



Addressing the Needs of Black, Asian And Minority Ethnic Communities in Relation to HIV

APPG On HIV And AIDS Inquiry

July 2021

Acknowledgements

We would like to thank the APPG for the opportunity to respond to the inquiry on the needs of Black, Asian and Minority Ethnic Communities, on behalf of our service participants, volunteers and staff at Positively UK.

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Overview of Positively UK

Positively UK is a leading charity that provides peer-led support, advocacy and information to anyone living with HIV in the UK, to manage any aspect of their diagnosis, care and life with HIV. Two-thirds of Positively UK's services participants are from racially minoritised communities, as it is nearly 60% of our staff. We are firmly committed to ensuring that the health, wellbeing and rights of those communities are upheld.

All our frontline staff are living with HIV and have accredited training in mentoring and treatment literacy that enables them to support others in an effective, compassionate and professional way. We work in partnership with the NHS; our peer work is integrated in HIV clinics across London. We run a range of peer-led support groups for women, heterosexual men and women, gay men, older people and young people.

Our workshops enable people to develop self-management skills to live a long and healthy life with HIV, to navigate a new HIV diagnosis, and to be supported when planning parenthood. Specifically, we have produced a series of events and workshops to explore and address the health needs of our racially minoritised service participants, to support them in accessing health and social care services, and to advocate for their rights to health.

We offer training to people with HIV to deliver effective peer support. We also collaborate with clinics and voluntary organisations around the UK to establish peer support programmes. We believe that people living with HIV are best placed to support each other and advocate for their own needs. To achieve this, we promote patient leadership through skills-building initiatives such as our [Project100 training](#) programme and [Changing Perceptions campaign](#).

APPG on HIV and AIDS

In our response we focus on:

- The impact of COVID-19 and lockdown on access to services
- Mental Health
- Loneliness & Isolation
- Access to support for mental health and emotional wellbeing
- Adherence to medication
- Impact of socio-economic factors
- Impact of racism stigma and discrimination
- Involvement in decision making
- Addressing Stigma
- Peer support
- Conclusion and recommendations

In order to provide evidence for this consultation we have engaged with our services' participants through a short survey.

A note on language

In this report we use the term 'racially minoritised'. We believe the term 'BAME' centres 'whiteness' and erases difference. The term 'racially minoritised' explicitly acknowledges the process (and cause) of differential allocation of power and resources¹.

Methods

We conducted an online survey composed of 25 multiple choice questions, with free text sections. Section one focused on the impact of COVID-19 and lockdown. The second section of the survey had specific questions for racially minoritised people, designed to respond to this consultation. The survey was open for 17 days and was publicised to all people with HIV through emailing those on our database and via social media and UKCAB.

¹ Selvarajah S, Deivanayagam TA, Lasco G, et al, [Categorisation and Minoritisation](#). *BMJ Global Health* 2020;5:e004508.

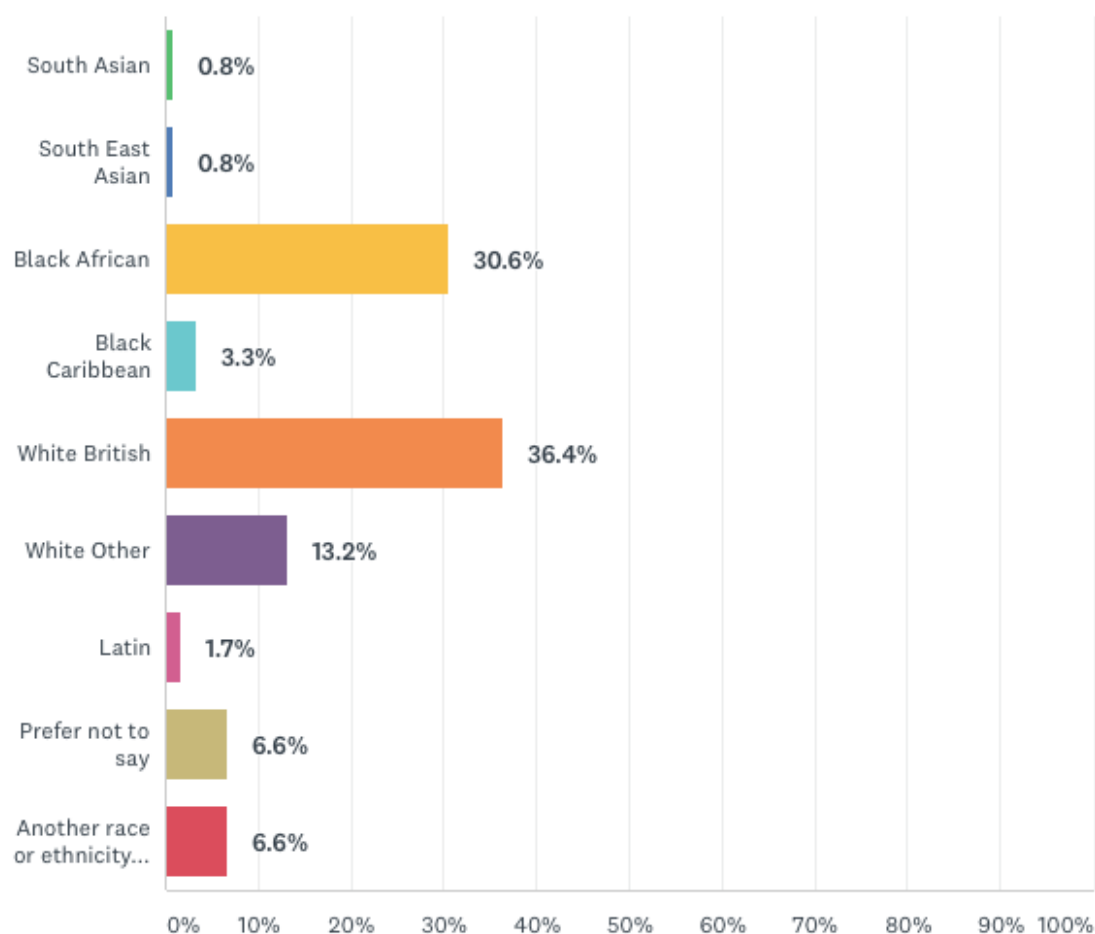
Results

On total we received 124 responses; 53 were from people who identified as from racially minoritised communities. For the purpose of this submission, we focus on the responses from those from racially minoritised communities.

Among the 53 respondents from racially minoritised communities, 79% were female and 11% male. We had no participants who identified as trans or non-binary. Most participants were aged between 45 and 54 years (51%); over one-quarter were aged 55+ (28%); only 2% were aged 18-25.

Seven out of ten respondents were Black African, 7% were Black Caribbean, with smaller proportions and numbers from other ethnic groups (Figure 1).

Figure 1: Participants per race or ethnicity



Impact of Covid-19 and lockdown on access to services among racially minoritised people living with HIV

Over half (51%) of racially minoritised participants reported that their access to HIV clinical services worsened during lock down, whilst 38% found 'no change', and 9% reported an improvement. Barriers included reduced clinical services (45%) and difficulties booking appointments (31%). Participants also reported problems getting medications and repeat prescriptions (13%).

"Although access to treatment/clinical services has increased, it's very difficult to explain physical symptoms for the clinician to understand the extent of the problem. Leaving me vulnerable if have been given the right prescription for my symptoms."

"Prefer face to face appointments. Hate phone calls and lack of human interaction if you will."

A minority (9%) found that access to HIV clinical services had improved during lockdown, largely as a result of the greater flexibility afforded by online service provision.

"[It's] easier to talk to consultants over the phone when there are no issues. There is always the option for a face-to-face appointment."

Three-quarters reported poorer access to general health care including GPs. Most of the difficulties accessing health care were due to reduced services and difficulties booking appointments; 10% identified poverty as a key obstacle in accessing health services.

In terms of sexual health screening, 41% had been able to access sexual health services, whereas 33% reported not being able to; the remainder reported no need for sexual health screening during this time.

Mental Health

It is well recognised that people with HIV are disproportionately affected by poor mental health (*Positive Voices 2018*). Mental health issues have been exacerbated by lockdown.

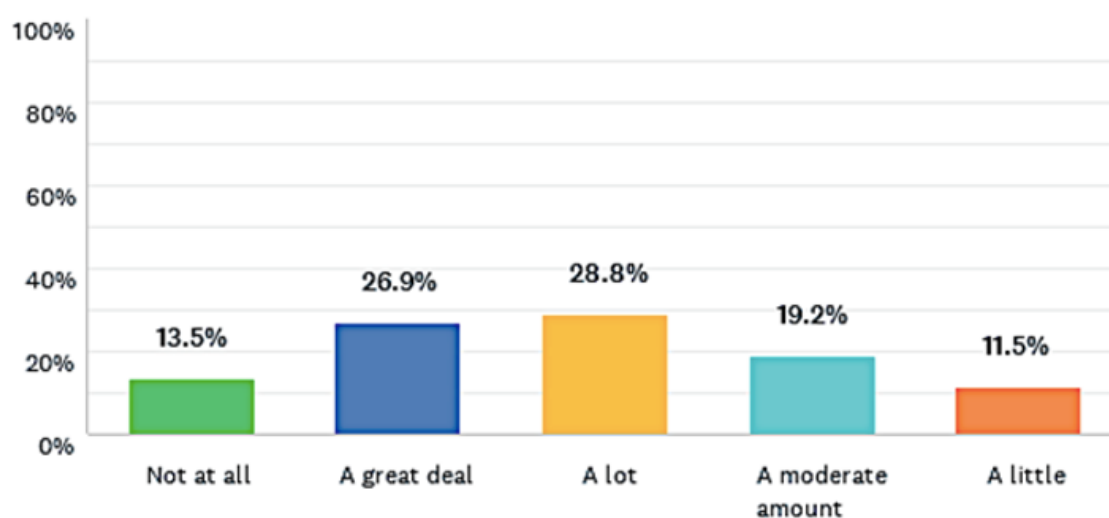
Recent research among women living with HIV has revealed that Black African women are more likely to report current psychological distress than White British women².

Overall, 64% of all 124 respondents of all ethnicities said that they had experienced mental health issues during the lockdown.

Loneliness and Isolation

Over half of racially minoritised respondents reported that loneliness and isolation had affected them a lot or a great deal (56%, figure 2).

Figure 2: Loneliness and isolation among racially minoritized people with HIV



² Solomon D, Tariq S, Alldis J, et al, [Ethnic inequalities in mental health and socioeconomic status among older women living with HIV: results from the PRIME Study](#) *Sexually Transmitted Infections* Published Online First: 29 March 2021. doi: 10.1136/sextrans-2020-054788

Impact of changes to clinical services

Whilst the majority (58%) of White British, and White Other respondents reported that changes to access to clinical services during lockdown had no or little impact on their mental health and well-being, only 29% of racially minoritised people reported no or little impact; nearly half (47%) stated that changes to services during lockdown had a great deal of impact on their mental health and wellbeing (Figures 3 and 4 below). **We suggest that this may point to a higher level of need for face-to-face clinical services among racially minoritised people living with HIV.**

Figure 3: Impact of changes in availability of support services among racially minoritised people

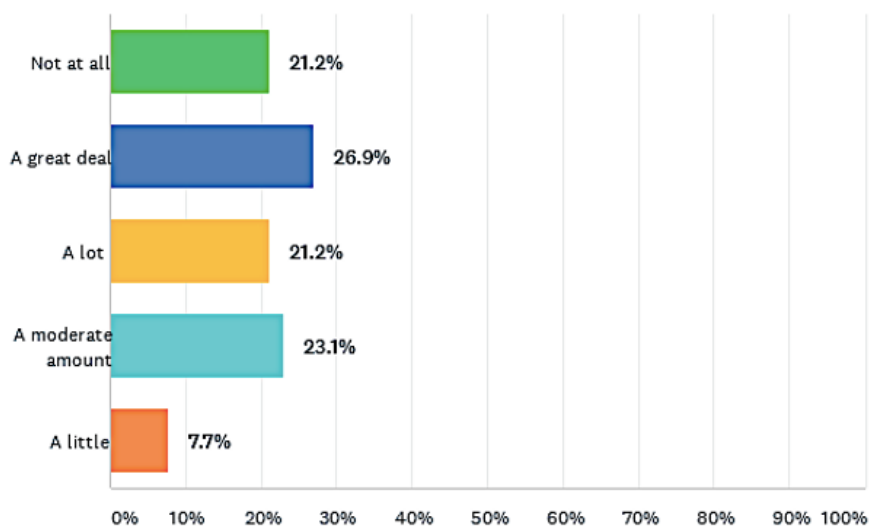
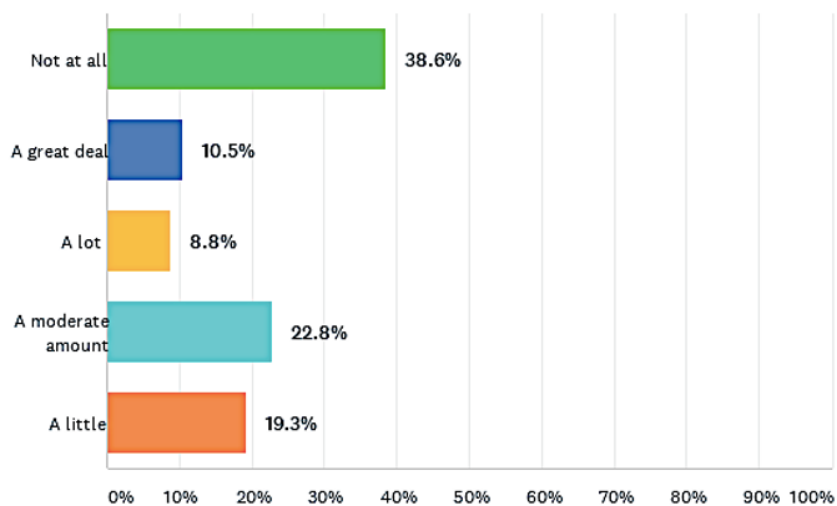


Figure 4: Impact of changes in availability of services among White British and White Other

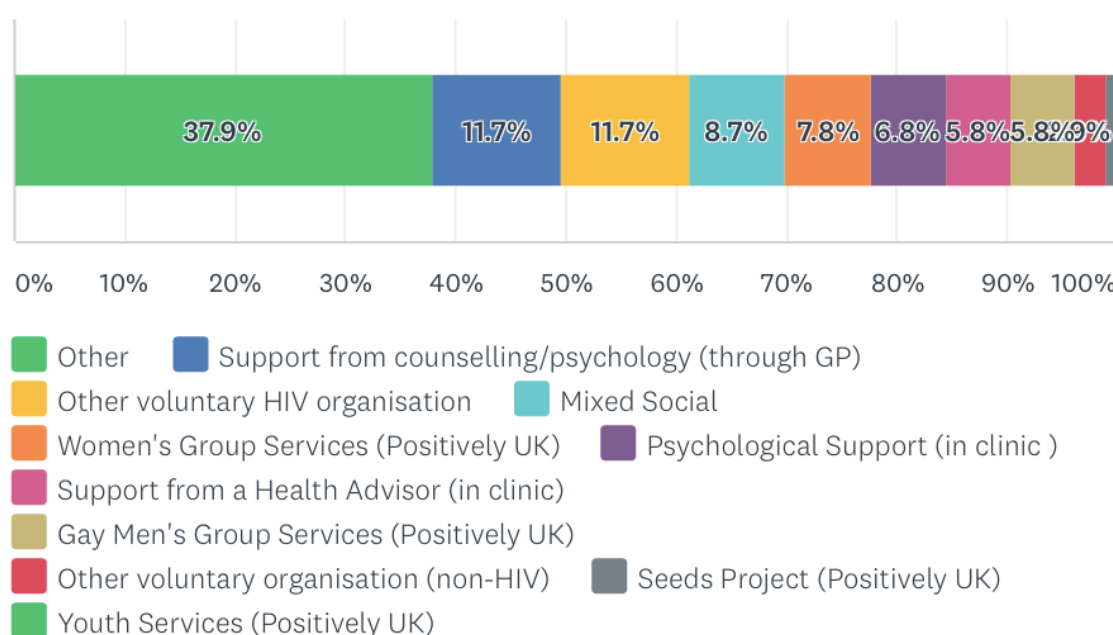


Access to support for mental health and emotional wellbeing

A large number of racially minoritised participants had used Positively UK services during lockdown as a source of mental health support (Figure 5).

“What services / groups have been supportive - all of the services at Positively UK, including advocacy and support accessing money to manage hardship and digital poverty! Thank you, Positively UK”

Figure 5: Support around mental health and wellbeing that people have been able to access during the pandemic

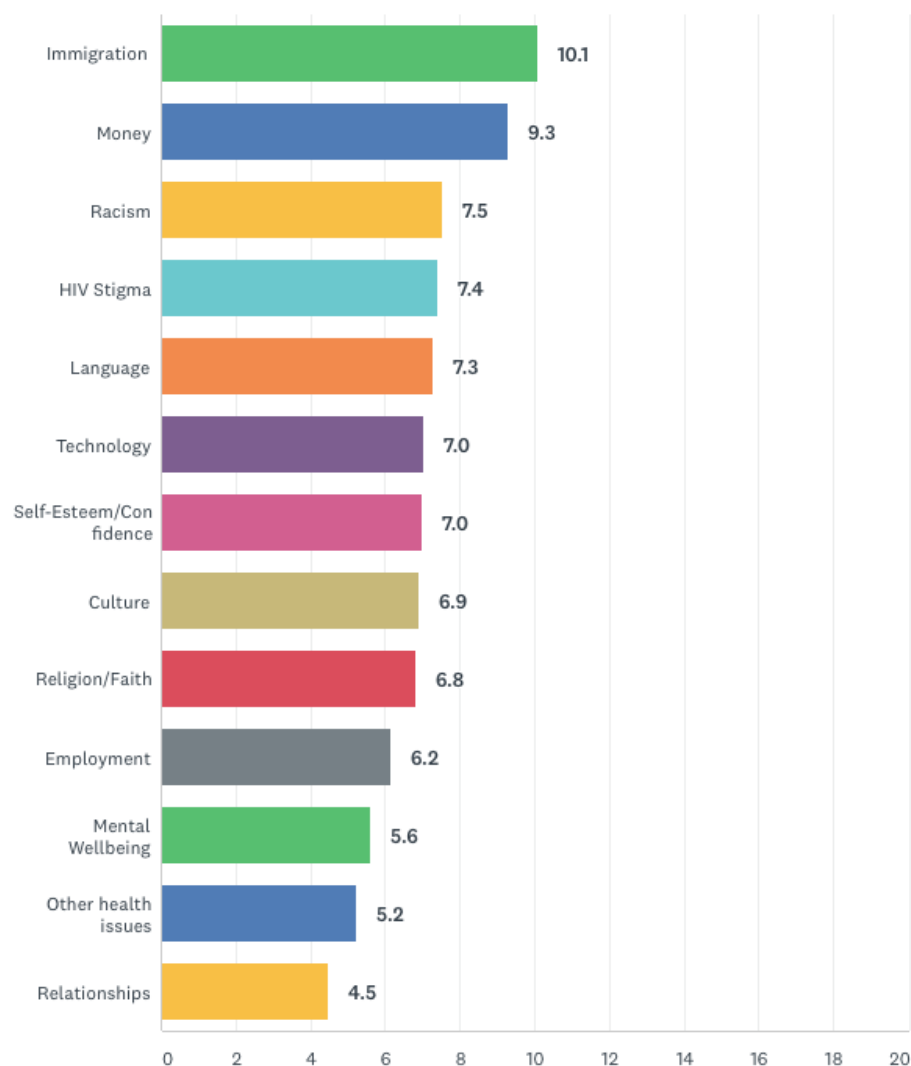


Adherence to Medication

One-in five (21%) racially minoritised respondents stated that their medication adherence had worsened during COVID-19; 41% stated that they had 'too much going on', a third (29%) reported that this was due to mental health difficulties, and 6% said they had difficulty obtaining prescriptions. This contrasts with 7% of White British, Irish and White Other respondents who reported a decline in adherence over the same time period. Socio-economic challenges

When asked to rank the most pressing issues they were facing, racially minoritised participants identified immigration, money, racism, language and HIV-related stigma as key (Figure 6).

Figure 6: Socio-economic challenges



'All the above listed affect black people all of the time at different stages of life!'

Nearly all (95.7%) racially minoritised respondents stated that racism, stigma and discrimination impact communities of color a great deal or a lot.

For many, the intersecting experiences of being from a racially minoritised group and to be living with HIV, amplified experiences of stigma and discrimination.

"Stigma being with HIV and double stigma for black. Before I was HIV positive a guy told me he could never date me as most African have HIV and he gives blood and he couldn't take the risk."

"We are rarely heard and seeing so many black people dying during the pandemic, and with all the theories which came out blaming them for dying in big numbers made us even more vulnerable. There is a blame culture that everything is blamed on black people and other communities of colour hence creating isolation, anxiety and delays accessing vital services when needed. Also reduce trust when sharing information for fear of being judged. We are marginalised getting suitable accommodation, accessing benefits and care especially mental health services. Sometimes due to language barriers can't get service needed, as cannot express the needs as no one to interpret. Even in jobs we are paid less than our colleagues when doing the same job etc."

"The assumption that because you are black and living with HIV all your illnesses are linked to HIV, sometimes I'd appreciate if I'd meet a healthcare professional and they paid more attention to what I am telling them rather than the HIV."

"People of colour live within communities in the UK. People are scared to be identified as this is associated with lifestyle and morality. Racism is still rife in some workplaces, healthcare settings etc. All this disempowers people of colour"

"You always have to be prepared. If you ask for something that it's your right you are immediately labelled. It's everywhere."

"A lot of white people think that black people are spreading HIV to white people. People of colour, black to be specific."

"[There are] no opportunities for black people living with HIV."

Some hadn't shared their HIV status with anyone, suggesting internalised stigma, which is known to be associated with loneliness, isolation and poor mental health.

"People won't even come around you if they know."

"Never encountered it because I don't talk about it with anyone rather than my consultant."

"I think stigma is the main problem within black African people"

"I have experienced a lot of stigma, discrimination, being thrown out of work places singled out, framed and exclusion or last. Persecution you name it everything"

Furthermore, respondents identified how being from a racially minoritised group and/or their immigration status negatively impacted their access to and experiences of health services.

"Both stigma and racism combined affect how black people receive services!"

"U can't get the medication except if u r citizen otherwise u get expulsion or leave to die just like me because I'm refugee they can't expulsion"

"Profound Isolation and lack of mental health support and supportive networks."

"Less services of black minorities group and support groups."

"I get raped when I was a kid by 4 people and even with that I can't get the medication because I'm just refugee here - also physical violence."

Addressing disparities

Involving racially minoritised people with HIV in decision-making

Over half (55%) of respondents stated that they were rarely or never involved in planning or policy or service provision.

"Most of the times we are never involved at all especially women "

"The HIV sector does [involve us] but not in other areas of health."

“Positively UK engages with all the communities of PLHIV”

“We would like to be at the table where decisions on healthcare and services are being designed for us.”

Addressing stigma

Education, raising awareness and training was identified as the priority with almost all participants including it in their suggestions; several respondents highlighted the need to train healthcare professionals around HIV and the impact of stigma.

Holistic person-centred support services, including poverty reduction and housing with a focus on those who are ill, experiencing emotional distress, and those with social needs.

Community engagement and campaigns, led by people living with HIV from racially minoritised communities (including outward-facing community events), with a focus on engaging women and under-represented ethnic groups (including South East Asian people).

Intersectionality, providing empowering spaces, where stigma can be analysed and understood in an intersectional context, in connection to other forms of oppression and discrimination, including racism and attitudes towards sex, gender and sexuality.

Peer Support

The majority of racially minoritised respondents found peer support to be helpful or extremely helpful (65%) whereas 10% stated that it was not helpful at all.

“[It] is the only space and with people where there is no stigma and hence to be able to talk and share...to be open about your HIV or any other statuses!”

“Peer Support has helped me a lot since I was diagnosed up to present. Without it I don't know where I would have been or done...”

“Having been diagnosed in 2002, I quickly accepted my HIV status through seeing other black women living well with HIV. I was supported and empowered to live well with HIV.”

“People of different races and genders mix at the Seeds project [a gardening project] and help and support each other’

The holistic and person-centred nature of peer support was recognised as highly beneficial.

“Peer support was a life saver during the pandemic as I live on my own. They kept in touch.... to make sure I was ok and re-assuring me and making sure I had all the information I needed and at some point, advocated for me to get food, top up my phone so I can keep in touch with loved ones back home, accessed a grant I was financially struggling. Made sure I attended on line Mixed social to reduce isolation by going through with me the process of joining.”

“Network supporting each other emotional, psychological, socially, financial or material.”

“Lunch positive. It’s the best social thing I look forwards to once a month. Good company, food for the soul, compare notes of meds, menopause, vivid, benefits system etc.”

However, there was recognition that groups needed to be even more diverse:

“There are no people from other ethnic backgrounds apart from just African or European. Very little people from Asian communities.”

Conclusions and Recommendations

Our survey highlights the wide-ranging impact of COVID-19 and lockdown on racially minoritised people living with HIV. It has had a significant impact on access to HIV services, primary care and sexual health screenings. Lockdown has exacerbated poor mental health, loneliness and isolation and this has been linked to problems with medication adherence. As we have seen throughout the literature on COVID-19, it has exacerbated existing social inequalities and health inequities. Immigration, poverty and racism were identified as the key challenges faced by racially minoritised people living with HIV right now.

Racially minoritised people living with HIV have no doubt that the intersection of racism, HIV-related stigma and discrimination impact on their ability to access services and live good lives. Moreover, the majority do not feel involved in the strategic planning and delivery of services, especially outside the voluntary sector.

In terms of addressing HIV-related stigma experienced by racially minoritised people we highlight the following key points:

Educate the general public, healthcare providers and schools.

Support services provided by the voluntary sector are fundamental in mitigating the impact of stigma and should be invested in.

Improve diverse community engagement and promote racially minoritised community leadership.

People from racialised communities living with HIV urgently need spaces and programmes where they can analyse and challenge stigma in an intersectional way that includes race, class, gender and sexuality.

Finally, there is need for a campaign developed and led by racially minoritised people with HIV that can challenge stereotypes and influence decision-making.

We must be guided by these communities when finding a way forward to a more equitable provision of services.

We recommend that the health and social-care sectors, both voluntary organisations and statutory bodies, develop Engagement, Diversity and Inclusion Assessments. Those would aim to increase transparency and accountability, and shed light on how to support the involvement of racially minoritised communities living with HIV in all aspects of service design, implementation, monitoring and evaluation.

We also recommend substantial funding for long term programmes by and for racially minoritised people with HIV which enable those communities to influence policy, service design and delivery.

We advocate for person-centred holistic peer support, that includes social activities, information updates, financial and practical support. This is a crucial source of support for marginalised people living with HIV, and should be accessible broadly.

involving +
advocating
learning +
+

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