

Experiences of the COVID-19 epidemic: a participatory qualitative study with people living and/or working with HIV in the UK

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Background

COVID-19 continues to impact the lives of people living with HIV, and those providing services in the UK. Since the early stages of the pandemic, HIV services have adapted to government restrictions and changes in demand for services, including community-based organisations, charities and clinical care. Early insights identified issues relating to confidentiality, closure/postponement of services and the prioritisation of adequate medication supply for service participants (1,2).

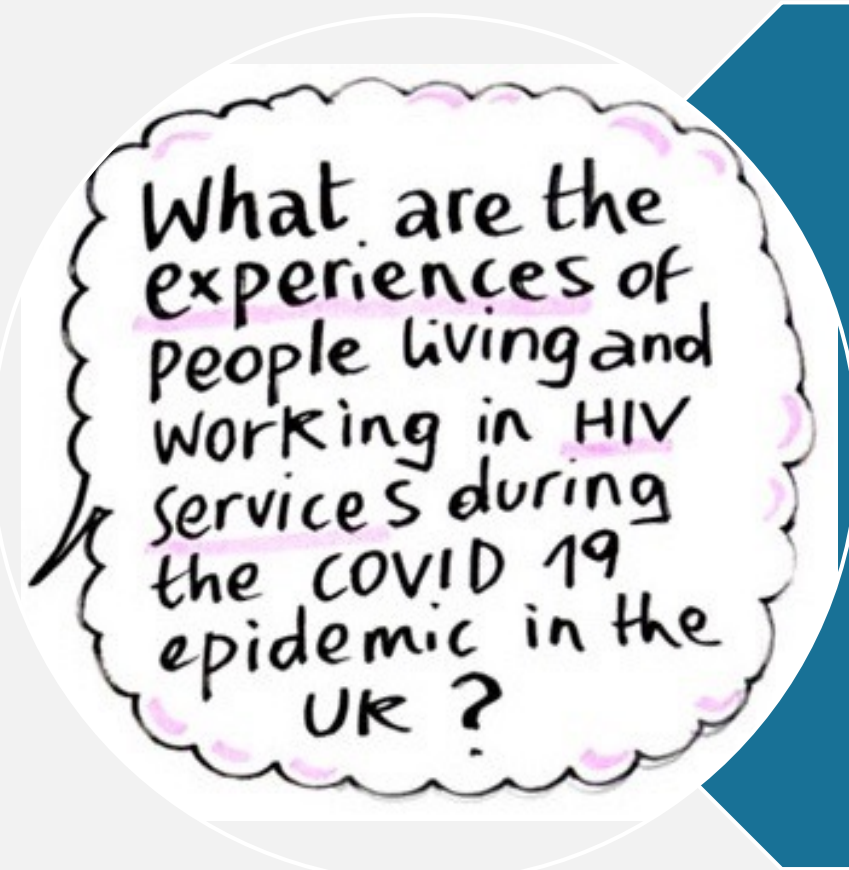
Our research aims to understand the **experiences of COVID-19 among healthcare, community-based/charity workers and people living with HIV**. We wanted to explore experiences of adaptations made to HIV services and wider implications to daily life, health and wellbeing as well as perceptions of the future of HIV care in the UK. Additionally, we aimed to **train and support people living with HIV as co-researchers in a co-produced research study** by building on an existing partnership between a University (Imperial College London) and a peer-led support charity (Positively UK).

Methods



June 2020

- “Let’s Talk About... HIV care” community involvement discussion *via* Zoom facilitated by Positively UK and an academic staff member from the Patient Experience Research Centre (Imperial College London).
- 25 people attended including people living with HIV, healthcare workers, charity and community workers.
- The discussion generated an insight report (1) which was used to shape the design and focus of a qualitative study, including areas which should be explored.



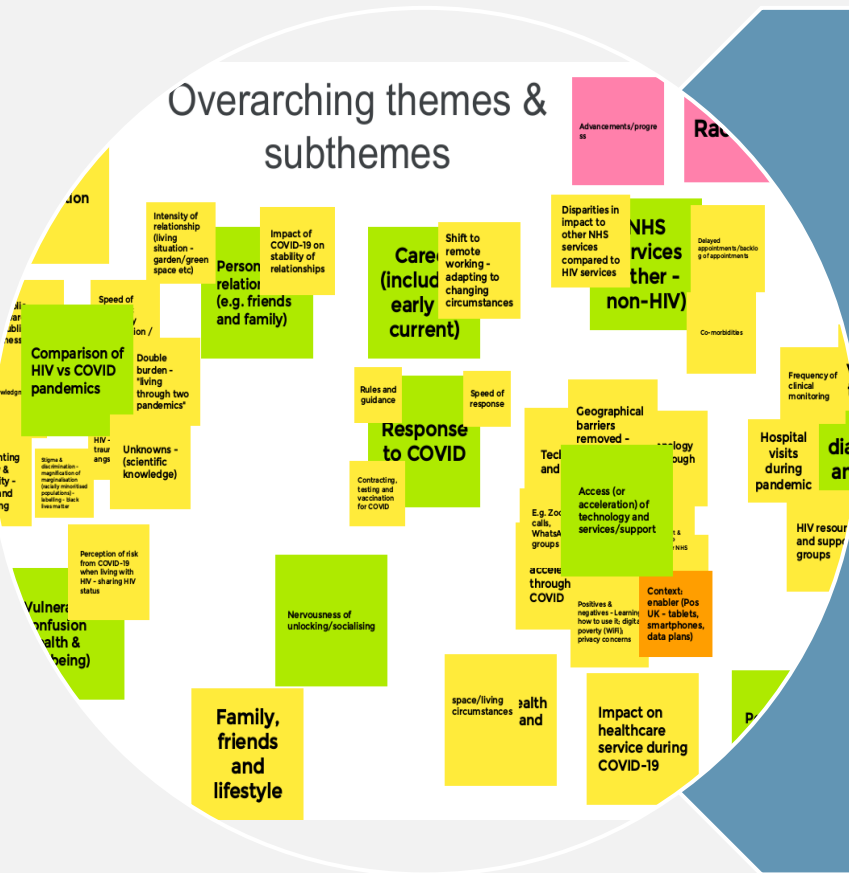
October-December 2020

- Online, semi-structured interviews *via* Microsoft Teams with 14 people working in HIV clinics/community based organisations and charities.
- Participants recruited through existing networks and contacts, including attendees of community involvement event.
- Data managed using NVivo and analysed by thematic analysis with inductive codes applied to an ecosocial framework (inductive-deductive approach).




January-September 2021

- Participatory team forms (including two peer researchers and three advisory group members living with HIV).
- Participatory approach included three research team meetings and four training sessions to equip co-researchers with skills to conduct and analyse interviews. Training resource later made freely available to others interested in training public members (3).



June-August 2021

- Online, semi-structured interviews *via* Zoom with 19 people living with HIV. 5 interviews completed by peer researchers. One interview was undertaken by telephone.
- Participants were randomly selected from the 2017 Positive Voices study (4).
- Data managed using NVivo and analysed by thematic analysis with codes categorised into themes and discussed as a team using Google Jamboard. These themes were later applied to syndemic theory.




September 2021-present

- Findings from both qualitative studies triangulated as well as with quantitative results from the 2017 Positive Voices study.
- Further seed funding received to continue working together to disseminate research findings including *via* video and an in-person event.
- Co-designed and delivered an event on ‘Co-Production in HIV Research’ on 6 July 2022 where attendees helped to prioritise our preliminary research findings from both studies.

Results

In total, **33 people** were interviewed online across both studies in Autumn 2020 and Summer 2021 (19 people living with HIV, 9 community-based workers and 5 healthcare workers). Participants were predominantly cisgender men (n=23) and living in London (n=21). After triangulating the data from both studies, we identified commonalities and differences in the data. The main themes identified in both studies are listed below. We also identified underlying principles of accountability, agency and inequalities. We present pseudonyms* of quotes from study participants.




COVID-19 Information and Guidance

Confusion at the start about whether to ‘shield’, with negative experiences shared about **increased feelings of isolation**, **“rulebreaking”** and **balancing risk and safety** (e.g., in relation to mask wearing and social distancing requirements).

- People living with HIV and service providers spoke of the role of charities and professional bodies (e.g., British HIV Association) in dispelling false information. Service providers felt pressure to remain up-to-date.
- Some rumours and misinformation circulated through social media, messaging platforms and communities which led to fear and confusion.

“...Certainly from me there was a little bit of downplaying of it (...) And looking back on some of the conversations that I had thinking about them, I probably was a bit like ‘I think it will be over in a few months’.”

(Chris*, HIV Nurse)




Social Determinants of Health

This theme mainly focussed on **work situation, finances, home environment and technology**.

- Service providers and people living with HIV described the challenge of being forced to share HIV status at work and at home, particularly when receiving shielding letters, taking medication and receiving remote support/teleconsultations.
- Access to technology helped to keep interviewees connected to family and friends, attend virtual support groups and access clinical care; however, concerns were raised among those who may be excluded.

“...I did say to work I’d got the shielding letter, which then they wanted to know the reasons why and I didn’t want to disclose the reasons why for that”

(Adam*, living with HIV)




HIV Care

Described at all stages of the continuum: **testing** (increasingly online), **treatment** (postal/courier), **engagement** in care (technology), **monitoring** appointments (postponed or made ‘physically distant’) and **health-related quality of life** (increased isolation).

- Most people living with HIV did not feel their care was interrupted but some did have concerns about the quality of care received (e.g., side-effects from ART, accessing psychological services, adapting to regimens).
- Service providers were concerned for those most vulnerable living with HIV who may still be missing from the service.

“...I just feel face-to-face is better because they can get more of a picture of how you’re feeling. I think that’s mentally just as well as physically”

(Susan*, living with HIV)




Health and wellbeing

Mental health was a major concern and described across multiple themes – experiences of isolation, loneliness and burnout/emotional fatigue among service providers.

- Difficulties accessing psychological support services often described; however, several spoke of the role of social and peer support for mental health and wellbeing.
- For some people living with HIV, the pandemic had triggered feelings of isolation, with some comparing this to receiving their HIV diagnosis.

“...lockdown came along and just made that (existing feelings of isolation) 10-times worse for them (service users)”

(James*, Peer Support Worker)




Society and social support

Some compared the stigma of the **early days of HIV and COVID-19**. Others disagreed and shared the view that because HIV was affecting marginalised populations, stigma drove the HIV epidemic and delayed response.

- Acknowledgement of speed of vaccine development and some optimism about impact for HIV vaccine development.
- All people living with HIV had accepted vaccine invitation - some received earlier due to work circumstances or volunteering. Some people spoke of hesitancy among friends/family whilst others sought assurance from health professionals.

“...it (testing positive for COVID-19) gives you a little insight into the stigma that some of our patients experience with being HIV positive”

(Lisa*, Healthcare Worker)



Future

Concerns for **emerging and widening health inequalities** including concerns of service participants having to negotiate food/financial insecurity. The pandemic provided opportunities for cross-sectoral collaborations and to **reflect on the future of HIV services**:

- Face-to-face support preferred by most although some speculated face-to-face HIV care may never return fully as not seen as cost-effective.
- Mixed acceptability of 6 monthly clinical monitoring moving to yearly as for some, this provides reassurance on health status and provided space for reassurance about the pandemic generally.
- Mostly negative perceptions of shifting HIV care to primary care - driven by context and confidence in GP. Some people worried about loss of specialisation.

“I’ve always felt very, sort of, comforted by the care that I’ve had. So I would prefer to go back to having an appointment every six months... Where I’d go along, see the nurse, have my bloods, get checked out and then go back two weeks later to see the consultant”

(Paul*, living with HIV)

Discussion

People living with HIV have had varying experiences during COVID-19, although the uncertainty of navigating a pandemic where knowledge continues to evolve is evident. As we conducted interviews at varying time points, the focus of interviews shifted (e.g., vaccines) making comparisons difficult. A strength of our work is the core element of co-production that has existed over the past 1.5 years and continues to grow. Looking ahead, a major concern across both studies, and our community involvement work was the mental health of people living with HIV. We argue that this should be the focus of service providers, commissioners and policymakers whereby a community-led approach in collaboration with key stakeholders should be prioritised.


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