European AIDS Treatment Group

Rapid Assessment Bulletin

EATG COVID-19 Community Response Project

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European AIDS Treatment Group

CONTENTS

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"COVID is a brand-new situation and no-one prepared us for it."
[Respondent]

Key messages

1. People living with HIV and at risk – or living with – a comorbidity or co-infection face increased burden accessing multiple services. Integration, and decentralisation of services should be a priority.

2. Community responses have been vital across the HIV sector filling gaps in care and support. A flexible and creative approach has proven invaluable, and it is paramount that community and civil society organisations are formally recognised as an important part of the health response.

3. Threats to psychosocial well-being are major and require sustained interventions to help prevent long-term harm.

4. Planning for a post-COVID world –moving from an emergency to a strategic and long-term response – must involve the community at all stages.

5. All interventions must be equitable and based on a person-centred approach.

1. Overview

The novel virus SARS-COV-2 has created global turbulence since it first emerged. Infection control measures led to the closure of clinical and community spaces to ensure the protection of personnel and health service users. Data collected confirm that access to testing, treatment, and support services for people affected by HIV have been difficult for a range of reasons,[1] affecting health outcomes, quality of life, and morbidity.[2]

The purpose of this bulletin, the fourth in a series of six, focuses on comorbidities or co-infections of HIV. These can include viral hepatitis, tuberculosis (TB), some types of cancer, mental health issues, opportunistic infections such as meningitis, and noncommunicable diseases such as diabetes and cardio-vascular disease. This bulletin considers viral hepatitis, TB, mental health, and relevant components of harm reduction for people who inject drugs.

2. Methodology

This bulletin uses two main data sources:

- Reports from community-based organisations (CBOs) and non-governmental organisations (NGOs), academic papers, and media sources.
- Interviews with 16 key informants involved in the HIV and health sectors, including organisational representatives and community advocates.

3. Results

General: continuing impact on the individual

- **Travel restrictions**: Particularly during the strict infection control measures earlier in the pandemic, when public transport was unavailable or severely restricted. Service users resorted to taxis or, if allowed, their own cars. Less challenging now, though many countries still have restrictions of some kind.
- **Attitudes towards health services:** Sometimes fearful, due to a wariness of coronavirus infection. Different perspectives of the safety in health systems can play an important role in maintaining care continuity. One respondent shared that, when friends questioned her decision to go to hospital, "I can get [the coronavirus] from the market. In hospital at least they have the rules."
- **Financial impact:** A huge and unprecedented impact on key populations in social and economic terms.[3]

- **Stigma:** 'COVID stigma', towards frontline workers[4] or those not wearing masks. Respondents note this includes from people affected by HIV, a curious transposition of stigma against people this group in the 1980s and 1990s. Also, generalised stigma against all marginalised groups, for example in Romania, including men who have sex with men, people who use drugs, and sex workers, scapegoated as responsible for coronavirus transmission. Migrant workers are also targeted.[5]

Focus: comorbidities

COVID-19 People living with HIV and comorbidities/coinfections have always faced a more complex and fragmented treatment pathway, especially in an acute disease phase. The impact of COVID-19 on health and community services adds an extra layer of complexity.

Viral hepatitis

Status: Hepatitis B affects 5-20% of people living with HIV, and hepatitis C 2-15%.[6] Due to the COVID-19 pandemic, there is:

- **Interruption of screening and community services:** Due to the COVID-19 pandemic Hepatitis services are significantly disrupted, including around testing and treatment initiation, with some reporting closure of community screening altogether.[7] In a global survey undertaken by the World Hepatitis Alliance,[8] only 36-38% of respondents from 32 countries reported people were able to access viral hepatitis testing. This can be due to closure, people not attending facilities due to COVID-19, or staff diverted to COVID-19 departments.
- **Increased difficulty accessing treatment:** People with hepatitis, as well as support staff, have been forced to stay at home as part of COVID-19 infection control measures. The World Hepatitis Survey states that 32% of respondents in Europe could not access medications.[9] The same survey suggested as key reasons the travel restrictions, health services refocusing on COVID-19, and people avoiding health facilities.
- **A need for clear information:** According to a respondent for this bulletin, there was initially a "lack of clear information for people affected by COVID-19 and also hepatitis", compared with, for example, information from UNAIDS about COVID-19 and HIV. Hepatitis services did adapt – as with the HIV sector – by providing telemedicine, information, and peer support, which was beneficial.
- **Disrupted continuum of care:** Impact differs between countries. In some countries, hepatitis service delivery stopped completely, with no indication when it will restart.
- **A community response:** for those already on treatment, health and community organisations adapted and strived to continue. Many changed the way they work to ensure medication is delivered to the home or available at more suitable locations. As an example, the UK-based Hepatitis C Trust created new opportunities for testing and targeting

underserved populations,[10] including the homeless.

TB

Status: Of people who developed TB in 2017, 9% were also living with HIV.[11] Due to the COVID-19 pandemic, there is:

- **A disruption in screening and treatment:** EATG's earlier bulletins confirmed testing disruption. There are also reports of TB facilities being closed or, as described by a respondent for this bulletin, "temporarily given for COVID". During the first and most restrictive infection control period, access to testing and diagnosis decreased and there were difficulties obtaining an x-ray or blood test.
- **Challenges maintaining direct observed therapy (DOT):** Service restrictions make this difficult. Alternatives, such as DOT video calling, were being explored prior to COVID-19. But, as the *sole* alternative, this is limited only to those with smartphones or computer access. For one respondent, "I wish in the time of COVID these innovations were accelerated, and this transition to innovative care smoother and swifter."
- **Resource diversion:** In some countries, machines used for TB testing (GeneXpert) were taken to other departments for COVID-19 testing.
- **A service response:** In cities with multiple NGOs and outreach workers and manageable client numbers, people affected by TB experienced less disruption, for example Bishkek, Kyrgyzstan. Elsewhere, some service users were given treatment to last 2 weeks. Stop TB and partners, prior to COVID-19, developed a dedicated smartphone app to improve communication sharing and community monitoring of TB services. This is being promoted as an important resource during the COVID-19 pandemic. The community also came up with other solutions, such as delivery of treatment to the patients when no public transport was available, visiting patients moved from daily to once-weekly treatment dispensing to ensure that they are adherent, and helping prison inmates with TB following release from prison. According to one respondent:

  "These types of initiatives were not supported by governments or donors before COVID-19, and they certainly weren't supported during lockdowns. They were fully dependent on the resources of community groups and community members."

Mental health

Status: Previous studies show that 15% of adults and 25% of adolescents living with HIV report depression or feeling overwhelmed.[12] COVID-19 has had a strong collective impact on mental health,[13] [14] [15] and for people living with HIV this pandemic adds extra burden.[16] Due to COVID-19, there is:

- **Increased isolation:** People with existing mental health problems were distanced from support groups, and access to services was often out of the question. HIV key populations,

such as people who use drugs, couldn't access sessions and socialise with peers. For one respondent, this was likely "the same for other KPs – it was difficult for gay men and chemsex users."

> *"[Mental health was] left out of the question – people were focusing on prevention and infection control, but not looking at mental health and well-being [of those] in a new situation. We are always talking about mental health, but this was left off." [Respondent]*

- **Stigma:** Towards people seeking tests for STI or access to PrEP; service questioned about why they are having sex during a lockdown when 'you're home alone'. This is in spite of symptoms of some STI not emerging for three or more months (i.e. from before lockdown restrictions). This can only add to feelings of loneliness and, perhaps more damaging, self-stigma.
- **Fear:** Summarised by one respondent – "it was scary for everyone at the beginning." People have experienced reactive depression, and there are reportedly increased rates of suicide, with an expectation future suicide rates will be affected by long term economic outcomes, such as unemployment.[17] For people affected by HIV, one respondent notes that there is a degree of paranoia – fear of the health system based on doubts that sufficient precautions are being taken, and the unnerving sight of health workers wearing personal protective equipment (PPE).
- **A broader impact:** People who use drugs, who are/were unable to make the money for purchase face increased stress and anxiety. Sex workers face many more personal and emotional difficulties when it is difficult to earn money.[18] For trans people, especially in countries such as Kazakhstan where bigger families are the norm, there can be a heavy psychological impact from living at home with unsympathetic family members.
- **A response:** Alternative modes of contact and support can provide a stopgap. For example, in Kazakhstan, the government provides a free-to-access website addressing mental health for all citizens, offering one-on-one calls with psychologists. In the UK, HIV community nurses are advised to reduce one-on-one contact and use Skype to maintain continuity. But alternative interventions are not a panacea for a condition exacerbated by feelings of isolation and negative ideations; it is therapeutically limiting. It's difficult to assess body language during remote conversations.

> *"As a result [of COVID-19], the mental state and mental health of people, especially among key HIV groups, has worsened." [Respondent]*

Harm reduction and people who use drugs

Status: Harm reduction services for people who inject drugs, are vital for reducing HIV and viral hepatitis prevalence, and include access to opioid substitution therapy (OST) and clean needles/syringes. One three-continent review suggested a 54% reduction in risk of HIV infection associated with OST.[19] A Canadian study, in relation to hepatitis C and OST access, found a 77% reduction in hepatitis C acquisition when OST was available.[20] Due to COVID-19, there

is/are:

- **Reduction in harm reduction services and access:** Skeleton services were maintained in larger city hubs, but elsewhere were often limited or non-existent, for example in Romania. In Greece, the community was "devastated" by COVID-19. This was not only lack of access to harm reduction support, but also basics such as food and water. Difficulties distributing clean needles and syringes are of concern in some countries, e.g. Russia. Shortage of naloxone and OST was noted in Romania and Bulgaria.
- **A change in demand:** A changing pattern of use is also emerging. There has been difficulty enrolling new clients without face to face interactions, threatening linkage to care. Also, in Ukraine, a shortage of street drugs led to an *increase* in people turning to available harm reduction services for screening and OST.
- **Problems traveling:** Travel restrictions during the early stages of COVID-19 severely impacted on people using drugs being able to obtain methadone, especially if only available in central hubs, for example Almaty in Kazakhstan.
- **A changing pattern of drug use:** There is evidence that the pattern of drug use has changed. There is a decline in some countries but only for some forms, mainly recreational drugs. The use of cocaine and MDMA appears to have been most affected, largely linked to the closure of the night-time economy and the implementation of stay-at-home measures. Decrease in the use of these drugs have been confirmed by wastewater studies in a number of European cities.[21]
- **A strong community and health response:** Mobile drug consumption rooms, and longer OST prescriptions (up to 30 days in Germany and noted by respondents in other countries such as Ukraine), access to take home naloxone, a rapid expansion of online and digital access points, and additional information sources (for example, podcasts). Also, advocacy to the central government in Greece by harm reduction advocates to raise awareness of the "ticking time bomb", especially for people who use drugs and are living with HIV.
- **A consideration of hardships:** Some drop-in-centres provided basic services, but through an open window where users could obtain sterile injecting equipment. Access to additional support, such as showers or laundries, were unavailable. Latterly, these have reopened, but the pandemic highlighted the crucial importance of these services on the lives of people who use drugs. In Amsterdam, people using drugs are especially vulnerable from loss of income following the crash in tourism. The local municipality created a range of alternative jobs.
- **Innovations:** Mobile services and take-home OST to avoid crowding at centres, and the general need for organisations to be creative in reaching out during a crisis.[22]

"Urgency on the level of solidarity and support is the thing we have seen." [Respondent]

4. Conclusions and implications

At this time, eight months into the pandemic, many aspects of the response remain in the 'emergency' phase. But a shift to long term, strategic planning is needed to ensure there is suitable preparedness against a virus likely to pose a public health threat for some time. Four themes can inform future policy and strategic planning for the care, treatment, and support of people living with HIV and comorbidities.

4.1 Mental health weaves throughout

COVID-19's impact on the mental health of people across the sector cannot be underestimated, including the context of HIV's comorbidities. Difficulties accessing services, lack of contact with groups, peers, support mechanisms, and medical consultations inevitably alter a person's capacity to deal with their health and well-being. There is risk of a sustained anxiety state that in the long term can be more harmful. This is exacerbated by stigma towards people refusing to use masks and therefore to 'blame' for themselves or others contracting the virus - echoing the early days of the HIV epidemic – or targeting specific groups as scapegoats. This notion of blame and being 'clean' (non-risk) or 'dirty' (high-risk) resonates with anthropological literature describing beliefs of contagion.[23]

Mental health services need to be prepared for the long-term impact of COVID, ensuring interventions are sustainable, efficient, and equitable.[24] For those involved with people living with HIV and/or comorbidities or co-infections, the focus should be on psychological well-being and quality of life.

4.2 The shape of services and support

When services are under stress, fragmentation exacerbates accessing suitable treatment and support. In community-oriented support mechanisms such as harm reduction, CBOs require support to maintain alternative ways of working to prevent decreased well-being and health outcomes. In situations where services and support are centralised, this problem is amplified for people living away from city hubs. All is complicated by the dominating, overpowering presence of COVID-19 which, for some time to come, will inevitably drag on health and community provision, forcing reduction or reallocation of personnel, equipment, and resources. The risk of losing focus on non-COVID-19 morbidities is acute.

For general health services, difficulties accessing disparate departments were amplified for people living with HIV during the pandemic, and the argument for integrated, locally accessible provision is stronger as a result of COVID-19.

4.3 The community response can be rapid – is it sustainable?

Evidence confirms that community-led responses and solutions can have significant positive impact on the lives of people living with or affected by HIV, and comorbidities. For all comorbidities discussed in this bulletin, CBOs have been at the forefront filling the gaps created by the COVID-19 response – at the same time as trying to protect *themselves* against infection. In the short term this has, in many instances, been remarkable. In the long-term, there are questions about sustainability and funding stability, the latter a key issue noted in several community reports.

4.4 Where is the person-centred care?

People living with HIV and living with – or at risk of – one or more comorbidities already face a multi-faceted health experience. They deal with multiple treatment regimes, prevention strategies, and consultations. Person-centred care focuses on the *total* health needs of an individual and is underpinned by a strong focus on human-rights. COVID-19 destabilised care provision at multiple levels and exposed fractures in what was likely already a fragile treatment and support infrastructure. Opportunities to provide person-centred care have been restricted, and affected people have faced immense challenges in accessing screening, treatment, and support, for multiple morbidities. Reliance on remote support has limitations:

> *"You can have a discussion face to face online with a doctor to ask about things, show your rashes on the cameras. But the human touch is missing. We haven't really found a solution to this. No one knows how long it will go on." [Respondent]*

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Appendix: Respondents

Name	Affiliation
Timur Abdullaev	Community Representative, Stop TB Partnership Board
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Eliane Becks	HIV Stigma Fighter
Andrii Chernyshev	Alliance Global
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Cary James	World Hepatitis Alliance
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Jeff Lazarus	University of Barcelona
Cristian Musat	UNOPA [National Union of PLHIV Organisations]
Roberto Perez Gayo	Correlation - European Harm Reduction Network
Filippo von Schloesser	NADIR [HIV advocacy organisation]
Shaun Watson	National HIV Nurse's Association (NHIVNA)
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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