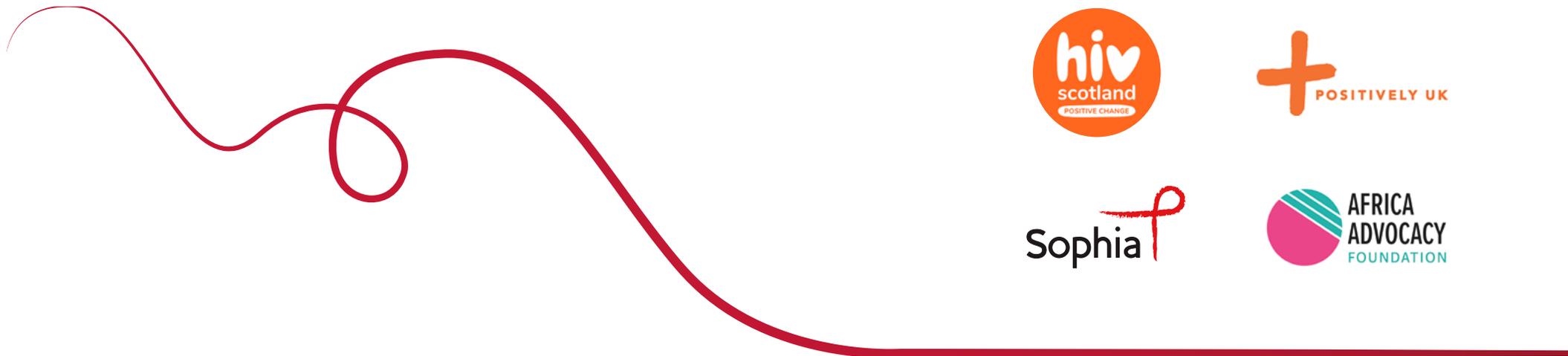




HIV, COVID-19 and quality of life: Perspectives from the pandemic



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Introduction

People across the UK and Ireland have faced unprecedented challenges as a result of the COVID-19 pandemic. **For people living with HIV, however, the pandemic has brought a unique set of struggles** as they have had to navigate life living with one virus in a world turned upside down by another.

The HIV Collective was created and funded by Gilead Sciences in May 2020 as a source of mutual support for patient organisations as they adapted to support people living with HIV throughout the pandemic. **21 patient organisations** from across the UK and Ireland engaged with *The HIV Collective* which aimed to address the 'imminent threat' challenges of COVID-19, but also to protect the future of the whole community, including the vital services provided by the charity and voluntary sector.

One of the key priorities for *The HIV Collective* was to listen to and learn from the HIV community about how COVID-19 has affected them. Before the pandemic, people living with HIV reported poorer health-related quality of life (HRQOL), self-rated health, and life satisfaction than the general population.¹ After a year of living in a world re-shaped by COVID-19, Gilead, in collaboration with four patient organisations – **Africa Advocacy Foundation (AAF), HIV Scotland, Positively UK and Sophia Forum** – carried out research to find out what has changed for people living with HIV.

The research revealed a wealth of insights about the **significant impact of the pandemic on people living with HIV and the HIV community as a whole**. Of the learnings uncovered, two in particular stand out: firstly, the toll that the pandemic has taken on individuals, and secondly, the vital role that patient organisations played in supporting the community, even as some struggled to fund the services that their members had come to rely on.

It is clear that as a collective we must find a way not only to support those living with HIV to live their best possible lives with the best possible access to care, but to ensure that the patient organisations who support them can continue to provide much-needed services. It will take collaboration across government, industry, the NHS, and the voluntary sector to achieve our shared goal – **helping people living with HIV to thrive, now and in the future**.

Methodology

To identify the impact of the pandemic on HRQOL, we carried out a **survey of 145 people living with HIV and 2,001 HIV negative people from the general population.***

Our survey probed respondents' experience of multiple aspects of daily life from the effect on their physical and mental health to the impact on their finances, use of support services, and their interactions with the medical community. **In-depth telephone interviews were arranged with eight people living with HIV** to further explore their lived experiences during the pandemic.

*Note: when conducting research sampling, groups with a low incidence rate, such as those living with HIV, require a lower overall base size to be 'representative' of the audience. With the incidence of people living with HIV in the UK being <0.2% of general population, we were able to represent the sample group using a relatively low number of respondents – in this case 145 people, or ~0.145% of the population. For larger population groups, a larger base size is required to be representative, therefore a higher proportion of people who are HIV negative were surveyed in this study - 2,001 people, or ~0.003% of the population.

Patient organisation collaborators



AAF welcomes this timely report that captures the experiences of people living with HIV during the COVID-19 pandemic.

The pandemic unravelled the health disparities faced by the Black and Minority Ethnic communities, and as an organisation we were faced with new challenges in order to meet the needs of our members, including adopting a virtual service delivery.

Many of our members reported barriers to access information, health services and culturally appropriate foods. We worked in partnership to provide culturally sensitive factual information on COVID-19 and HIV, advocacy to health services, digital and literacy support and ethnic hot meals. Without these services, many of our members would have reported substandard health outcomes.

- Africa Advocacy Foundation



The intersections faced by people and communities living with HIV are glaring in this report, and more needs to be done to address poverty and mental health. The persistent reporting of disparities in health outcomes has been highlighted further during this pandemic and it's now time to say this is no longer acceptable. Sophia Forum's peer support and advocacy work with women living with HIV continues to shine a light on the specific needs of women that must be included when developing future services – both clinical and community-based. We cannot have a one size model approach to our holistic care and needs as we move forward.

- Sophia Forum



Patient organisation collaborators



In step with the findings of this research, a 'meaningful' commitment to community engagement is more important than ever on the path towards HIV elimination by 2030. HIV Scotland has continued to connect and support people living with HIV in Scotland through our Community Advisory Network, maintaining those essential social bonds and connections throughout the pandemic. For those who required additional support during this unprecedented and challenging time we also made access to free wellbeing services available. We are grateful to the Scottish Government for their commitment to supporting HIV services by funding HIV Self-Test Scotland, enabling access to free HIV self-testing kits, throughout the pandemic, for people across Scotland.

- HIV Scotland



With people living with HIV often experiencing increased mental and physical health challenges, this research shows how these difficulties have been worsened by the COVID-19 pandemic. Thankfully, it also demonstrates how important peer support and voluntary sector support has been for so many during these challenging times. Positively UK will continue to reach out and offer support to anyone living with HIV who wants to make a connection with others.

- Positively UK

A far-reaching impact on daily life

Our research shows that **people living with HIV are 55% more likely** than the general population **to report that their daily lives have been affected by COVID-19.**

The pandemic has affected multiple areas of their lives:



Physical health



Mental health and
emotional wellbeing



Financial wellbeing



Interactions with
health services

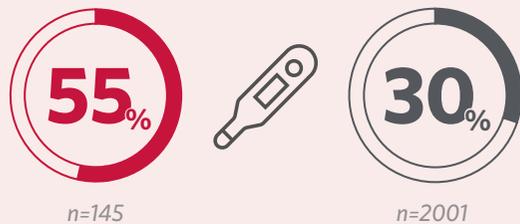
These are all areas which are highly interrelated with far-reaching impacts on quality of life and health outcomes for people living with HIV.²

Widening the health gap for people living with HIV

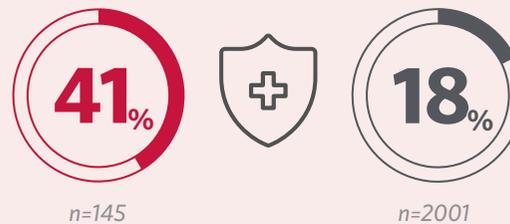
Before the pandemic, people living with HIV reported poorer physical health than the general population – **with 73% rating their health as “good” or “very good” in a Public Health England study, compared to 76% of the general population.**¹

Our research suggests that this gap may have widened further as the pandemic took its toll on the community.

Over half (**55%**) of people living with HIV report that their **physical health** has deteriorated since **COVID-19** measures were introduced (compared to **30%** of the general population)



Two in five (**41%**) people living with HIV were advised to **shield** (compared to **18%** of the general population)



One in five (**19%**) people living with HIV had to **self-isolate** – due to **COVID-19** symptoms or a positive test (compared to **12%** of the general population)



There was a lot of drop in stuff I could access before physically in person, I can't access any of those things now, it wasn't like I was accessing them every week, but it was nice to know they were there if I needed them.

Male, 49

It's worsened my existing physical and mental state...being separated from friends and colleagues and other family members, you lose that human touch and that interaction that is so important. And losing your freedom, being stuck in the house, there is a feeling of helplessness to it all.

Male, 55

A profound impact on mental health and wellbeing

For some people living with HIV, the pandemic has brought about a combination of **isolation, financial stress, and fear about COVID-19**. At the same time, some people living with HIV report that they haven't been able to access mental health services when they needed them most – either due to lack of availability, long waiting times or complicated application processes.

Four fifths (**81%**) of people living with HIV report feeling **more stressed or anxious** since March 2020 (compared to **54%** of the general population)



While **over three quarters (78%)** say their **mental health** has been affected by having less social contact (compared to **47%** of the general population)



Over a third of people living with HIV (35%) have **accessed mental health services** during the pandemic (compared to **13%** of the general population)



COVID has brought up all those initial fears, anxieties, stresses that I had when I was first diagnosed...COVID came and opened them up again... I mean in the beginning when we were diagnosed, and for a long time a simple common cold could kill you when you're living with HIV, so this brought all that back again.

Female, 60

I think the misinformation at the start, some people were told to wrongly shield, that would have added to people's stress levels. Generally, not having information about people with HIV and COVID, it's not been communicated very well.

Female, 34

A profound impact on mental health and wellbeing

“
And then the isolation, I mean I led a secluded life before by choice, but isolation is new. The difference is the choice has been taken away from me, I mean I could get up and go and meet my friends and have a cappuccino in Costa, just having people around me, talking to somebody else...and then I can't travel to see my children and my grandchildren, so I think that's one of the worst parts.

Female, 60

The immense disappointment and isolation can easily drive people to the point of suicide. I resent the respite centre being closed because we could have worn masks as I see it. I really miss social communication. It all comes down to the lack of face-to-face contact and the long hours of darkness in the winter.

Male, 65

”

Paying a heavy price

Our research suggests that people living with HIV are more likely to have suffered financially during the pandemic compared to the general population. **Immigration status, housing, family makeup and health conditions** can make it difficult or impossible to gain employment.

On top of this, organisations which were relied upon for **financial support** have not been able to sustain the same level of support throughout the pandemic.

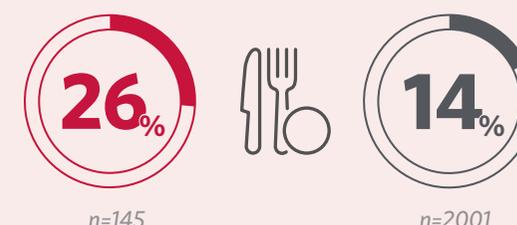
Almost half (**48%**) of people living with HIV have had regular incomes affected by COVID-19 (compared to 30% of the general population)



53% of people living with HIV are worried about meeting financial payments (rent, bills etc; compared to 35% of the general population)



26% of people living with HIV have used a food bank or received food parcels (compared to 14% of the general population)



Because I am somebody who lives on social benefits, what has impacted me was the assessment that was conducted prior to the lockdown. The decision to reduce my income impacted me big time. Finances, it's stressful and one has got to cope with what is provided.

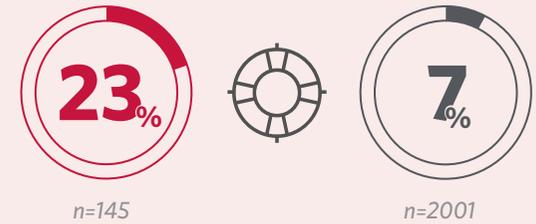
Male, 56

Paying a heavy price

People like me, when you're not allowed to work, I'm reliant on organisations for support, but those I rely on have been hit hard by the pandemic so they're not able to help me like they used to financially. The resources given to them are limited, so the resources they can offer me are limited. I was living in a limbo already because of my immigration status and at the same time I don't have money to buy anything I need.

Female, 40

23% of people living with HIV have accessed **financial support services** (compared to **7%** of the general population)



Disruption to HIV care

Throughout the pandemic, people living with HIV have commonly experienced delays and cancellations in care, and **only one in seven (14%) prefer the 'new normal' of remote appointments.**

Moving to remote appointments left some people feeling that their consultations were **unproductive**, especially when these were with a different healthcare professional.

You can do it over the phone, but here people's health is being compromised a lot you see. When it's just over the phone you can't express yourself very well, it's like a one-way traffic, they just tell you information...I was not able to see my consultant, I saw a different consultant. She was not used to my problems, and the consultation did not achieve much.

Male, 55

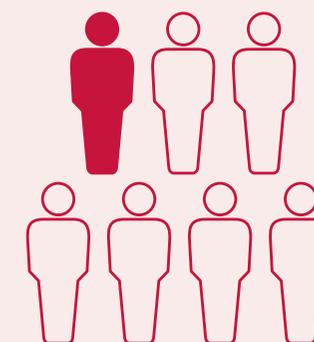
I think it would have made things a lot harder if I didn't already have that pre-existing relationship with my doctor, that would have been more complicated. It's hard to talk openly with someone you don't know over the phone, compared to the same set up in person, but because I had that pre-existing relationship it was easy.

Female, 34

Four fifths (79%) of people living with HIV have had consultations delayed or cancelled since March 2020



Only one in seven (14%) people living with HIV prefer 'new normal' of remote appointments



Disruption to HIV care

86% of people living with HIV have had consultations go digital during the pandemic...



...despite 65% preferring face-to-face appointments.



Face-to-face appointments are preferred because:

84%



Feel more **comfortable** speaking in person

52%



Have more **time** to speak to their healthcare professional

60%

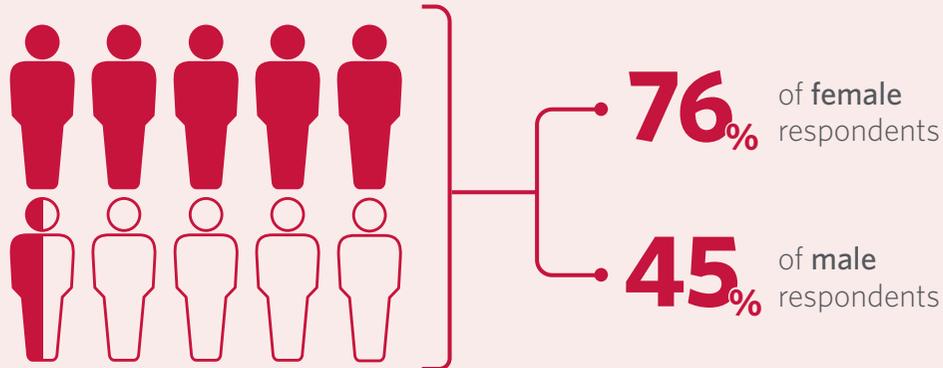


Get more **information** about their health and treatment

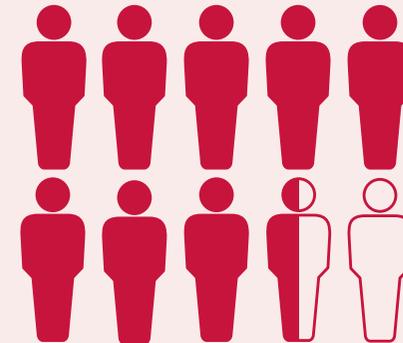
Turning to patient organisations for vital support

HIV patient organisations **have provided a lifeline to many** throughout the pandemic.

Over half (**56%**) of people living with HIV surveyed were a member of a patient organisation



Over eight in ten (**84%**) agree that patient organisations have been a valuable source of support during the pandemic



We have support groups, there are so many things that happen in the support group – socialising with fellow peers and feeling empowered, you get knowledge by the people...when you have a conversation with the people who are living with same experience, you feel empowered.

Male, 56

These groups are so great because when you meet and talk to people who have experienced the same problem as you, it can really make a difference, not to say doctors are not helpful, but they do not suffer the problems that we go through.

Male, 55

Turning to patient organisations for vital support

The most commonly accessed service through patient organisations was **peer support (54% of respondents)**,



followed by **social events (53% of respondents)**



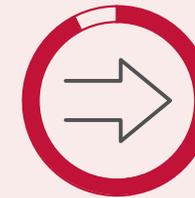
39% of people living with HIV who accessed mental health services said they did this through **patient support groups**,



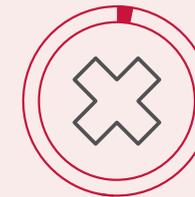
while **37%** said they accessed support through the **NHS**



9 in 10 (91%) of patient organisation service users plan to **continue engagement** after COVID-19,



only **2%** said they would **not continue engagement** after pandemic is over



I'm pretty bowled over by the innovative ways organisations are approaching wellbeing, and recognising that wellbeing is pretty important and it's not just about adhering to your medication. It's almost like the medical side of things is like a by-product, and I suppose that's right, the biggest disease around HIV at the moment is the stigma, and the various ways it can affect people's lives, covertly and mentally, and a lot of services are stepping up to tackling that.

Female, 30

The future

When HIV spread across the world 40 years ago, people living with HIV, healthcare professionals, supporters and advocates built the foundations of the community and the patient organisations that play such a crucial role in the lives of people living with HIV today.

Our research suggests that **the pandemic has driven increased engagement with these organisations**, at a time where groups are experiencing a downward trend in the levels of investment they receive.³

I've been using more and more services to help me with my condition, but now the services are going away from Corona and lack of financial support from the government. We are tired of our situation, we want to be able to meet up in our support groups so we can share, so people can interact, have food together, do some other activities together, I think that is very, very, very important.

Male, 55

These organisations were brilliant at finding me things to do, which was amazing for my emotional wellbeing and really helped to sustain me throughout the pandemic because initially I did react to it quite terrified...I would go as far to say the social aspect and the sense of community is more important than the information services they provide...it's more or less lifesaving, and it's exciting, you never know what they're going to do, what sort of projects are coming up, it's really engaging.

Female, 30

Prior to the pandemic, research conducted by **Public Health England** showed

38%

of people living with HIV had accessed a **support group** at least once in their lifetime...



16%

of these were in the past year.¹



The future



“

As the pandemic developed, it was clear that our members were experiencing great unmet need, due to a lack of provision by both local authority and other organisations. AAF had to renegotiate our delivery contracts with our funders as well as source new funding to meet this unmet need.

- Africa Advocacy Foundation



HIV organisations over the last year have been profoundly impacted by COVID 19, with resources stretched to full capacity. We need long-term, sustainable funding to help provide the services people living with HIV need and want. The innovation and commitment to support our community has been overwhelming, but we have also been unable to reach some of the most marginalised people due to poverty, poor health and for some complexities of non-disclosure within family households. Political will and wider industry support and voluntary sector support is essential if we are to attain the quality of life we deserve as people living with HIV.

- Sophia Forum

”

71%

of people living with HIV report at least one **positive change** from the pandemic, compared to **62% of the general population**. These largely centre on **positive relationships and feelings of community**.



n=145



n=2001

What we can do

Medical advances mean that many people living with HIV today can expect to live as long as someone who is HIV negative. Despite this, the findings set out in this report have laid bare the **challenges that persist within the HIV community** when it comes to achieving and maintaining quality of life, particularly during the COVID-19 pandemic. It is abundantly clear that **patient organisations have played a crucial role** in supporting people living with HIV at a time when their quality of life and their physical and mental health was - and still is - under strain.

Through the provision of welfare benefits advice, peer support, counselling and health and wellbeing services, patient organisations have helped people living with HIV to stay connected and to take care of important aspects of their quality of life throughout the pandemic. These groups will also be central in helping people living with HIV to navigate the 'new normal' of HIV care beyond COVID-19 - an area that our research has shown is a key area of concern for people living with HIV. The value of these organisations is undeniable, yet uncertainties about funding and support are putting the future of these groups - and the people they support - at risk.³

We have made immense progress together as a HIV community but there is still more to be done. Now more than ever we must collaborate as one community, and we echo calls made by the HIV Commission for stronger alliances within and beyond the HIV sector.⁴

In the healthcare setting, collaboration is key to achieving the highest standards of care - supporting people living with HIV to navigate the care pathway and to effectively manage comorbid conditions.

Partnerships between wider stakeholders - from industry, government, to academia and the voluntary sector - have long played a role in accelerating progress in HIV. Through pooling of resources, sharing best practice and aligning on health messages, these partnerships help ensure the most vulnerable people in the HIV community are not left behind.

Whilst funding uncertainties and the 'new normal' will undoubtedly create challenges for new and existing partnerships **it is crucial that we unite as one community to overcome these challenges, and to support people living with HIV to not only live, but to live well now and in the future.**

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