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Stories of HIV activists during COVID-19 in the UK

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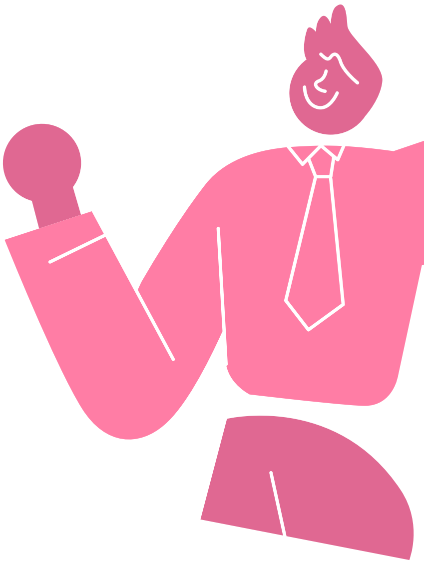
Introduction

Since March 2020, the COVID-19 pandemic and the measures put in place to halt the spread of the virus, have transformed our understandings of health and disease at individual and social levels. Its effects may last for decades, disproportionally harming those who were already vulnerable (1). Healthcare activism and service delivery may forever be transformed by the lessons learned during COVID-19. Despite the World Health Organization identifying sexual and reproductive health as being essential during a pandemic (2), the fact is that services such as HIV and STI prevention, testing and treatment faced unprecedented disruption as sexual health clinics redeployed staff to other areas or faced staff sickness (3). These shortages contributed to the appearance of increasing barriers to access sexual health services. Alongside these, however, the power of technology was often harnessed to provide remote services, such as health prevention and testing, creating an environment of innovation in service delivery and regulatory frameworks (4).

Several pieces of work have already explored the transformation of sexual health during COVID-19, how communities responded to sexual health promotion during the pandemic, or the complex relationships between HIV and COVID-19 (5–9). This report focuses on the personal experiences of HIV activists during the pandemic. In recent years, there has been a growing interest in the histories and practices of HIV activism (10,11). Within this context, we sought to better understand how HIV activists from different backgrounds responded to, learned from, and (re)organized in the time of COVID-19. In listening to their stories, we learn about the broader transformations occurring within their organizations and how knowledge is exchanged between individuals and groups.



In this report, we draw from from those individual stories to open a conversation about HIV activists and activism within broader health movements, the mobilization of knowledge, and activist resilience and wellbeing. These stories tell us about how individuals responded to COVID-19, but they also provide insight for future pandemic contexts. As we write this report, the UK and many other countries across the world face a variety of pandemic threats, from monkeypox to ebola, that may keep these discussions relevant for years to come.

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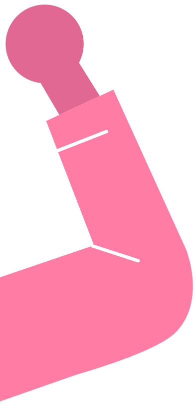


Methodology

These are stories. This report relies on two forms of qualitative methods: focus-groups and interviews. Qualitative methods are “a variety of research techniques and procedures associated with the goal of trying to understand the complexities of the social world in which we live and how we go about thinking, acting, and making meaning in our lives” (12). In taking this approach, we follow recent similar projects on the history of HIV that take the personal story as their source (10,13).

In particular, the stories in this report arose from a focus-group session held in an unseasonably warm day of April 2022, and a series of semi-structured interviews held online throughout that summer. A total of six participants shared their experiences. All of them were members of an HIV advocacy group based in a large city in the north of England which frequently works with and supplements the community outreach of government services around sexual health and wellbeing. The participants came from a variety of backgrounds and experiences: some were former academics turned activists, who were already at the forefront of activism in the 1980s and 1990s. Others had recently left their day jobs to start working for the organization when COVID-19 hit. Some were in their late fifties; others were in their late 20s. Given how small the world of HIV activism in the UK is, we have chosen to not provide much more detail about the participants to ensure their anonymity. When necessary, personal details have been removed or altered.

The focus group was facilitated by the three authors and each one of the interviews was conducted by a different author. They were all recorded and transcribed by a transcription company, and jointly analyzed by the authors. The research process was approved by the University of Edinburgh EMREC (reference: 22-EMREC-003).

Activism before COVID-19

In order to understand how activists responded to and were impacted by COVID-19, we must first understand their position before the emergence of COVID-19. This issue was raised both during the focus group and the interviews, and there was broad agreement among participants. Before the pandemic, the organisation was working with marginalised communities (largely brown and black gay and bisexual men) to build health literacy, to provide HIV/STI prevention, access to care/services, and to encourage wellbeing through community contact and activities. Throughout this work, an activist character is clear among participants: they are activists first and foremost. They are driven by a passion to improve the world around them. One of the participants, who had just recently joined the organization, explains:

Everyone within the team feels like they're in the work, working together, working in collaboration because we want to change the world. We want to see shifts in the world.

Their organization is profoundly committed to supporting often underserved or marginalized communities, whose needs are not met by other services:

I think we've always focused on marginalized communities and making sure that they had access to information.

This commitment is, in part, fueled by an awareness of their own marginalized position. Many of the participants identified as members of the same communities for whom they developed materials or in which they did outreach programs:

Our organization is embedded in our communities. So we work for our communities and with our communities because we are our communities.

Positioning themselves as insiders to these groups allowed for a shift in their dynamics: they did not 'speak to' communities but, instead, 'spoke with' their peers in their very settings they shared:

We're not coming with and saying 'we're looking to fix this for you' or 'we're the experts'. Actually, we live and breathe this. We go to the parties. We go to the sex clubs. We have the same concerns you do.

COVID-19 and HIV

There is a growing body of work that highlights how, despite some differences, there are significant similarities in the experiences of and responses to COVID-19 and HIV (14,15). In our study, participants–especially seasoned activists–corroborated this viewpoint, specifically in their reflection(s) upon their own experiences responding to early AIDS crisis in the 1980s and 90s. Some of the senior participants in this research had experienced the AIDS crisis first-hand. In the UK, the AIDS crisis refers to a period, between the late 1980s and early 1990s, in which the absence of effective HIV treatment caused an epidemic of death (13). One participant explained that it was in that context that his activism began:

I was volunteering on an AIDS helpline with a lot of older guys and what they were putting out into the world just felt like sticking a plaster. So, in 1997, with my husband, we set up a grassroots gay men's health project which was very activist. I have a long, long, history of activism.

Some participants share similar first-hand activist backgrounds, whereas others have instead learned about the AIDS crisis through historical or personal accounts. Regardless of their background, as HIV activists, they are all intimately familiar with the history of HIV in the UK. Thus, it is not surprising that they find abundant similarities between HIV and COVID-19. One explains:

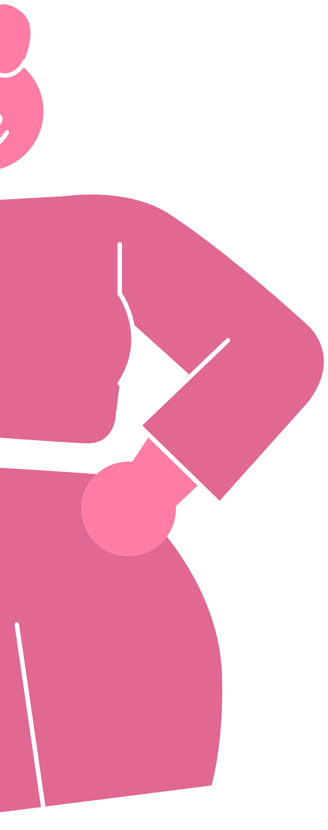
Even in the first weeks of COVID-19, there was a clear similarity. We had loads of stuff to learn from the time that we had lived.

This is one of the founding reasons why/how the activists justified mobilising their knowledge – because they recognised the similarities and thus the ability to adapt/transfer knowledge to the new pandemic.

These similarities included an awareness of the intersection of pandemics with inequality or racism, the importance of communication, or the need for structural solutions. However, they are also aware of the differences between both pandemics. Another participant, who also lived through the AIDS crisis, explains how he became increasingly angry at facile comparisons between HIV and COVID-19:

> **I thought, well, actually, no, it's not quite the same. There's not the homophobia and racism and all these things which are attached to the epidemic. [...] How is it different? The government are acting. They may be crap, but they're acting. You know, so that's the difference. So, it's not the same pandemic. It's very different in that sense.**

In this section, we have witnessed how activists often drew from their experiences of HIV and AIDS to navigate the complexities of COVID-19, remaining aware of the similarities and differences between both pandemics. We will now turn to some of the key issues they experienced during COVID-19.



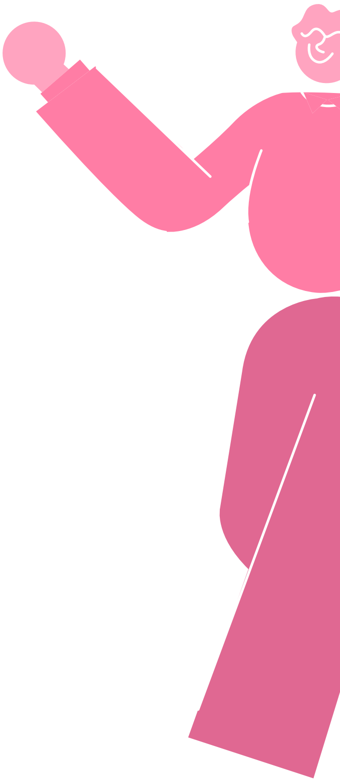
Key issues

The COVID-19 pandemic led to transformations in individual lives and organisational responses. Both activists and their group organising had to operate in new and unstable situates to respond to urgent needs in their communities. Across the focus group and interviews, participants narrate how these transformations took place, sometimes intentionally but oftentimes organically. Many of these new ways of working or relating to communities are, they say, here to stay.

The pandemic saw a sharp increase in participants' workload. They had to rapidly switch their services to online platforms, respond to increasing demands for information from service users, and engage with stakeholders such as policymakers and journalists to share advice and information. One participant explains how the increasing demand led to long hours and the need to sometimes step away.

Because it was relentless. And I recall days of sitting at my desk, you know, from whatever time in the morning and then suddenly turning around and it'll be dark outside. I had to step off the treadmill a few times.

Increasing workloads and personal responses to the crisis, including fatigue and burnout, led to uncertainty and worry. There were also practical challenges: some participants contracted COVID-19 and became sick, others had pre-existing conditions or inadequate housing which required additional support. Participants recall how there was a clear learning curve to consistently apply self-care to their daily lives. This was further complicated by the participants' own belonging to the communities they work for, which made it harder to disengage from work:



We tried to ensure that after a two- or three-month period we were taking a week off. We'd say 'you have to take a week off'. And there was no work. I would disengage from social media. My work and life interact because of the job. Just taking those block pieces of time off is really important. And obviously because we couldn't travel, we weren't sure about what to do that week and not get yourself drawn back into that work. That was difficult at first.

Participants often returned to their knowledge and experience of HIV and AIDS to navigate this new context. At times, this familiarity with HIV helped them to identify research needs, target specific communities, or highlight gaps in existing support that had to be addressed. For example, one participant explains how early survey findings about loneliness, casual sex, and COVID-19 were not surprising in light of knowledge derived from HIV:

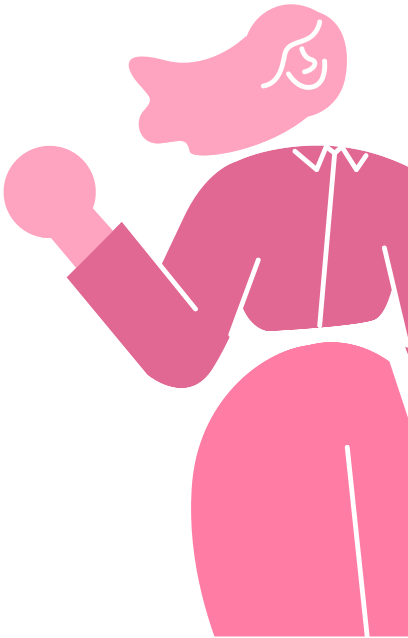
In terms of harm reduction for COVID-19, there were many parallels to HIV in terms of the often tricky questions that we were asking 15 or 20 years ago about HIV. Can I get HIV from oral sex? How likely is it? Do condoms help? We were being asked these same questions during COVID-19.

In light of this knowledge, there was also a clear awareness of specific needs the organization felt were not being adequately met by mainstream messaging or services:

Nobody was speaking to queer communities or black and brown communities in the way that we were.

Most significantly, participants' experience of the AIDS crisis allowed them to feel more comfortable with the changing nature of evidence in a pandemic. One participant explains that, during the AIDS crisis, evidence and scientific knowledge evolved and changed rapidly. This previous experience allowed them to understand how there is a clear need to provide clear guidance to people that allowed to make their own choices, even if this changed frequently:

We were making sure that whatever we had was as evidence-based as possible. We accepted that information could shift, we were growing and learning collectively. That meant that what you say tomorrow might change in a week's time and that's okay. To accept that you're never necessarily going to have the right answer. We had clear harm reduction principles around even in the middle of a really scary pandemic: we were not going to tell people what to do with their lives.



While knowledge about HIV and their capacity to identify unmet needs was important, as an organization, they also had to adapt to a transformation in the funding framework — with COVID-19 becoming the key priority, new projects and funds had to be developed. At times this was a dramatic experience. One senior participant explains:

At times, there was a worry about not surviving as an organization.

Nonetheless, they survived. This was possible thanks, in part, to a structure that allowed for flexibility:

The structure that we have allows us to do things without red tape and limitations. In other organizations in the field, there's a lot of things you can't do, usually for really silly reasons. Whereas we can do whatever we want, kind of, and whatever we feel would benefit our community.

This allowed them to produce landmark health promotion and harm reduction campaigns that spoke to specific communities in clear, evidence-based, yet approachable ways. It also allowed them to be critical of existing interventions and discourses. One participant, who contracted COVID-19 and suffered from long Covid, explains that his involvement in long Covid activism was short lived:

I was living with long Covid for about 18 months and dipped my toe into long Covid activism. I realized I just didn't have the energy to do it. I had the tools — but not the energy to deal with the most incredibly white, middle-aged group. They complained about how difficult it was to get benefits. I told them to imagine how much harder it would be if they were an immigrant who hardly spoke English!"

Lessons learned

The participants in this project evidence the extent to which COVID-19 became a transformative moment for HIV activist organizations and activists themselves. Amid a pandemic, these participants mobilized their knowledge and experience to continue providing essential services to their communities. In this section, we ask what is there to learn from these participants' stories about activism during COVID-19? First and foremost, the ways in which their experiences and knowledge of HIV and AIDS were mobilized to more effectively respond to COVID-19 reaffirmed the participants' expertise and relevance.

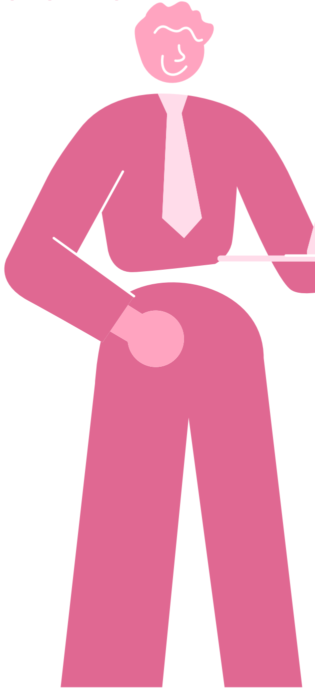
I think what COVID-19 did, for me, at least, was to reaffirm our skills and our knowledge in particular areas. We were able to transform the HIV side to COVID-19. If we did this for COVID-19, then maybe we can do it for diabetes, and for queer migrants and for other communities. The model works. The experience works.

Knowledge and expertise were not only reaffirmed but also transferred from senior, more experienced activists to novice ones. One of the newest members of the organization explains:

I was always trying to figure out how HIV and COVID-19 were similar. COVID-19 gave me an opportunity to learn first-hand what AIDS must have felt like. I just asked people a lot of questions. And I have other friends in their 40s and 50s and asked them too what their experiences were like and how similar they were for me to learn and to inform myself.

The COVID-19 pandemic was not only an opportunity to transfer knowledge but also to further define and develop an activist identity both as an organization and as individuals. One participant explains that the organization changed its own identity thanks to the pandemic, becoming more explicit about its beliefs:

We've stuck our flag in the ground about being quite queer. And that's been really useful and liberating and it's really helped us position who we are and what we are and stopped being apologetic.



In turn, these newfound identities also allowed them to identify new areas of work and priorities:

We're dipping our toes into more community research. We're looking at building up our evidence base and we are really keen to develop the research arm of the organisation. We do a lot of partnership work with researchers and universities already. But I think we're trying to embed that in the work that we do so we lead and we're in charge of it.

Finally, the pandemic also reminded them of the need to partake in consistent self-care practices that allow them to continue their work:

We now talk more about how we look after and nurture our team. We recognize that looking after each other is the biggest part, or one of the biggest parts of this work. We have to be healthy activists. Because if we're not healthy for our community, then we might as well stay home.

Moving Forward

These are stories of HIV activism during COVID-19 in the UK. In them, we have seen how COVID-19 generated a context in which activists — both as institutions and individuals — changed and evolved. The participants in this project evidenced how they used their positions to develop and refine harm reduction approaches and communication tools that spoke to unique communities, often left out of mainstream messages. They also explain how they redeployed existing knowledges and experiences of HIV and AIDS to the new context of COVID-19. One example is their capacity to effectively work with uncertain or changing scientific evidence while seeking to empower individuals.

As individuals, the participants prove just how resilient and committed they are to the causes that drive them. They were transformed beyond their institutional affiliations: through processes of surviving, learning, and adapting. Furthermore, not only where their knowledge and experience reaffirmed as relevant, but also shared with newer generations, allowing for the continuity of their work. COVID-19 and, more recently, the outbreak of monkeypox, evidences the ongoing need for activists and their unique skills. These stories illustrate how activist experience can be deployed in the face of new and emerging infections.

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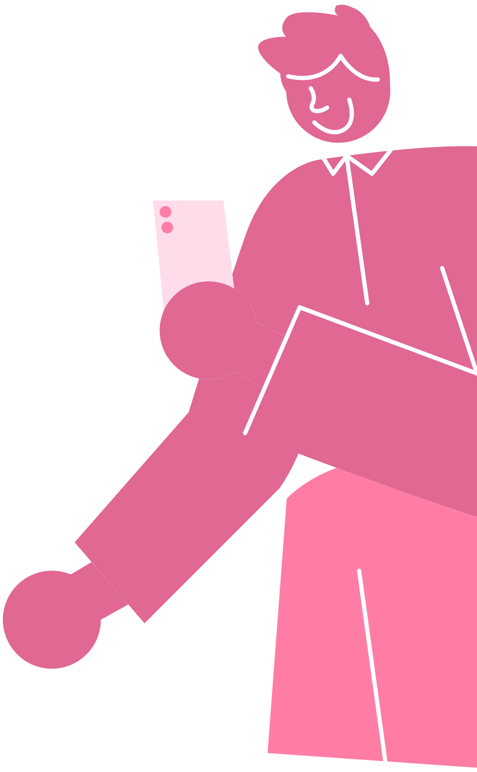

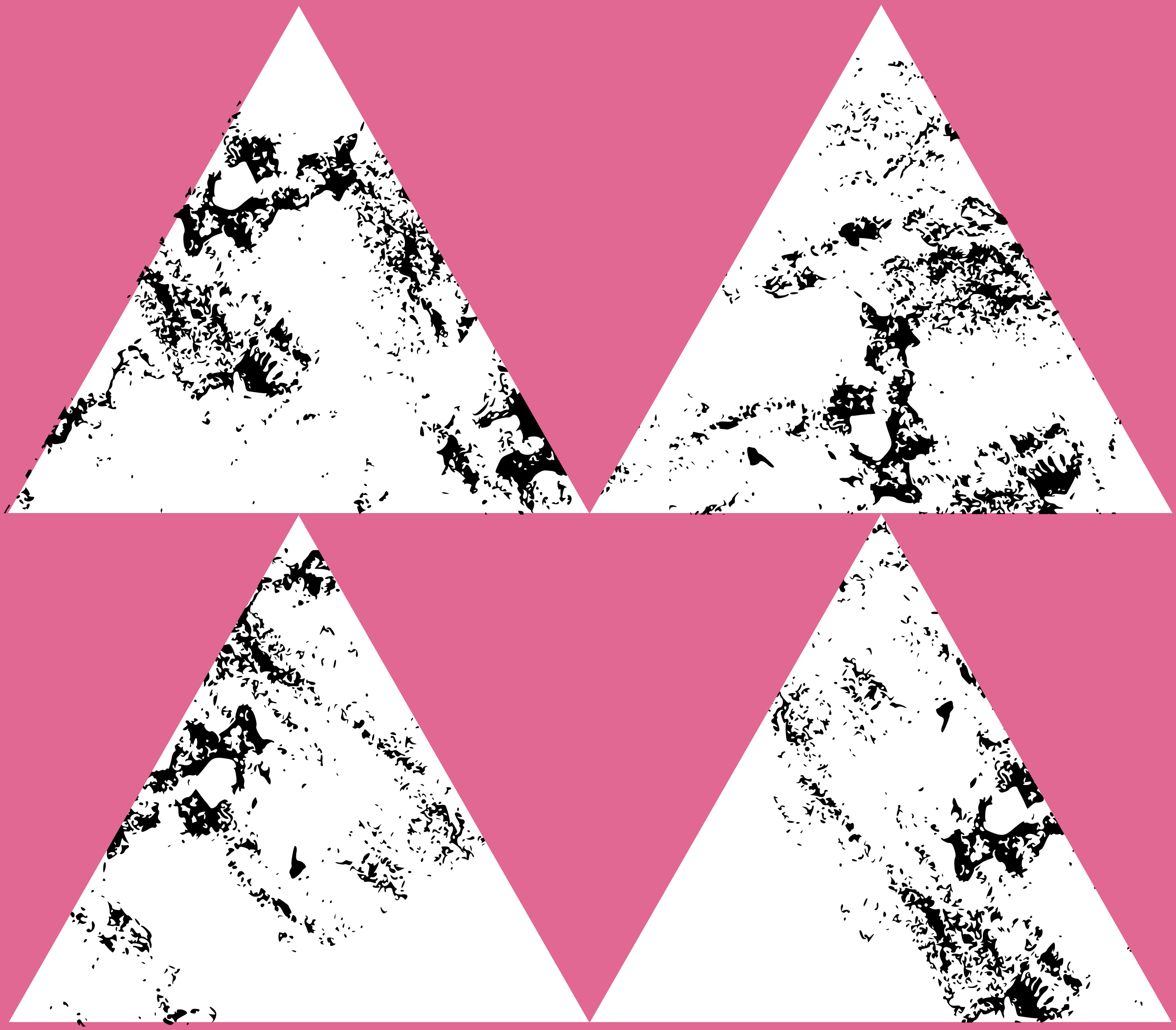

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