



Patrons:
Professor Jane Anderson
Professor Baron Peter Piot
Judge Michelle Brewer – Barrister
Alice Welbourn

APPG Inquiry into HIV and COVID-19 **Response from Sophia Forum, June 2020**

1. About Sophia Forum

2. The Sophia Forum promotes and advocates for the rights, health, welfare and dignity of women living with HIV through research, raising awareness and influencing policy. We work directly with women across the UK to educate and empower them on issues including sexual and reproductive health, mental health and the menopause. This direct contact enables us to find out the issues that are of primary importance to women living with HIV and tailor our advocacy and policy outputs accordingly. Recent publications have focused on the experiences of young people (18-30) living with HIV, as well as the needs of women 45 years and over ageing with HIV.

3. Survey Introduction

4. We sent out a survey across our social media channels in order to capture the experiences of women living with HIV during the COVID-19 pandemic. We received 75 responses in total. Below is a breakdown of the characteristics of the respondents¹:
5. 92% identified as women (both cis and trans women), 5% as non-binary and 3% as intersex.
6. 4% of respondents' gender identity is not the same as that assigned to them at birth.
7. 81% were heterosexual, 11% bisexual, 3% lesbian and 3% pansexual.
8. 43% identified as White British, 28% as Black African, 11% as Black British, 7% as Black Caribbean, 7% as White other, 4% as White Irish and 1% as mixed ethnicity.
9. 40% of respondents were between the ages of 45-54, 32% were aged 55-64, 11% were aged 35-44, 7% were 65+, 7% were 25-34 and 4% were 18-24.

10. Responses to Inquiry Questions

11. **Has access to HIV treatment, care and support services been affected by COVID-19? If so, can you tell us how?**
12. Of those who answered our survey, 45% said that they have had trouble accessing HIV care during the lockdown period, with the primary issues being cancelled appointments and consultations, cancelled blood tests and a lack of access to GPs and consultants. While some of these were

¹ Totals do not necessarily add up to 100% due to rounding.

routine appointments, one respondent said that she has had 'vital appointments' cancelled. There was also concern at not being able to see medical professionals face to face.

13. There were positive stories, with one respondent stating that her clinic had been 'brilliant' and that the local HIV charity 'has really upped its game as far as outreach and online support has gone.' However, it was clear that others had much worse experiences, particularly one individual who was diagnosed with HIV two weeks into the lockdown period. Not only did the results come as a shock as she had not been aware that she was being tested for HIV, but she was not given any useful medical information or signposting to support services. This was especially difficult for her as she was told she was an elite controller, but was not informed of what this meant and had to resort to Facebook to find the answers she needed. She feels that because her status as an elite controller means that she faces a lower risk, this has meant that she has been 'left in limbo,' and while she had to risk catching COVID-19 in order to come into hospital to have her bloods taken, she has not yet seen a consultant and has been told that her situation will not be discussed until after three months when the COVID-19 situation had subsided. As a result, she has been 'left this whole time lost confused and hurting' and she now feels 'a bit lost and alone I don't know anyone who would understand how I feel.'

14. Is there evidence to suggest that COVID-19 is affecting adherence to HIV medication or treatment for co-morbidities? Please explain

15. The only responses we received regarding medication were all positive, with good feedback for clinics who had either delivered medication to individuals or who had arranged for their patient's prescription to be renewed at the beginning of lockdown to prevent them from running out during this period.

16. What are the main concerns being voiced by people living with HIV during this pandemic?

17. By far the issue that concerned most of our respondents was mental health, which I go into in further detail in the answer to the following question.

18. 25% of respondents said that their main concern during lockdown had been access to their HIV clinic, with the inability to visit the clinic and have tests being 'frustrating.' There were also concerns with the lack of access to other health and support services, with one woman who lives in a rural area finding it difficult having no services open, in particular the fact that she is now unable to go to appointments with her alcohol counsellor.

19. 13% of those surveyed said that their physical health has been their main concern, with 9% saying that their physical health had prevented them from accessing a service. For one woman, the lack of movement caused by long periods working from home has caused her osteoporosis to worsen. Two others have been facing increased difficulty at home as their helper or carer stopped visiting them due to the pandemic. This has made daily tasks such as washing themselves and cooking hot meals 'very challenging.'

20. 11% of people said that the risk of losing their job or being furloughed was their greatest concern, with 9% saying that they were concerned that they would not have enough money to pay for the rent, food or bills. One respondent was concerned that, even though she is on Universal Credit, she has debts that she is now unable to pay.

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21. Many people are also worried about contracting COVID-19, concerns which were exacerbated by a lack of information as to how this would affect them as a result of their HIV status. 21% of respondents have been prevented from accessing services because they were put on the shielding list by the Government, and a further 17% were not put on the shielding list but were prevented from accessing services as they were self-isolating due to concerns about their own health. Some of those who have had to go out either because they are a key worker or for medical appointments have been 'anxious' because of their situation, and one respondent who was on the shielding list but who had to go into hospital a few times for tests because of their HIV status found the experience 'terrifying.' Respondents also highlighted the need for more information on the effects of COVID-19 and HIV combined and what they should do if they were to catch Coronavirus.
22. Problems and concerns resulting from the pressure of having all family members self-isolating together or from having to care for relatives was also a key theme. 5% mentioned caring responsibilities as one of their key concerns, with caring for elderly parents and children being mentioned most frequently. A particular problem in this area was the stress of being unable to help with the children's schoolwork due to not having the electronic equipment needed to access this or not understanding the work they had been given. There were also problems resulting from the 'intensity of family dynamics' and a lack of support for this.
- 23. Mental health is being impacted for many people during this crisis, are people living with HIV disproportionately impacted and if so, what mental health support are they able to access?**
24. When asked what their main concern during lockdown had been, 45% of those surveyed responded with mental health (increased anxiety and/or depression,) almost double the amount of people who chose the second most popular answer, access to HIV clinic. A further 8% of people said that their main concern had been feeling increasingly isolated or afraid, and 20% said that since lockdown, their mental health has prevented them from accessing a service.
25. Some people have seen a positive effect on their mental health, through living with supportive family members or having more time to do exercise and take long walks which has improved their mental state.
26. However, a great deal more respondents had seen their mental health deteriorate, with feelings of isolation being by far the most common problem experienced. Not being able to see close family members, particularly ones who are at more risk such as those who are pregnant, aging or terminally ill, has been especially difficult. Others have found the lack of face to face contact very hard to deal with, which means that individuals have missed the support of HIV support groups which they find helpful. One woman who is a single parent described how 'days turned into weeks of loneliness ... it's been very, very hard mentally.' Some respondents found the cancellation of regular social activities such as volunteering particularly difficult, with one saying she wished she could find something 'that would make me feel wanted.' For one respondent though, it was the fact that she was able to work while others were not that made her feel especially isolated. Some of those who felt isolated were also affected by a lack of motivation or interest in general aspects of life, which seemed to go hand in hand with other issues including poor self-care, lack of sleep and appetite, a low mood and feeling 'trapped' or 'helpless.'
27. Naturally, the fear of COVID-19 as well as the heightened number of deaths throughout the population has affected people's mental and emotional states. While several people stated that

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they were afraid of catching COVID-19 or becoming ill from something else and then being admitted into hospital where they were more likely to catch the virus, others talked about how the worry of friends and family who had been ill or who were more at risk was causing them to lose sleep. Some talked about how hard it is to be surrounded by the reality of a high number of deaths, and this was especially difficult for one respondent who works for the NHS and who was therefore directly confronted with people dying on a regular basis.

28. Other respondents noticed other aspects of their health affecting their mental health, including the long-term effects of not getting as much physical exercise as before. For those who are going through the menopause, symptoms of this such as tearfulness seem to be intensified, making one individual concerned as to how much of her symptoms and experiences are 'normal.' For one respondent, these problems have been exacerbated by a shortage of HRT patches.
29. While so many people have been experiencing deterioration in their mental health, there have also been concerns that mental health support services have been more difficult to access. One woman said that she now found it difficult to receive counselling since she does not have a confidential space at home to talk, while another said that 'there is no support for returning to work, or find[ing] a new job, when you are affected by mental health issues.'

30. What employment issues are people living with HIV having in relation to COVID-19?

31. 11% of those surveyed said that their main concern during lockdown had been the risk of losing their job or the fact that they had been furloughed, and 3% of people said their main concern had been the fact that they needed to keep travelling to work as their employment required this. 5% of people said that being a key worker and therefore the need to keep working prevented them from accessing a service.
32. While there was some concern about a lack of support to help people back into work, the most common employment-related issue brought up by respondents was the concerns of those who had to continue going to work because they were key workers. This ranged from increasing anxiety about catching COVID-19 (made worse by fear of how this would interact with their HIV status) to the mental and emotional struggle of a working environment in which there were a growing number of deaths.

33. Why are BAME communities disproportionately affected by COVID-19 and is this effect more acute for BAME people living with HIV?

34. Comparing the survey answers given by our BAME correspondents with those given by our white correspondents, there was a noticeable difference in several areas. Firstly, 51% of BAME respondents stated that they have had trouble accessing HIV care compared with 40% of White respondents. While the primary reason for white respondents not being able to access services was the fact that they had been put on the government shielding list, this reason was only fourth for BAME respondents who had been unable to access services. Instead, the most common reason given by BAME people for not being able to access services was the fact that, while they were not on the shielding list, they had chosen to self-isolate as they were concerned for their own health (this was the case for 26% of BAME correspondents but only 10% of white correspondents.) It seems likely that for at least some of these people, this concern was down to the fact that they believed that their ethnicity made them more vulnerable, as one respondent stated that she was

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scared of contracting COVID-19 'due to my ethnicity and HIV status' and another said that she had been 'traumatised and scared I may be at risk of getting COVID-19 as I come from the community worst hit.'

35. Both BAME and white respondents were equally likely for their mental health to have limited their access to services (20% for each group,) but a much larger proportion of BAME individuals linked their experiences and responsibilities with family and/or children as a key factor in preventing their service access (20% of BAME respondents compared with 3% of white respondents.) This was echoed in the written comments we received, where BAME individuals reported increased isolation due to being a single parent or commented that they had experienced a 'lack of support to manage family issues.' BAME people were also far more likely to state that their physical health had been a barrier to them accessing services, with 14% of BAME respondents stating that this had been the case compared with 5% of white correspondents. Furthermore, 18% of white individuals taking this survey stated that they had had no problems accessing any services throughout the lockdown period, while only 3% of BAME individuals said the same thing.
36. When asked about their primary concerns during the pandemic, both groups gave mental health, access to HIV clinics, physical health and employment as their top four concerns (although for white respondents employment shared this position with other issues including increasing isolation and not having enough money to pay bills.) However, there were very clear differences in the numbers of people citing these issues as concerns. 57% of BAME respondents said that their primary concern was mental health compared with 35% of white respondents, 20% of BAME respondents said that their primary concern was physical health compared with 13% of white respondents, and 14% of BAME respondents said that their primary concern was loss of employment or having been furloughed compared with 10% of white respondents. White individuals were 50% more likely to say that access to their HIV clinic was their primary concern, (30% of white respondents compared with 20% of BAME respondents,) which is interesting considering that in our survey more BAME individuals have actually had trouble accessing HIV care (as mentioned above.) Finally, while 10% of white respondents stated that they had no concerns regarding lockdown or the pandemic, this only applied to 3% of BAME respondents.
37. The written comments we received from the BAME people surveyed regarding their mental health concerns were also generally more extreme than those received from white individuals. One BAME respondent talked about her 'unbearable loneliness', while two gave long lists of different symptoms of their poor mental health. We also received one particularly concerning comment regarding the treatment by the authorities of Black individuals, with the respondent stating:
 38. *I fear going out as a Black person but more so now. A Black friend [was] stopped twice in 3 days just for walking in April he was 2 minute[s] from his place both times on his own. He got put in the back of the police car and got questioned. My fear anxiety and anger has been so high. Need to talk about what it's like for [us] as minority groups.*
39. **How has your organisation adapted its HIV services and the work it does during this COVID-19 crisis?**
40. We had been planning to start a research project during this period on women ageing with HIV, which would have involved face-to-face interviews and focus groups with women living with HIV. As a result of the pandemic, we have had to delay the start of this project and rethink the practical aspects, rewriting our research proposal to replace the face-to-face aspects of data collection with remote data collection through video calls and platforms that enable instant

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messaging including email and WhatsApp. However, we foresee potential problems for some of those we would like to survey who do not have access to relevant IT equipment and may also be experiencing 'data poverty.'

41. We also have a second project, Project WISEUP, which is an advocacy weekend for women living with HIV. We had a planned a weekend involving the national launch of a campaign which has now been put on hold due to COVID-19.
42. **Has COVID-19 had a financial impact on your organisation or do you think it will? Are the government measures sufficient?**
43. The funding we had secured for the research project mentioned above is still available for us so we will be able to continue with this project. However, we have significant concerns about accessing core funding for our organisation and project funding to take our planned work forward.
44. **When we move towards a gradual easing of COVID-related social measures, what do you think the priorities are for the Government around HIV?**
45. Ensuring patients get to access their clinics and consultants for face to face appointments, as there is a lot of concern that the model of remote access will be adopted on a longer term basis which could be detrimental in delivery of care to patients.
46. That financial support is provided to vital third sector organisations to deliver key services that are literally lifelines to some patients.
47. **During the COVID-19 pandemic, what further measures need to be put in place to retain the UK's progress in surpassing the UNAIDS 90-90-90 targets?**
48. The roll out in the routine commissioning of PrEP in England must not be further delayed as a result of COVID-19. Prevention programmes, and continuation of the HIV Commission, must remain a priority. The re-opening of sexual health GUM clinics is a priority for vulnerable groups at risk of domestic abuse and sexual exploitation. In addition, there is an urgent need for an injection of cash into women's services, given the significant increase in domestic homicide and violence against women and girls, which is a recognised cause of increased acquisition of HIV for women. Testing remains crucial if we are to prevent new transmissions of HIV, and so additional funding for PPE to allow organisations to set themselves up to deliver socially distanced testing services is essential. Similarly, PPE will be necessary to facilitate peer support so that patients do not disengage from care, especially as new diagnoses are being reported through testing during the pandemic.

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