

Insight Report: COVID-19 Community Involvement- “Let’s Talk About...HIV Care”

Vasiliki Papageorgiou*¹, Emily Cooper¹, Jane Bruton¹, Silvia Petretti², Philippa Pristerà¹, Helen Ward¹

¹ Patient Experience Research Centre, Imperial College London, UK

² Positively UK

*Correspondence: vasiliki.papageorgiou17@imperial.ac.uk

Date of activity: 23 June 2020

Report originally published: 15 July 2020

Updated: 17 January 2022

Table of Contents

Executive Summary.....	2
Background	2
Impact of COVID-19 on HIV Care	2
Call overview and agenda	2
Attendee recruitment	3
Key Insights Summary.....	3
Poll 1: How would you say your life has changed during COVID-19?.....	4
Poll 2: In your experience, how much has HIV care been impacted by COVID-19?	4
Breakout Room Discussion Themes.....	5
Post-call feedback from attendees (n=11/25)	10
Conclusion and next steps	11
Acknowledgements.....	12
Appendices.....	12
Appendix 1: Demographic of public attendees	12
Appendix 2: Event registration and Zoom call set-up.....	14
Appendix 3: Further insights following the Zoom call	15
Appendix 4: Post-call feedback.....	16



This work is licensed under a [Creative Commons Attribution-NonCommercial 4.0 International License](https://creativecommons.org/licenses/by-nc/4.0/).

Executive Summary

Background

This informal session led by the Patient Experience Research Centre (PERC), in collaboration with [Positively UK](#), invited people living with, affected by, or working in HIV to share their experience, views, questions and concerns on accessing HIV care during COVID-19. The aim of the call was to gather feedback on specific areas to help guide a proposed qualitative (interview-based study) looking to explore experiences, specifically on:



- 1. Challenges and concerns in managing HIV care during COVID-19**
- 2. Challenges in the provision of HIV care during COVID-19**
- 3. Opportunities presented for HIV care during COVID-19**

We also wished to inspire new ways to rapidly engage and involve communities remotely during a public health emergency, through strengthening partnerships with existing groups (in this case, Positively UK).

Impact of COVID-19 on HIV Care

COVID-19 has had an impact on HIV services across the UK, including testing, treatment and care provided. Before the pandemic, some HIV services in the UK had already begun to transition towards a self-care (or 'collaborative care' model) through community-based nursing and e-consultations. However, for some people living with HIV this will be a new and unfamiliar experience. At the start of the outbreak, people living with HIV were included in government shielding recommendations despite the fact that the majority are healthy with an undetectable viral load.

Researchers at PERC are setting up a study to explore the experiences of people living with, affected by, and working in HIV during COVID-19. We collaborated with Positively UK, a peer-led organisation that offers a holistic approach and specialised services to improve the health and wellbeing of people living with HIV. We carried out community involvement to gather early evidence of the impact of COVID-19 on HIV care to inform our interview topic guide as well as any other feedback on our approach. This work will feed into a larger doctoral research project (using the 2017 [Positive Voices survey](#) data) looking to explore the impact of social determinants (e.g. housing, employment, income etc.) on the health and wellbeing of people living with HIV. This doctoral research project is in collaboration with colleagues based in the HIV Section at Public Health England.

Call overview and agenda

We ran a community involvement Zoom call on Tuesday 23 June 2020, 5pm-6.30pm which was attended by 25 people from across the UK– see **Appendix 1** for demographics. Those who we received feedback from had been living with HIV or working in HIV services/charities for several decades, although we are unable to comment on the wider group.

The agenda included (1) introduction to PERC and Positively UK; (2) background to the project; (3) our plans for research; (4) Q&A (although no questions were asked during the session) and pre-discussion anonymous polls; (5) breakout room discussions facilitated by one member of Positively UK and co-facilitated by a PERC staff member (5 rooms; 4-7 community members per room); (6) next steps.

The breakout room discussions primarily focussed conversations on the challenges, concerns and opportunities presented in HIV care during the COVID-19 outbreak.

Attendee recruitment

We recruited through our personal networks, social media and an email invite was sent to over 250 people who Positively UK engage with. See **Appendix 2** for further details on recruitment, event registration and technical requirements of the Zoom call.

Key Insights Summary

Overall, we identified 8 key themes with summarised comments from breakout room discussions given below. Further detail of these can be found in the next section.

1. Misinformation, conflicting/delayed messaging and shielding advice

- This primarily focussed on conflicting government advice regarding people living with HIV being sent text messages and receiving letters informing them that they need to shield.
- However, there were also some discussions around conspiracy theories, the UK government response and rumours within the HIV community.

2. Avoiding, delaying or being prevented access to healthcare (including GP, hospital appointments, sexual health/HIV services)

- This was predominantly centred around a fear of acquiring COVID-19.
- Some health professionals also described how many people living with HIV assumed services were not open during COVID-19, when they in fact were.

3. Maintaining an adequate supply of medication, managing regimens and adhering to therapy were conflicted by issues around privacy and confidentiality

- People described some challenges around maintaining adequate supplies of medication, being unable to adapt their regimen, and continuing adherence to antiretroviral therapy during lockdown.
- Lockdown has resulted in a re-emergence of concerns regarding privacy and confidentiality, particularly among people living with HIV who have not shared their HIV status with members of their household.
- There were some concerns that people may have to share their HIV status in situations that made them feel uncomfortable; for instance, when ensuring an adequate supply of medications.

4. Adapting HIV services to a new model of self-care, and digital exclusion

- Despite a shift towards virtual support groups and telemedicine which functioned for some people, digital exclusion was considered to be a real barrier for those who do not have easy access to the internet, phone or computer.

5. Re-deployment of HIV staff during COVID-19

- Some health professionals who had joined the call reflected on their personal experiences, and that of colleagues, who had been re-deployed to intensive care units during COVID-19.

6. Impact on self and feelings of isolation when shielding/during lockdown

- Lockdown resulted in people being isolated from their usual support systems which will have negative consequences to mental health.

7. Wider negative impact on finances, food security and housing and the disproportionate impact on the most vulnerable and marginalised groups living with HIV

- This was a widely discussed concern across the breakout rooms and was often linked to conversations around the most vulnerable and marginalised people living with HIV and equally, difficulties for people accessing services.
- Breakout rooms discussed concerns for the most vulnerable (e.g. homeless, newly diagnosed, experiencing domestic violence, migrants, racially minoritized communities, people living below the poverty line etc.).

8. Longer-term health and economic consequences of COVID-19

- This was discussed in relation to those having had COVID-19 (e.g. long-term side effects) but also in relation to the provision of care and services by charities and other methods of support.

Poll 1: How would you say your life has changed during COVID-19?

Nineteen of 25 call participants took part in this anonymous poll and were almost equally divided between saying life had changed somewhat negatively (n=10), and somewhat positively (n=9).

Poll 2: In your experience, how much has HIV care been impacted by COVID-19?

Twenty one of 25 call participants took part in this poll; 10 said extremely or very, 10 somewhat or slightly, and one said not at all.

Breakout Room Discussion Themes

We have performed a rapid analysis of the key themes that came through during the breakout room discussions and summarised below the main points that were raised. The discussions focussed on new challenges and concerns, but also potential opportunities for HIV care as a result of COVID-19.

People who were unable to join the call but wanted to share their views were invited to do so by email. Their insights can be found in **Appendix 3**.

Please note: *the following insights came from an **involvement**¹ exercise and should not be interpreted as research results. In other words, the insights reported below will be used to help refine our research question and to influence the design and delivery of a future research study (including the interview topic guide).*

1. Misinformation, conflicting / delayed messaging and shielding advice

- Mixed messaging from government about who should and shouldn't shield led to confusion and anxiety among people living with HIV (particularly those who did not receive one). Some attendees reported receiving letters themselves and some working in clinics explained that they did not know who had and hadn't received a letter. Some attendees were themselves shielding.
- The language used in shielding letters left some feeling traumatised, vulnerable and fearful.
- One group discussed the belief held by some people that antiretrovirals are protective, which is not known. This was given as an example of misinformation and panic.
- Conflicting information given in different regions in the UK and internationally has left people feeling confused about whether or not to follow the shielding advice.
- In addition, the delay of UK government action has resulted in a lack of trust or feeling conflicted about the accuracy of the guidance provided.
- However, it was also recognised that there are several resources available to the HIV community and wider public to remain well-informed. Two attendees specifically spoke about completing the open-access course on COVID-19 produced by the London School of Hygiene & Tropical Medicine.

2. Avoiding, delaying or being prevented access to healthcare

- Some felt that the negative media/government messaging (e.g. stay at home, do not travel if non-essential) may have resulted in people being too scared to access services, or to people assuming that services were not open during COVID-19. This was seen as particularly the case for certain more vulnerable groups, for example there was a feeling that poorer outcomes from COVID-19 among racially minoritised communities has led to fear around accessing services. There is a real concern that some people may have completely disengaged in care.
- Some were anxious about their experience of intensive care if they had a severe response to COVID-19.
- One person living with HIV described previously being able to see HIV consultants if they needed to urgently attend A&E or walk-in clinics.

¹ Defined by the NIHR as "research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them": <https://www.nihr.ac.uk/patients-carers-and-the-public/i-want-to-help-with-research/> [Accessed 13 July 2020]

- Another group discussed how the COVID-19 crisis may have a long-term impact on primary care services as people may now be “*put off*” engaging with GP practices after experiences during the pandemic. They discussed the “*disappearance*” of some GP practices with reception staff left to do triage and feeling that there was no or little access to doctors. This resulted in some not wanting to call their GP or HIV clinic when they had experienced symptoms.
- People described a lack of access to routine blood tests (e.g. every 4-6 months) potentially posing a risk to health, with regular tests being reassuring for some. Some noted that they felt some people living with HIV seemed to prefer to stay at home but were now beginning to come for blood tests. It was not felt that lack of PPE was a barrier.
- In contrast, one group also discussed how at the start of COVID-19 they saw a re-engagement by people who had previously been disengaged with their care who were now worried about their HIV.

3. Maintaining an adequate supply of medication, managing regimens and adhering to therapy were conflicted by issues around privacy and confidentiality

- Several groups discussed how adherence to medication became a new challenge for many, particularly for those who had not shared their HIV status with those they were living with (e.g. family members) and no longer had access to a private space to take medication. Some spoke of reports from people living with HIV missing doses or pills due to this.
- Before lockdown, people living with HIV were able to adapt or ‘personalise’ their doses however, this was no longer possible as this required a consultation and were told to keep their prescribed regimen. One person described visiting hospital to take medication for the first time and, despite seeing a different clinician, they found the consultation went well.
- There were fears that medical supplies would be interrupted or affected due to COVID-19; for instance, some people living with HIV asked for 6-month supplies to avoid frequent visits to maintain supply. This seemed to be a concern for some doctors and pharmacists.
- It was felt that being able to access pharmacies or clinics to collect medications would not be possible for some people based in more remote, or rural, locations. Two people living with HIV described visiting the hospital in order to access extra supplies of medication; one found the experience unnerving, another felt scared and returned home “*feeling contaminated*” after having to use public transport to get there as their local pharmacy could not give the prescription.
- Some described a lack of privacy and confidentiality when ‘isolating’ or being in lockdown with others in the household (e.g. young people living with HIV).
- Issues of having private phone calls/online and taking medication as there is no access to a quiet or confidential space; this would normally be provided by the clinic or support groups.

4. Adapting HIV services to a new model of self-care, and digital exclusion

- It was felt that changes would be good for people who do not want as much contact and would prefer self-care.
- However, concerns of managing poor mental health, confidentiality, accessibility/language barriers and the benefits of face-to-face interactions were raised; one group spoke of the ‘doorknob’ moment as people leave the office and someone raises something that had not come up during the consultation. Some people are fearful of using technology or do not want to speak to someone they do not know by phone.

- There were concerns about digital exclusion and a recognition that there is no “one size fits all” model. A shift to remote and online services (e.g. support groups, appointments) would work for some, but people raised concerns about inequalities in accessibility. For instance, where English is not a first language or where people do not have access to the appropriate technology.
- People living with HIV based in rural rather than urban areas expressed concerns about a lack of follow-up, support network and difficulties if they preferred face-to-face consultations.
- A telephone consultation was felt to be more of a “check-in” rather than holistic; a physical meeting provides communication which is non-verbal.
- Others considered that the rapid digitisation of services has encouraged people living with HIV to become more ‘digitally savvy’ but recognised that the NHS would need to invest more in digital capacity. For instance, many NHS staff do not have the equipment required for online services (e.g. old computers, no or limited number of webcams).
- Referrals for other services (e.g. mental health) have been delayed; one person felt their mental health telephone appointment was brief, rather than a holistic conversation they were expecting and leaving them feeling disappointed by a lack of follow-up.
- Regular peer support and social support within HIV clinics provides a safe space for people to share; people valued interacting in this way physically and expressed worries about where or how their peer support group members are. Tea and coffee stations which used to play an important role have been removed.
- People living with HIV expressed worries about what would happen between appointments during lockdown and what was happening at their clinic; for instance, some had appointments/consultations delayed after hearing from their Clinical Nurse Specialists while others had no contact from their clinic at all. One felt that this may affect when and how they present to the clinic if needed to do so.
- One group discussed how COVID-19 provided the opportunity for more community-based care through building on the notion of keyworkers. They felt a triage system is needed for telemedicine, with continued need for some face-to-face consultations, for example for test results. It was reflected that it is important to have others around to support newly diagnosed and for clinics and charities to run digital audits to reveal certain vulnerable groups.

5. Re-deployment of HIV staff during COVID-19

- People working in HIV services spoke about their experiences of being re-deployed to intensive care during COVID-19 with issues of “not feeling part of the team” and then facing challenges when re-integrating back into a team (HIV/sexual health) that had changed its ways of working during their absence.
- Attendees felt that re-deploying staff was manageable in well-resourced areas (e.g. London) but more difficult for future planning in smaller, more rural areas with the pandemic highlighting the disparity of services across the UK. For instance, rural clinics running on lower staffing levels which would potentially leave people without a service if staff were re-deployed or a reduction in services being offered.
- Some colleagues had experienced trauma when being re-deployed to COVID-19 wards and expressed feelings of vulnerability intruding into their daily lives.
- One healthcare professional described staff being re-deployed at short notice, leaving few to arrange prescriptions.

6. Impact on self and feelings of isolation when shielding/during lockdown

- Several spoke of an increase in mental health problems related to social isolation and, for example, an inability to access support groups. People were particularly concerned for people who had never engaged with HIV organisations prior to lockdown. Despite this, peer mentors were able to link people to one another and peer navigators were also able to provide phone calls.
- However, it was felt that virtual support groups now provided an opportunity for a support network for some who would not normally be able to access them such as those based in more remote locations.
- Peer support had mostly stopped, leaving a gap for people who are newly diagnosed who may not be receiving the support they need. One person living with HIV described not wanting one-to-one video meetings when offered; some felt emotions communicated in person are lost when meetings are not conducted in person.
- For some, lockdown was an emotional reminder (or 'triggering') of their initial HIV diagnosis experience; one person described a 14-day quarantine as *"...another thing to add to what I am."* Another person felt described being *"locked down within myself"* whilst someone described feeling more *"aware of their infectiousness again"* in a non-traumatic sense, but rather as a strong memory.
- However, some felt lockdown gave them the opportunity to spend more time taking up new hobbies, studying and exploring support beyond HIV groups, or building links with HIV support groups based internationally. Others described taking up new (mindfulness) classes or attending weekly meetings which were now at a time and a place convenient for them as they have moved online, as well as the adaptation of other peer support groups to online which provides some continuity (e.g. Positively UK Seeds Project).
- There are anxieties with the easing of lockdown when COVID-19 is still circulating. Life is now different to before; life has a *"new normal."*
- However, others viewed COVID-19 as a positive catalyst for conversations with people feeling more comfortable to ask for support and less embarrassed to ask for help. Some felt able to talk about COVID-19 with friends and family who are unaware of their status to determine how they talk about viruses and *"involving people in conversations gay men have been having for years, kind of feels like welcome to conversation."*

7. Wider negative impact on finances, food security and housing and the disproportionate impact on the most vulnerable and marginalised groups living with HIV

- We heard of concerns for the homeless who had been re-housed during lockdown and were not guaranteed housing security now restrictions were being lifted.
- Financial hardship was a key area of concern, particularly for those submitting/accessing benefit claims who now needed to complete this online. Stories were shared of people not receiving financial support they required or waiting for personal independence payment (PIP) assessments. One attendee spoke of having to use their savings as they are self-employed and have yet to receive anything through the furlough scheme.
- Food security was a challenge for people on low incomes, the homeless and the most vulnerable people living with HIV. One person based at a charity providing nutritional support services discussed people being lost during referrals and therefore being missed, and some people with HIV unable to access food when shielding.

- Some struggled to go to the shops during lockdown and were generally fearful about leaving their homes. Some made face coverings but are fearful of others not wearing face masks; *“I protect myself, but they don’t.”*
- One group discussed how community initiatives were much faster at responding to COVID-19 than ‘more traditional’ organisations due to their agile set-up (e.g. food banks knew who to support and already had links established).
- One attendee described being put on local council list and having volunteers to provide support with COVID-19; another visits shops once a week and finds the protective measures in supermarkets reassuring.
- Concerns were raised for the most vulnerable being missed, lost or dying without any support and who we aren’t hearing from. *“People can easily slip through the net”; “Their voices aren’t heard.”* People also spoke about this in relation to the Zoom conversation itself who they felt were not in the room for this session.
- Some discussions focussed on the disparities of poorer outcomes being reported Black, Asian and minority ethnic (BAME) and more deprived communities resulting in people being worried about accessing services with the media amplifying these anxieties. Some spoke of BAME staff living with HIV feeling even more frightened to engage with care. Again, this was linked to past ‘triggering’ experiences during their diagnosis and the AIDS epidemic; however, some did not agree that there were similarities between COVID-19 and the early days of HIV in relation to multiple deaths and fear.
- Concerns were raised for people living with co-morbidities such as cancer who assumed that no treatments or services were available.

8. Longer-term health and economic consequences of COVID-19

- One group discussed concerns long-term consequences of people living with HIV who had COVID-19; for instance, lung damage, follow-up with GPs or specialists.
- Charity workers and community support staff expressed concerns of the long-term effects of an economic downturn and austerity on their services and funds. Specifically, there were worries for smaller charities who may not have secured funding and rely on fundraising resulting in a disruption and closure of HIV services with the voluntary sector being heavily disrupted.

During the call, some people also explained why they had joined the call. For instance, a clinician joined to see whether the method (Zoom conversation) would be a good way to get patients involved in service change. Another described wanting to hear from people living with HIV due to only having contact with clinicians to date.

Post-call feedback from attendees (n=11/25)

When asked to rate their experience of taking part in the Community Involvement Zoom call, all of the eleven respondents gave the call a 6/10 or above with three rating it 10/10.

Over half of respondents (n=6) reported that they would be extremely likely to join another Zoom call like it to hear about and discuss important topics relevant to COVID-19 and HIV. The remaining respondents reported they would be somewhat likely to join another call.

When asked what they liked most about the session respondents selected an average of 2.4 elements each with 'Discussions around the impact of COVID-19 on HIV care' being the most popular, chosen by ten out of eleven people. The 'Anonymous polls' were liked by four out of the eleven as was the 'Background information to the project'.

Four respondents provided other reasons they liked the session, this included a good mix of people who had a positive HIV diagnosis with those who are not living with HIV, the sharing of first-hand personal thoughts feelings and experiences of both patients and frontline staff. They enjoyed exploring the commonalities and differences.

Four out of eleven respondents heard about the call by email from either the National HIV Nurses Association (NHIVNA), Positively UK, UK Community Advisory Board (UK-CAB) or another HIV organisation. However, a further two stated they heard from other sources, again citing UK-CAB and Positively UK, and another cited a website which they reported as the Positively UK site. One participant mentioned a WhatsApp group and another Twitter, the remaining two heard through word of mouth.

When asked how strongly they agreed that that they had made an impact on research none of the respondents 'strongly agreed' or 'strongly disagreed'. The majority (n=6) 'agreed' or 'somewhat agreed'.

When asked for recommendation about how the call could be improved the suggestions included the following ideas:

- More Zoom training and technical support (e.g. person on the call for technical issues)
- More introductions to people at start of call
- More people living with HIV rather than just Positively UK/ PERC /Clinicians
- WhatsApp involvement for those who can't access online

The preferred method of remote involvement that was chosen as one of the respondent's top two choices was 'Group conference (Zoom) calls' as used in the session. Other popular choices included 'Anonymous online surveys/ forms' and 'Online discussion forums.' When asked their preference for online involvement opportunities rather than in person there was no clear answer, of the ten that answered half said 'maybe' while two said 'yes' and three said 'no'.

The topics suggested by respondents for future Zoom call included:

- Anxiety caused by COVID-19 (related to peoples understanding of risk and the information available)
- Specific, known HIV-related conditions
- Supporting those who are living with HIV to connect online for peer support
- Ageing and HIV

See **Appendix 4** for full table of feedback responses and **Appendix 5** for feedback from a de-brief call with all facilitators.

Conclusion and next steps

Our report highlights some of the key areas of HIV care that people living with, affected by and working in HIV feel have been affected by COVID-19.

The insights from this activity will be used to help focus the design of the qualitative study, particularly the interview topic guide. The community involvement call has emphasised some key areas regarding the longer-term health and economic consequences of COVID-19, impact of lockdown on self-identity and vulnerable groups living with HIV which we plan to explore further with our research. Feedback received from the call is also useful for planning how and where to recruit participants and will be used to inform the ethics application we are currently preparing for submission. We will also remain mindful that our topic guide and methodology remain open to new ideas and experiences as the project progresses. The involvement activity has emphasised the need to ensure the research remains accessible to all (e.g. people with no internet access).

We will continue to work with Positively UK during the next planning stage (and eventual undertaking) of this study to ensure our work remains meaningful and relevant to people living with HIV.

Acknowledgements

We would like to thank all those who attended and the breakout room facilitators: Joyce (Positively UK), Mina (Positively UK), Helen (Positively UK), Meerat Kaur (PERC), Julie (Positively UK), Will Viney (PERC) and Mel (Positively UK).

Appendices

Appendix 1: Demographic of public attendees

As event registration was hosted on Eventbrite, which is a US-based company we were unable to ask some sociodemographic questions at this stage in order to adhere to GDPR regulations. We decided to ask these following the event through a feedback form hosted on Qualtrics which meets GDPR requirements.

Table 1: Demographic details provided during event registration (n=23/25)

Characteristic	n (%)
Age (in years)	
Mean (range)	65 (25-78)
Approx. age group	
18–24	0 (0.0)
25–34	2 (8.7)
35–44	6 (26.1)
45–54	4 (17.4)
55–64	5 (21.7)
65–74	4 (17.4)
75–84	1 (4.3)
No response	1 (4.3)
Gender	
Female (including transwomen)	13 (78.3)
Male (including transmen)	9 (39.1)
In another way	0 (0.0)
Prefer not to say	0 (0.0)
No response	1 (4.3)
Location	
Yorkshire and the Humber	1 (4.3)
West Midlands	1 (4.3)
East of England	1 (4.3)
Greater London	13 (78.3)
South East England	2 (8.7)
South West England	2 (8.7)
Northern Ireland	1 (4.3)
Prefer not to say	2 (8.7)

Table 2: Additional demographic details provided during feedback (n=10/25; data not available for 15 attendees; 1 attendee gave no demographic details but gave feedback and so is included in Table 3)

Characteristic	n (%)
Ethnicity	
White (English/Welsh/Scottish/Northern Irish/British)	7 (70.0)
Mixed / Multiple ethnic groups	0 (0.0)

Asian / Asian British	0 (0.0)
Black / African / Caribbean / Black British	0 (0.0)
Any other ethnic group	1 (10.0)
Prefer not to say	0 (0.0)
No response	2 (20.0)
Experience of HIV (could select multiple options)	
Currently living with HIV	7 (70.0)
Friend or loved one of someone living with HIV	1 (10.0)
HIV advocate supporting people living with HIV	3 (30.0)
Healthcare worker supporting people living with HIV	4 (40.0)
<i>Advanced Nurse Practitioner</i>	1 (10.0)
<i>Consultant Physician</i>	1 (10.0)
<i>Health Advisor</i>	1 (10.0)
<i>Peer Mentor</i>	1 (10.0)
Charity worker supporting people living with HIV	2 (20.0)
Community worker supporting people living with HIV	1 (10.0)
Approx. years living, supporting or working in HIV	
Mean (range)	21 (5-36)

Appendix 2: Event registration and Zoom call set-up

Attendee recruitment

We invited attendees through a number of existing channels / contacts and asked that the information was shared with anyone who might be interested in joining. Specifically, an email invite was sent to a Positively UK mailing list, but we also contacted other charities, community support groups and professional networks by email and/or social media (full list below). We also shared a link to the Eventbrite page on social media (Twitter) and asked key stakeholders to share/retweet.

- **Charities/community groups:** Positively UK, National AIDS Trust, Positive East, SWIFT, Terrence Higgins Trust, Sophia Forum, CHIVA, Naz Project, HIV Scotland, The Sussex Beacon
- **Professional networks/contacts:** BHIVA, HIV section at PHE, BASHH, NHIVNA, DHIVA, HIV Prevention England,
- **Information/advice:** UK-CAB, HIV iBase, NAM/Aidsmap

Event registration

Attendees were asked to register for the call via Eventbrite, which included providing some basic demographic details (gender, geographic location); these were restricted to meet GDPR requirements. We therefore asked more sociodemographic information in the feedback form which is hosted on Qualtrics (a service recommended by Imperial College London for hosting data).

44 individuals registered for the call via Eventbrite of which 24 joined on the day. An additional 1 person was given direct access to the Zoom call by PERC (see **Appendix 1** for demographics).

Zoom call technical requirements and troubleshooting

The team allowed for people to join in the first 10 minutes before the session began and shared a holding slide that provide attendees with tips on how to navigate and use Zoom. The team also did a quick run through of these once the meeting began.

Unmute here if you wish to speak, but mute again when others are speaking

Click here to open the Group Chat box where you can share your comments, questions and ideas throughout the call with everyone or just the hosts

Best to keep video turned off to stabilise the call. But OK to turn on temporarily if you wish to introduce yourself or if you are speaking

To rename yourself, hover your mouse over your name in the "Participants" list and click "Rename"

You can leave at any time. Feel free to write a message in the Chat box before you do

You can also use the "raise your hand" option if you'd like to ask a Question

The diagram shows a Zoom meeting control bar with icons for Unmute, Stop Video, Participants (11), Chat, Share Screen, Record, Reactions, and Leave Meeting. Below the bar are arrows pointing to these icons with explanatory text. To the right, there is a separate row of icons for 'raise hand', 'yes', 'no', 'go slower', 'go faster', and 'more'.

All facilitators (PERC/Positively UK) were set up as co-hosts, which supported attendee management as well as troubleshooting. We asked Positively UK staff to lead facilitation of breakout rooms (if they felt comfortable doing so) and had a second facilitator (PERC staff member) to notetake and manage attendees who may be struggling. This was the set-up in all but one breakout room; the other breakout room had a PERC staff member leading, Positively UK member taking notes and second PERC staff member taking notes/troubleshooting. PERC staff recorded breakout rooms to their computers and shared the notes and audio recordings via Box after the call.

Appendix 3: Further insights following the Zoom call

We invited anyone who did not want to, or were not able to, join the Zoom call to share their insights by email with Vas. Their comments (in relation to the 3 breakout room questions) are below. We have only added those that did not otherwise arise during the discussions on the day.

1. What new challenges have emerged during COVID-19?

- A person living with HIV spoke of issues queuing for shopping for basic items (e.g. milk, bread) due to living with several chronic health conditions. They found online shopping was otherwise OK.
- A peer support worker added after the call that people living with HIV who are also diabetic/had high blood pressure have complained of getting food they are told not to eat (e.g. high in sugar, salt etc.)

2. What are your key concerns regarding HIV care during COVID-19?

- A person living with HIV felt that people living with HIV will be “added to the bottom of the list” by those involved in managing their care.

3. What changes have there been in the provision of HIV care? Any opportunities?

- A person living with HIV described changes to ordering medications online.
- They also suggest that there was an opportunity to learn from COVID-19 in relation to HIV care, in particular by listening to patients.

Appendix 4: Post-call feedback

Table 3: Responses to post-call online feedback form (11/25)

Characteristic	n (%)
On a scale of 1–10, how would you rate the call?	
<5	0 (0.0)
6	1 (9.1)
7	2 (18.2)
8	4 (36.4)
9	1 (9.1)
10	3 (27.3)
How likely are you to join another Zoom call like it?	
Extremely likely	6 (54.6)
Somewhat likely	5 (45.5)
Neither likely nor unlikely	0 (0.0)
Somewhat unlikely	0 (0.0)
Extremely unlikely	0 (0.0)
What did you like most about the session, if anything? (multiple select allowed)	
Introduction to the Patient Experience Research Centre and Positively UK	4 (14.8)
Background to the project	4 (14.8)
Anonymous poll (s)	10 (37.0)
Breakout room discussions	0 (0.0)
None of it	4 (14.8)
Other: <ul style="list-style-type: none"> I was very impressed with the mix of non +ves and +ves and with the mix of frontline and clients - though it would have been nice to have had more clients on there. And also what I really found very interesting was hearing first hand from frontline staff and the challenges they had and how open they were and they care and concern shown. It was very important to contribute in the breakout rooms as a patient. Personal experiences. In the breakout group, people were very open and willing to share their thoughts, feelings and experiences It was interesting and useful to hear the experiences of others. Exploring commonality and differences. 	
Reason why: <ul style="list-style-type: none"> It's important to get an assessment of how covid is impacting the HIV community. This is a good start...but I do worry that there will be 'selection bias'...not sure how to overcome that, though! And the sample size might be a bit small, too...the discussion was OK, but maybe could have been more focussed and structured, to get clearer inputs...some of the feedback was a bit "rambling" and unfocussed (sorry to be blunt...no offence intended!). Maybe a clearer definition of personal experience versus experience seen as part of our volunteering or other work might have been useful, too 	
How strongly do you agree that you have made an impact on research?	
Strongly agree	0 (0.0)
Agree	4 (36.4)
Somewhat agree	2 (18.2)
Neither agree nor disagree	4 (36.4)

Somewhat disagree	0 (0.0)
Disagree	1 (9.1)
Strongly disagree	0 (0.0)
Do you have any thoughts on how we could improve these calls, the process of taking part or make it more accessible?	5 (55.6)
Yes:	
<ul style="list-style-type: none"> Some WhatsApp and phone calls surveys. The most deprived people otherwise do not have the chance to participate. Arrange for team including breakout room facilitators to meet before the start of the call...so that everyone is on hand to assist people struggling to get in and the meeting begins on time. Having a Zoom expert on standby might also be useful. Our breakout group sorted out technical problems amongst ourselves. Turning of video makes a huge difference to participation when bandwidth is low or poor connection causes image and sound to break up Facilitate group introductions when everyone has joined - ask each person in turn to quickly introduce themselves. Was good to have Positively UK & PERC plus all the clinicians. But there were only a few PLHIV such as myself. I did also worry if I spoke too much. I need more training re Zoom 	
No	2 (22.2)
Don't know	2 (22.2)
In general, what would be your preferred method of remote involvement? Select top 2 choices	1 (5.0)
Anonymous online polls	4 (20.0)
Anonymous online surveys/forms	8 (40.0)
Group conference calls (e.g. via Zoom)	4 (20.0)
Online discussion forums	0 (0.0)
Directly by email	1 (5.0)
Via WhatsApp chats or equivalent	0 (0.0)
Other – please specify and/or share your thoughts on other ways we could engage and involve people, e.g. reviewing materials and in influencing research	2 (10.0)
Phone calls	2 (10.0)
Would you prefer to attend online involvement opportunities, rather than in-person, particularly once social distancing measures have lifted?	
Yes	2 (20.0)
Maybe	5 (50.0)
No	3 (30.0)
How did you hear about the call? Select all that apply	
By email, please specify:	4 (36.4)
<ul style="list-style-type: none"> Regular positing from HIV organisation NHIVNA Positively UK ...hmmm...not sure where now...UK-CAB probably 	
On a website, please specify:	1 (9.1)
<ul style="list-style-type: none"> Eventbrite and Positively UK 	
Social media, please specify:	1 (9.1)
<ul style="list-style-type: none"> Twitter 	
Word of mouth (friend or colleague)	2 (18.2)
Other, please specify:	3 (27.3)

<ul style="list-style-type: none"> • Uk cab • Through our all ladies WhatsApp group here in Ireland • Positively UK 	
<p>Any final comments, including any suggestions for future topics that you would like to see discussed with people living with, affected by, or working in HIV?</p> <p>Yes:</p> <ul style="list-style-type: none"> • We need to address the anxiety caused by covid...in many cases, OVERanxiety...we need to rebuild confidence as we come out of lockdown and social distancing...finding ways to assess our own personal risk may not be easy for everyone, but this will be the way forward...Government cannot be expected to provide "rules" to cover every eventuality...rather, there will be guidelines and advice for us to make our own decisions...but not everyone will be comfortable with that, and people's views of 'risk" are often poor or ill-informed... • Specific, known, HIV related health conditions • How can we, those who are +, connect online, in a safe way, with others to be there just for a chat, peer support etc • Ageing and HIV <p>No</p>	<p>4 (66.7) 2 (33.3)</p>

Appendix 5: De-brief with facilitators

Vas hosted a 1hr de-briefing meeting with all facilitators (all but one attended). Before the meeting, a Padlet board was created for facilitators to anonymously leave their feedback of their experiences specifically: (1) what did we learn, (2) what went well, (3) what could be improved and (4) what next. During the call, Vas shared this Padlet and added notes – the Padlet remained open afterwards for anyone to add any additional comments.

The key things we found that worked well were:

1. **Positively UK facilitating** – having community members who were part of the process and shared their experience whilst facilitating helped participants to open up. All Positively UK staff members were women from a range of backgrounds, which differs to normal activity run by the charity and seemed to work well.
2. **Having a mixed group of participants** – allowed the group to hear from all perspectives (e.g. clinicians explaining how things are working in practice on the ground; PLHIV explaining first-hand experience with HIV care; charities/voluntary sector describing changes in service use). In particular, one group found that discussions around the economic impact of COVID-19 was particularly helpful to hear from different perspectives.
3. **Open and honest discussions** – people were open to sharing their experiences from a clinical and personal level. This is likely to have been guided by the points above.

The key things we thought could be improved:

1. **Digital exclusion** – are there other ways we could involve people who do not use Zoom?
2. **Gender balance of facilitators** – all but one facilitator were women.
3. **Timing** – although we gave 40 minutes for discussions, it was felt that perhaps this could have been extended.
4. **Issues joining breakout rooms** – one person emailed to say they had issues joining the breakout room and then were not able to join the call. Vas emailed them to say they can share feedback if they wish by email. We also found that 2 participants left the call accidentally during breakout room discussions but were able to join after. For future – perhaps instructions should be circulated or said about how to re-join if people accidentally leave or their internet connection drops.