

Rapid Assessment Bulletin  
EATG COVID-19  
Community Response  
Project



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Living with HIV in a COVID-19 world:  
challenges, responses, and lessons to learn

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Link to the recording of the e-meeting:  
[https://bit.ly/EATG\\_e-meeting\\_NOV20](https://bit.ly/EATG_e-meeting_NOV20)

## Key messages

1. COVID-19's impact differs between countries, as do ways in which people living with HIV have been affected. Common features are increased stress levels and external factors amplifying anxiety, such as barriers to free movement. Stress and anxiety caused by COVID-19 can lead to increased risk-taking and possible exposure to HIV infection.
2. Lack of effective communication by decision makers does affect general understanding of COVID-19 and, as collateral harm, how people with HIV may be seen.
3. Existing vulnerabilities have been exacerbated for [depending on country] the homeless, people facing difficulties at home, and migrant communities. Creative solutions are being implemented, but these require a robust support system and well-placed personnel, such as street social workers in Helsinki.
4. COVID-19 has shown that much more public participation in health decision making is required, and the need to protect privacy and human rights.
5. Trust, between patients and care services, and between populations and governments, is vital for an effective response.
6. A long-view is required – COVID-19 will be a feature of our social landscape for some time. Planning should acknowledge this.
7. Funding is a concern for CBOs. The HIV space has been squeezed during 2020. Ensuring the voice of people affected by HIV is loud, front, and centre could be pivotal in maintaining sustainability.

## 1. Overview

The COVID-19 pandemic has now been a reality for 10 months. The purpose of this fifth EATG rapid assessment bulletin is to explore the lived experiences of communities affected by HIV during the COVID-19 pandemic in different parts of Europe, at a time when many countries are experiencing an increase in new infections whilst still facing difficulties resulting from earlier in the pandemic. It draws on contributions from stakeholders directly involved in working with communities affected by HIV and offers a snapshot of the current situation of living with HIV in the pandemic. It will:

- Focus on levels of disruption and the impact on people living with or affected by HIV and comorbidities.
- Highlight effective interventions during the last 9-10 months.
- Explore the long-term – what are the main issues, and lessons learnt so far, to consider from now and into 2021?

## 2. Methodology

This bulletin is derived from an e-meeting with panellists from five European countries: Cyprus, Finland, Poland, Portugal, and Russia. The meeting was held on Monday 23 November 2020. Questions explored were:

1. What examples are there of how the COVID-19 pandemic has directly affected - and continues to affect - the lives and day to day living of people affected by HIV?
2. How are the essential basic living needs of people affected by HIV being disrupted during the pandemic?
3. How are the essential care needs [support or medical services] of people affected by HIV being disrupted during the pandemic?
4. What are the long-term effects of the COVID-19 pandemic on the lives of people affected by HIV into 2021 and beyond?

## 3. Results

### 3.1. Examples are there of how the COVID-19 pandemic has directly affected – and continues to affect - the lives and day to day living of people affected by HIV?

Supporting the **mental health** of people living with HIV has always been a prominent issue. With the dichotomy of COVID versus non-COVID there have been challenges maintaining an HIV focus. Impact at the emotional level was noted in [Portugal](#). “PLHIV are strong, but they see themselves as vulnerable”. There was poor communication about COVID-19 and risk, and a

belief that HIV – as an immune system disease – was connected in some way.

The situation differs slightly in Finland. Here, the **emotional impact of COVID-19 is shared by everyone (HIV, or non-HIV)**. As with other countries, most consultations are now virtual. As with Portugal, early media reports suggested people living with HIV were a risk group, leading to HIV community organisations receiving many calls from HIV-negative family members of people living with HIV asking if the affected person was in danger. Contrary to some other countries, there was no treatment interruption, and one element strong in Scandinavia is **trust** – there is a close and mutually respectful relationship between the HIV community and clinical services.

In Cyprus, **interruptions and disruptions in clinical services led to people affected by HIV needing to find other solutions**. This was not helped by restrictions on movement – still an issue at the north-south border, where evidence of a negative coronavirus test is required to pass through. Movement out of cities is also restricted without a negative coronavirus test certification (valid for 3 days). Rapid tests are available but have to be obtained privately, as do PCR tests. Anyone crossing the north-south border in Cyprus is required to self-isolate afterwards. Both these factors limit the number of people crossing. In Cyprus, community health workers are under immense stress.

The situation in Poland is characterised by **continuing mental health problems and increased levels of stress, especially around access to medications and appointments**. Poland at this time (November 2020) faces a rapid increase in new coronavirus infections and is currently under lockdown (which includes schools closed until January 2021). Many doctors usually working on HIV are redirected to COVID-19 services. There are also legal issues emerging in Poland, with HIV transmission being specifically criminalised during 2020. This impacted directly on antiretroviral treatment (ARV) access.

For Russia, during 2020, ARVs have been delivered to the home, and there was **general concern of stockouts** which continues, especially Ritonavir, proposed as a possible treatment for severe COVID-19 symptoms. A key challenge is Russia's fragile support system for people living with HIV, and fears of further COVID-19 burden into 2021 which could affect ARV access. In Russia there are also **HIV denialists** who are now often COVID-19 denialists, sharing misinformation about pharma conspiracies. Civil society categorises this as requiring a form of 'harm reduction' and ensuring people access to correct and accurate information.

### Key messages

- *The impact of COVID-19 differs between countries, as do ways in which people living with HIV have been affected. One common feature is increased stress levels and external factors*

that amplify anxiety, such as barriers to free movement.

- Lack of effective communication by decision makers does affect general understanding of COVID-19 and, as collateral harm, how people with HIV may be affected.

### 3.2. How are the essential basic living needs of people affected by HIV being disrupted during the pandemic?

The coronavirus pandemic has been a “big change for everyone” in Portugal. **Key populations face the biggest challenge**, for example around treatment access and the need for basic information. Migrants, sex workers, transgender people, and people who use drugs face particular problems. For example, sex workers find it difficult to generate income in any lockdown context, and transgender people face barriers obtaining required medication. For undocumented migrants, earlier in 2020, there was a national lifting of restrictions in access to the national health system. However, these measures have expired and some migrants face access barriers once again. CBOs such as GAT are central in maintaining support, providing medication and maintaining as many services open as possible, especially for key populations. Funding is available, but Portugal’s economic crisis is of concern for all communities. Sustainability of services is seriously threatened going into 2021.

In Finland, **vulnerable people face challenges around basic needs**, especially people who use drugs, the homeless, and sex workers. In Helsinki, ‘street social workers’ were a huge help to CBOs who didn’t have the resources to help all homeless people. Since Spring 2020, organisations have expanded their services to pre-COVID-19 levels for the homeless and other vulnerable groups.

Fears of the future affect everyone in Cyprus. For people affected by HIV, **unpredictability around access to clinics, and the need to deal with another health issue** influences their day to day lives. Financial instability is an ongoing burden on the lives of many people, and the bulk of support – including psychological – is virtual or by telephone.

**Significant problems accessing care and support by people forced to stay at home** is noted in Poland, especially when a partner or children are also at home. Current [as of November 2020] COVID-19 control measures are restrictive, with schools (apart from nurseries and kindergartens) and many retail outlets remaining closed. Work is difficult, and seeking support when, for example, a partner is abusive is extremely hard if the whole family are in the same home. Discussions with a therapist whilst sitting alone in a car are not unusual. HIV testing has to be done in the open air; feasible, but during the winter will be difficult. Generally, people living with HIV “feel lonely”, though one benefit of moving to virtual support is that CBOs are able to reach more people away from Warsaw centre, providing a vital opportunity that can be

taken further post-COVID-19.

For Russia, levels of social insecurity are the same for all people, whether or not living with HIV. For **specific key populations there was increased risk of HIV transmission** arising from personal responses to increased stress, for example people who use drugs, or an increase in chemsex use in large cities. Additional government financial support is necessary, though can be limited. Funding for families with children decreased some of the burden.

### Key messages

- *Existing vulnerabilities have been exacerbated for [depending on country] the homeless, people facing difficulties at home, and migrant communities. Creative solutions are being implemented, but these require a robust support system and well-placed personnel, such as street social workers in Helsinki.*
- *Stress and anxiety caused by COVID-19 can lead to increased risk-taking and possible exposure to HIV infection in communities.*

### 3.3. How are the essential care needs [support or medical services] of people affected by HIV being disrupted during the pandemic?

Though the situation in Portugal is not 'catastrophic', with treatment available for home delivery, **support of people receiving PrEP** is jeopardised. Ensuring their access to services has been difficult, and this is likely to continue. Two priority issues emerge for 2021. One is the need for more **public participation in health decisions**. Currently, there are no formal ways to be heard, and COVID-19 highlights the need for increased community collaboration and participation is required when governments make important health decisions. Issues around **data control and privacy** are also crucial. Personal and sensitive data are being used during 2020 in ways not acceptable outside the COVID-19 context, for example sending the police lists of coronavirus-infected people. Human rights are at risk.

The situation in Finland is not quite as extreme, though health services remain affected, including support for people receiving PrEP. **Trust in health care staff and officials is an important enabler**, with evidence of patients preferring *more* telephone conversations with doctors, potentially reducing the need for face-to-face meetings.

In Cyprus, currently [November 2020] in a post-lockdown phase, psychological support and counselling are in place, and more people are reached through webinars. **But there is an underlying fear a more severe lockdown may return**. A key challenge for people affected by

HIV is that, if there is a need to move from one part of Cyprus to another for treatment, **they are required to say why, hence being forced to reveal their HIV status**. One overall benefit has been an increased awareness generally of the need for testing as an important public health activity. This awareness can be utilised in the HIV context.

Due to COVID-19's dominance, Poland is now [November 2020] seeing **significant delays in health service access**. There are initial reports of an increase in late presentation of new HIV infections. Screening for sexually transmitted infections is also affected, and linkage to care (especially for hepatitis C) is impeded.

For Russia, **CBOs delivering ARVs to individuals' houses has been a vital and successful response**. There are reports of stockouts in some locations of both local and Global Fund supported resources. Here, the government provides treatment cover but for a shorter duration - sometimes only for two weeks - requiring more frequent hospital visits. One strategy CBOs are pursuing is based on the notion of '**socially significant diseases**', falling under the same Ministry of Health unit. Here, clustering HIV, TB, hepatitis, and COVID-19 could lead to beneficial legal changes and increased funding.

### Key messages

- *The COVID-19 experience demonstrates that much more public participation in health decision making is required, and the need to protect privacy and human rights.*
- *Trust, between patients and care services, and between populations and governments, is vital for an effective response.*

### 3.4. What are the long-term effects of the COVID-19 pandemic on the lives of people affected by HIV into 2021 and beyond?

In Portugal, it's **important to appreciate that we'll be in this situation for some time**, with the likelihood of further COVID-19 waves before a vaccine is fully rolled out. Strong CBOs are required, but many are threatened by economic challenges. There's a need to **promote more public participation**, bringing the voices of people living with HIV to decision makers. There's a need to force ourselves into the decision-making spaces and show 'we are there'. Otherwise, community organisations may be denied funding.

COVID-19 as a distraction is also noted in Finland, **where COVID-19 has squeezed HIV's space**. Earlier in 2020, virtual meetings were popular, but they are less so now [November 2020]. Though in some ways they are limited in what they can offer, there is potential to reach people



away from capital city hubs.

In Cyprus, a key issue for 2021 is the **need to maintain focus on testing and prevention**, and to sustain organisations working on this. There's a need to fight for **human rights** values, for example protecting **personal data** and ensuring anonymous testing is really anonymous.

For Poland, COVID-19 has changed mindsets, and it's important to continue being flexible and open-minded. **One development in 2020 has been increased open access for self-testing**, and it's hoped this will continue post-COVID-19, as should virtual/remote support for people unable to attend in person. Funding is required, and a key barrier is that HIV is less of a priority and there could be difficulties obtaining funding in the new political context. In Poland, there are **currently significant threats to LGBT rights and women's sexual and reproductive health rights**, and robust advocacy is required to **repeal recent legislation that criminalises HIV transmission**.

### Key messages

- *A long-view is required – COVID-19 will be a feature of our social landscape for some time. Planning should acknowledge this.*
- *Funding is a continuing concern for CBOs. The HIV space has been squeezed during 2020. Ensuring the voice of people affected by HIV is loud, front, and centre could be pivotal in maintaining sustainability.*

## 4. Implications and recommendations for communities to meet future needs and address emerging challenges

Though there are many common experiences across the European region, a range of contextual challenges face CBOs and people living with HIV. Disruptions are universal, though there are also benefits, such as innovations that extend the reach of CBOs using virtual and remote options.

### Core elements

1. There are significant variations in the level of lockdown – infection control – in different countries.
2. The impact of COVID-19 affects all people, but for vulnerable and key populations this can be especially severe.
3. Communication is vital to ensure citizens are aware of important information, and that decision-makers hear the voice of communities.

### **Interventions that show benefit**

1. Home delivery of ARVs.
2. Remote/virtual support can increase the reach of services, and this is an opportunity for the future. Whilst not as beneficial as face-to-face interactions, it has the potential to reach many more people in areas away from central city hubs
3. Increased access to self-testing for HIV screening, which is an opportunity to expand this intervention post-COVID-19 to improve HIV screening and prevention.
4. Drawing on existing support mechanisms, such as Helsinki's street-based social workers, to benefit those most in need.

### **Issues that require special attention in 2021**

1. Data protection and maintaining human rights – the relative flexibility of data sharing during the COVID-19 pandemic must be monitored and if necessary curtailed.
2. A comprehensive reset of HIV care services in the new post-COVID-19 era will be necessary, taking lessons learned from 2020 into a context where COVID-19 will dominate much of the public narrative, and funding for HIV services more difficult.

### **Key issues for future policy advocacy**

1. Fighting to regain the HIV space. COVID-19 dominates much of the health agenda. How can CBOs regain the focus on people living with HIV?
2. COVID-19 has exposed weaknesses in public participation during health crises when important decisions are being made by policy makers. CBOs must be louder, focused, and assertive.
3. Strengthening the notion of "significant social diseases", diseases with a particular public health relevance that include HIV, TB, hepatitis, and COVID-19 to raise their profile and attract increased funding.
4. COVID-19 has raised the profile of public health generally. Can this be capitalised to highlight the importance of HIV and other testing for populations most at risk?

## Focus group panellists

Sincere thanks to our panellists for participating in the e-meeting. They were:

**Magda Ankiersztejn-Bartczak:** Foundation of Social Education (Poland)

**Ricardo Fernandes:** GAT (Portugal)

**Denis Godlevskiy:** ITPC (Russian Federation)

**Zoe Kakota:** AIDS Solidarity Movement (Cyprus)

**Sini Pasanen:** Positiiviset ry, HivFinland (Finland)

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## About the European AIDS Treatment Group:

The European AIDS Treatment Group (EATG) is a patient-led NGO that advocates for the rights and interests of people living with or affected by HIV/AIDS and related co-infections within the WHO Europe region. Founded in 1992, the EATG is a network of more than 180 nationally-based members from 47 countries in Europe. Our members are PLHIV and representatives of different communities affected by HIV/AIDS and co-infections. EATG represents the diversity of more than 2.3 million people living with HIV (PLHIV) in Europe as well as those affected by HIV/AIDS and co-infections. For more information, please visit [www.eatg.org](http://www.eatg.org)