PrEP awareness

has focused on the general public. The importance of incorporating conversations around PrEP into policy, e.g. in line with MECC, and ensuring that staff have the tools to act sensitively and knowledgeably, were highlighted. These suggestions are also likely to help combat stigma, as making such discussions routine reduces taboos and dispels negative associations (Calabrese et al., 2017).

The role of stigma is also made apparent by participants' opposition to the promotion of PrEP as being for people at "high risk". Previous research has shown that racially targeted anti-HIV campaigns worsen the effects of stigma (National Aids Trust, 2014; Rogers et al., 2019) and an emphasis on identity-based risk does not actually promote PrEP uptake (Calabrese, 2020). As Golub (2018) notes, given that HIV itself is socially stigmatised, individuals "at risk" are discredited by association, rendering such designations inherently stigmatising. People's desire to distance themselves from stigmatised attributes may cause such messaging to have an alienating effect, as exhibited by the present sample's instinctive resistance towards the vulnerability inherent in identifying with a "high risk" group. Prior research has also shown that feelings of vulnerability can lead to denial, with counterintuitive results (e.g. avoiding PrEP altogether so as not to feel like a victim) (Morris & Swann, 1996). The suggestion to focus on when to start PrEP made by one of the participants was novel and provides a less emotionally charged alternative.

Medical Mistrust

Medical mistrust was identified as another obstacle to raising PrEP awareness effectively, preventing people from seeking out or obtaining accurate information. Historical medical mistreatment was cited as a reason why BA people would be unwilling to engage with new medications, as was the presence of misinformation and conspiracy theories. US findings on the subject were therefore found to apply in a UK-based sample for the first time. These results are in line with Jaiswal and Halkitis's (2019) description of medical mistrust as arising from historical and ongoing injustices experienced by marginalised groups. As the authors note, it is important to avoid the conceptualisation of medical mistrust in this context as a "cultural barrier", which implies it to be a characteristic of the marginalised population at hand, rather than a result of systemic mistreatment. The responsibility to rebuild trust and overcome conspiracy beliefs must lie within the institutions and entities that have created an environment of mistrust in the first place (Jaiswal & Halkitis, 2019). Participants' suggestion to hold in-person events and validate people's experiences highlights this point of view and represents a step in the right direction.

Local Engagement

Participants made a number of suggestions on how local engagement could help raise PrEP awareness effectively and appropriately. Engaging communities in health promotion, research, and policymaking has previously been proposed as an effective strategy for improving health among disadvantaged populations challenged by financial barriers, language barriers, poorer health literacy, and a lack of awareness of existing health resources (Riggs et al., 2012). However, the exact components underlying successful community engagement are not well-understood (Cyril et al., 2015). In the present sample, the benefits of collaborating with community groups to organise in-person events were highlighted. Furthermore, it was proposed that placing brief, essential pieces of information about PrEP in spaces frequented by the BA community would be ideal. This point echoes findings from Di Giuseppe and colleagues (2019), who identified religious events and festivals as opportunities to raise awareness. The present study extends the list of venues to include libraries and churches. The influence of faith groups within the BA community was also discussed by the present sample, confirming a report by the National Aids Trust (National AIDS Trust, 2014).

In line with findings from US samples, participants noted how practical concerns such as ease of access and suitable timing should be considered when planning awareness-raising events. According to the COM-B model of behaviour change, individuals' engagement in desired behaviours depends on their capability (C), opportunity (O), and motivation (M) (Michie et al., 2011). The location and timing of events are relevant to the physical opportunity component of this model. Ensuring that events are geographically convenient and do not clash with work schedules is thus thought to increase people's likelihood of attending. Social opportunity is also a part of the COM-B model, comprising cultural norms and social cues. In the present study, participants described how choosing a location too well-connected to the community could trigger concerns about anonymity, a finding echoed by the US samples (Rice et al., 2019; Rogers et al., 2019; Witzel et al., 2018). Providing people with the opportunity to learn more about PrEP, therefore, necessitates accommodating to both physical (i.e. time, location) and social (compliance with cultural norms) aspects.

Diversity of the BA Community

Participants made the point that to raise awareness appropriately and effectively, diversity within the BA community ought to be recognised. Different mediums of advertisement were said to reach different age groups, and the variety of faiths within the community would necessitate engagement beyond the church. Though this issue had not come up explicitly in the

literature before, research involving Black MSM has discussed similar points through the lens of intersectionality theory. Intersectionality theory attempts to understand the ways in which different social identities interact to influence behaviours and their outcomes, recognising the heterogeneity of minority populations (Witzel et al., 2018). Multiple, intersecting identities (e.g. race, poverty, gender, and sexuality) are seen to impact a person's exposure to discrimination, access to healthcare, opportunities, and interpersonal relationships (Rogers et al., 2019). In the context of raising PrEP awareness, successful promotional efforts may require tailoring to the diverse interests and requirements of subpopulations within the community. In Di Giuseppe and colleagues' (2019) focus group, for example, gender was brought up as a factor influencing individuals' interest in PrEP, with PrEP viewed as an empowering tool for women struggling to negotiate safe sex with partners who refuse to use condoms. Efforts to promote PrEP to women could therefore benefit from focusing on this feature. The present study expands on this point by suggesting that similar adjustments could be made according to the target audience's faith and age, too.

Strengths and Limitations

This paper builds on the currently very limited body of research on the subject of PrEP awareness within the UK's BA community. A number of findings from US-based samples were replicated whereas other points were entirely novel. The present study's primary focus on PrEP awareness rather than uptake served to highlight key issues pertaining to the spread of information, e.g. misinformation, how to present information to avoid stigmatisation, and whom to target when spreading information. Having the sample consist of individuals currently working in sexual health also contributed to the breadth of points identified, as participants were able to communicate with fewer inhibitions than the general public may have. Furthermore, participants had a range of experiences to draw on – e.g. Come Correct, promoting the COVID-19 Vaccine – that helped them determine what had worked and what hadn't in the past. Finally, their position as healthcare professionals allowed participants to describe the challenges involved in raising awareness as experienced on the providers' side. As previous research has shown, competent and helpful staff are a critical component of people's ability to access the information they need. Any insights on the barriers to this on professionals' side, as well as the general public's, are beneficial and help design future interventions.

On the other hand, a number of limitations must be recognised. The present sample was made up of only two participants, and though they did have a broad range of experience, this number is insufficient to reach saturation – i.e., the point at which additional data would not lead to new themes (Given,

2016). Indeed, the diversity of findings from the three previous UK studies illustrates how many more perspectives remain to be voiced. Additionally, one participant mostly drew on her experience working with young people. Though narrowing the focus in this way sheds light on the particular experiences of this subpopulation of the BA community, the points made by this participant may not apply in the same way to older segments of the population. Because both participants worked in healthcare, their experiences are also not directly representative of the general public, and the perspectives presented on behalf of the general public are second-hand accounts. After working in sexual health for an extensive period of time, their concerns may differ from those that members of the public would describe for themselves. Finally, because the participants knew each other, they may have been less inclined to disagree than strangers. This may have restricted the presentation of alternative viewpoints throughout the discussion.

Implications

A number of implications follow from this research. In practical terms, raising awareness of PrEP effectively and appropriately will necessitate consideration of the effects of stigma on both healthcare workers and the general public. Advertisements must assure prospective PrEP users of confidentiality and avoid stigmatising language. Relatedly, staff must be knowledgeable and sensitive when discussing PrEP with potential users. American researchers have described ways of increasing staff sensitivity and education (Rogers et al., 2019); similar programs could be developed in the UK. To reduce stigma, PrEP-related conversations in healthcare must also become more routine. Having staff discuss PrEP with all patients, rather than just those at "high risk", might constitute a more inclusive approach (Calabrese, 2020). Furthermore, medical mistrust within the BA community must be accounted for when attempting to raise PrEP awareness, and in-person events provide the opportunity to address concerns. Essential information about PrEP should be made available at venues frequently accessed by the BA community (e.g. libraries, community walls, places of worship).

Following the COM-B model of behaviour change, it is necessary to ensure that individuals have both the physical and social opportunity to attend educational events about PrEP. This means determining times and locations with care, balancing confidentiality with ease of access. Results also build on intersectionality theory, highlighting the presence of multiple intersecting identities within the community that might influence how people ought to be reached. Different segments of the BA population in London may consider different information relevant and might benefit from different approaches to raising awareness.

Future Research

The present study is only a first step towards understanding the concerns relevant to raising PrEP awareness within the BA community. Research with larger samples, as well as samples involving the general public, is required. Yet, even recruiting the two participants involved in this study was a challenge. Lack of smartphone access or data were obstacles preventing some potential participants from joining the study, and it was difficult to coordinate a time that suited more than two people. Not only did this limit the number of participants who could ultimately take part, but it is also likely to have biased the representativeness of the sample. Future researchers should take into consideration such issues when planning recruitment so that they are able to also represent more deprived segments of the BA community.

Many of the points made throughout the focus group were novel and require expanding on. Having recognised the diversity of the BA community in London, it will now be necessary to conduct more in-depth research on communicating information according to the preferences of subpopulations. Similarly, participants' warnings against marketing PrEP as ideal for people at "high risk" means that better approaches must be identified. Golub (2018) has suggested that instead of risk-based marketing, for example, messages could take a more empowering approach, indicating PrEP for "people who want to reduce their anxiety about HIV" or "take greater responsibility for their sexual health". More research is needed to determine what the best approach might be for London's BA population.

Finally, with respect to the longer-term goal of increasing PrEP uptake, it is important to remember that raising awareness in itself will likely be insufficient. Though the lack of awareness within the BA community is certainly an obstacle, knowledge does not often equal behaviour change on its own (Nwokolo et al., 2011). Further research is needed to understand the barriers and facilitators to uptake within samples from the general public that are PrEP-aware.

Conclusion

The present paper focused on increasing awareness of PrEP within London's BA community. A number of novel insights and areas for future research were identified, shedding light on an under-researched area. Participants advocated for reducing stigma, addressing medical mistrust, increasing community engagement, and recognising the diversity of the BA community to raise awareness appropriately and effectively. In spite of the study's limitations, recognising these barriers and opportunities for improvement

constitutes the first step towards ensuring that all those who could benefit from PrEP know about it and can take full advantage of its potential to remedy existing health inequalities.

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Appendix A

What is PrEP?

- PrEP stands for Pre-exposure HIV Prophylaxis. It is a pill taken by people who are HIV-negative, taken before sex as a way of reducing the risk of being infected with the virus if they are exposed to it. Ideally PrEP is taken on an ongoing basis, starting before sex and continuing after.
- PrEP works for men and women, cisgender, transgender, heterosexual and gay people.
- Although highly effective when taken regularly, as directed, PrEP does not prevent other sexually transmitted infections (STIs), or pregnancy.
- Before starting PrEP, you need to have an HIV test and a kidney function test.

Sources:
https://www.nhs.uk/conditions/hiv-and-aids/prevention/
https://prepster.info/free-prep-uk/

Accessing PrEP

- As of 2020, PrEP is free and available through the NHS to people who are considered to be at higher risk of becoming infected with HIV, no matter their immigration status. They include, but are not limited to:
    - People with a current or previous partner with HIV
    - People who are, and/ or who have a current or previous partner who is from an area with high HIV rates
    - People who have multiple sexual partners
    - MSM and women who have unprotected sex with MSM
    - People with a history of STIs, hepatitis B or C
- Uptake has been much higher among some groups than others. While awareness and uptake are highest among gay and bisexual men, for example, previous research has shown that Black African men and women – especially those who are heterosexual (straight) are less likely to know about PrEP or how to access it.
- It is obvious that there may be difficulties in accessing PrEP by communities who could benefit from it, which is unfair and needs to be addressed.

Current Aims

- Our aim with this focus group is to better understand the barriers faced by members of our local Black African communities in terms of

accessing information about PrEP – what it is and how to access it. As noted earlier, current statistics have highlighted poor awareness of PrEP within BME communities. We want to remedy this so that anyone who could potentially benefit knows about PrEP and is able to learn more and access it, if they choose to.

- Your comments are really appreciated and will be used to come up with key recommendations to be taken forward by local authority sexual health commissioners and commissioned service providers, so thanks again in advance.

Any questions?

Appendix B

Student 17065184: Yeah. That makes sense. I was going to ask because of your experience working in healthcare specifically, what do you think the challenges people face might be in healthcare?

Participant 1: Yeah. And you see it- like I said, you see it with the COVID vaccine as well, you do see it with the COVID vaccines. [Participant 2] and I, we've been doing assemblies on the COVID vaccination and you hear young people talk about, you know, this isn't something for our community, this is- they're trying to get rid of- there's all these conspiracy theories, you know, people are saying they're putting chips in your arms, they're doing this, they're doing that… so I think there has to be consideration for the historical and political impacts faced by Black African communities.

- Parallels w COVID vaccine
- Parallels w COVID vaccine
- Medical mistrust
- Conspiracy theories
- Consideration for history behind medical mistrust

Student 17065184: Yeah. Do you think… what would be the best ways to recognize that?

Participant 1: I think it's about the way you give out information. If you're giving out information to people face to face, I think, hear those concerns and validate those concerns, and… yeah, I would just hear those concerns out, and you know not dismiss them. Um, but this is why representation is so important as well, because if people are saying "Oh well, you know, can't think of any famous actresses right now, but Jada Pinkett Smith is taking PrEP, so it must be okay!" But yeah, I think that representation matters, but also for professionals who are promoting this information, especially if you're doing face to face or education sessions, it's about listening to people's concerns, validating it and not dismissing it. Um, yeah that's what I would say.

- How to manage medical mistrust
- Recognising reasons for medical mistrust, don't dismiss them
- Importance of representation

Partners

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