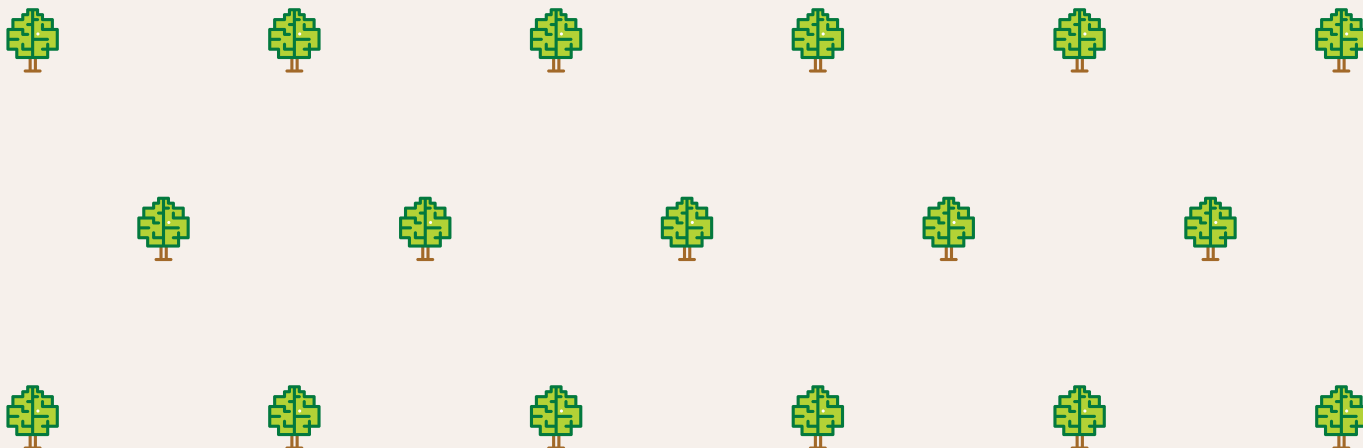


SHORT REPORT

MENTAL HEALTH OF PEOPLE LIVING WITH HIV and staff of organisations working in the field of HIV in the WHO European Region

ENGLISH | FRANÇAIS | ITALIANO | PORTUGUÊS | ROMÂNĂ | РУССКИЙ | УКРАЇНСЬКА





Acknowledgements

We would like to thank all the respondents of the survey for their time and the information provided. We will strive to use it as best we can to improve mental health services for people living with HIV in the WHO European Region.

This work was the result of the involvement of a diverse set of individuals from the European AIDS Treatment Group (EATG), acknowledged below:

Questionnaire development: Maryan Said and Miran Šolinc

Survey translation and dissemination: Mario Cascio, Mihai Lixandru, Viktor Tretiakov, Willian Gomes

EATG project Officers: Marina Cogne and Bojan Cigan

EATG Program Manager: Ann-Isabelle Von Lingen

HIV & Mental health Project Advisory Group: Nyambe Mukelabai, Nataliia Moyseeva, Kiromiddin Gulov, Ivana Benković, Mario Cascio

Data analysis and preparation of report: Daniel Simões



Copyright:

© 2021 European AIDS Treatment Group
Interoffices | Avenue des Arts 56 -4c, 1000 Brussels, Belgium

Suggested Citation: Simões, D. on behalf of the EATG HIV & Mental Health project team.
Short report on mental health of People living with HIV and staff of organisations working in the field of HIV in the WHO European Region. Brussels, Belgium, January 2021.

The HIV & Mental health project has been developed by the EATG, and was made possible through a grant from Gilead Sciences, Merck Sharp and Dohme and ViiV Healthcare Europe Ltd. EATG acknowledges that the sponsors had no control or input into the structure or the content of the initiative.



Introduction

This report aims to present a summary of the results of a survey conducted by the European AIDS Treatment Group, part of its “HIV & Mental Health” Project, which aims to explore the existing knowledge about the interplay of mental health, well-being and HIV and translate it into practical recommendations for both community organisations and healthcare professionals in the European context.

The survey was designed to provide an overview of:

- The existing landscape of mental health services available in HIV organizations in the WHO European Region and commonly reported mental health issues in the organizational context,
- Explore self-reported mental health status, symptoms commonly associated with mental health disorders, impact of HIV in mental health and use of mental health services by people living with HIV (PLHIV) in the WHO European Region.

The results shown here are a summary of the full data generated by the survey. For detailed results, including Tables and Figures, you can consult the full report, available [here](#).

This exploratory, cross-sectional survey targeted two groups: People living with HIV and persons working in HIV organisations at the local, regional or international level in the WHO European Region, and was divided in two parts:

- A first part with 8 questions focused on individuals working in HIV organizations (OW) and inquired about availability of mental health services targeted to people living with HIV, as well as the frequency of common mental health issues encountered in their daily work.
- A second part focused on people living with HIV, with an additional 40 questions covering:
 - Demographics (gender identity, age, sexual orientation, type of location of residence, employment and housing status, difficulty facing daily expenses)
 - Time since HIV diagnosis, treatment status and treatments missed in last month
 - Self-assessed mental health knowledge, previous diagnosis of mental health condition or experience of symptoms before and after HIV diagnosis; current or previous use of professional mental health treatment or other mental health support services (including peer support).
 - Self-rated mental health status and report of symptoms commonly associated with depression
 - Perceived impact of HIV and HIV stigma on one’s social and emotional well-being
 - Impact of COVID-19 on perceived mental health status, and mental health support received during COVID-19 pandemic

The survey was launched on International Mental Health day 2020 (10 October), and remained open to respondents for 3 weeks, until 3 November 2020. It was available in 7 languages (English, French, Italian, Portuguese, Romanian, Russian and Ukrainian) to reduce language barriers and maximize the number of respondents across the Region.



2. Results

The survey reached 646 people living with HIV from both EU/EEA countries (389 respondents from 14 countries), and non-EU/EEA countries in the Region (257 respondents; 13 countries). A total of 359 individuals working in HIV organizations responded to the survey,¹ 187 from EU/EEA countries, and 172 working in HIV organisation from non-EU/EEA countries.

2.1 Persons working in HIV organizations in the WHO European Region

87.7% of EU/EEA and 89% of non-EU/EEA respondents reporting to be part of an HIV organization reported to be part of a key population or community organization.

The most common mental health issues reported to appear in their work were depression (64%), anxiety (68.4%), isolation/loneliness (59%) and shame (51.3%); all reported by over half the participants. These were followed by self-blame (46.3%) and sleep disturbances (38.6%). Harmful and regular use of drugs and alcohol was reported frequently as well (39.5%). There was an exceptionally high number of respondents that reported suicidal ideation, particularly in Eastern countries (14% EU/EEA; 28.5% non-EU/EEA).

Mental health support services provided by organizations to persons living with HIV were mostly peer support (65.5%), psychological support (60.4%), and help groups (51.5%). In general, availability of these three types of services seem higher in the Eastern part of Europe, whereas therapy sessions are equally reported in both parts of the Region.

Regarding mental health resources, tools or services considered to be lacking in respondent organizations, 41.2% considered psychological support missing, and 59.5% claimed more therapy sessions. Percentages are similar across regions, although a bit lower among the non-EU/EEA respondents. Existence of referral systems for mental health responses, although mentioned less frequently, was also considered necessary by 35% of respondents.

Respondents from EU/EEA countries reported therapy sessions (51.5%) and psychological support (42.9%) to be missing more frequently, with referral systems close behind (38.7%). The situation appears to be similar for respondents from non-EU/EEA countries, although therapy was reported to be missing more frequently (68.2%) and psychological support less frequently (39.2%). Referral systems were reported to be missing by 31.1% of participants.

Over half of EU/EEA (53.5%) and non-EU/EEA (54.8%) respondents reported increased mental health issues in their work context during the COVID-19 pandemic.

In terms of service delivery during the pandemic, 56.6% of non-EU/EEA and 20.9% of EU/EEA respondents reported to have provided their usual psychological support services. These results may have been impacted by the different lockdown and restriction measures implemented in different timelines in the EU/EEA and non-EU/EEA countries.

Online psychological and peer support were the services most reported, by 62.1% and 55.6% of respondents from the non-EU/EEA countries, and 36.9% and 33.2% of EU/EEA respondents. Online therapy sessions were provided by 11.8% (EU/EEA) and 11.2% (non-EU/EEA) of respondents' organizations, less than half of which reported providing referrals (23.5% EU/EEA; 39.1% non-EU/EEA).

Those providing their usual services seemingly have available mostly online psychological support and peer support (both non-professional support) options, followed by referral systems to other services. Those not providing their usual support appear to have set up referral systems in most cases, having them alongside online psychological and peer support. Online therapy is scarcely available, although seemingly more availa-

¹ Categories are not mutually exclusive; same respondent can be included in both sub-samples.



ble among organizations implementing new services.

Other services offered during the COVID-19 pandemic included home visits, meal delivery, pick-up of HIV therapy for those unable to go to hospital, mail ART by post, an emergency shelter (for situations of violence), shelter for others in need, online support in addressing isolation and economic support, among others.

2.2 People living with HIV (PLHIV)

2.2.1 Demographics

People living with HIV respondents were mostly cisgender men and women (57% and 37% respectively), self-identified as heterosexual (52%) or gay/lesbian (41%), and reported living mostly in capital cities (32%) or other big cities (24%).

Age ranges between 30-49 years old represented over 60% of the sample. Most respondents had completed high school level or higher education (85.1%), most frequently University (38.1%) or College (21.2%). The majority (66.9%) of respondents were employed, and either rent (34.7%) or own (45.4%) their house.

Respondents were similarly distributed in terms of time since HIV diagnosis (23.1-24.1% on all categories), except those diagnosed for less than one year (5.51%). 87,2% report being on ART and undetectable, which roughly matches the 89,8% who report to not have missed any treatment doses in the last month or have missed only 1 or 2.

2.2.2 Use of mental health services, help seeking, and diagnosis or experience of symptoms related to mental health disturbances

Most respondents (53.8%) reported never to have had a mental health examination, with a higher proportion in the non-EU/EEA countries (64.8%, compared to 47% in the EU/EEA).

Only 31.7% of people living with HIV from the EU/EEA countries and 23.2% of people living with HIV from non-EU/EEA countries reported ever having been treated for mental health problems, despite 55% of the overall sample mentioning symptoms or diagnosis of a mental health condition after their HIV diagnosis (**Table 1**).

Reasons for the low levels of reported treatment can be varied and may be an area to explore in the future, as several factors can influence this decision, from lack of knowledge, no availability, financial constraints, difficulties accepting that mental health support is necessary, and even stigma around both mental health and/or HIV.

Additionally, people living with HIV from non-EU/EEA countries reported difficulties in accessing treatment in 22,9% of responses (55 persons), whereas this percentage is 12% in the EU/EEA respondents.

Among those to have ever been in treatment/therapy, the percentage reporting difficulties in accessing them increased to 19.5% in EU/EEA respondents, and 32.7% in non-EU/EEA respondents. Further insight into the type of access difficulties would be welcome in future research.

When looking at respondents who asked for help (**Table 2**), social workers and psychologists account for only 22.4% of responses (22.7% EU/EEA; 21.9% non-EU/EEA). The most reported sources of help were family/relatives (much more pronounced in the non-EU/EEA respondents at 41.1%, compared to 27.1% in EU/EEA respondents) and friends (57.7% EU/EEA; 41.1% non-EU/EEA). HIV organisations (13% EU/EEA, 16.1% non-EU/EEA), general practitioners (11.9% EU/EEA; 3.1% non-EU/EEA) and HIV clinicians/nurses (12.2% EU/EEA; 9-4% non-EU/EEA) ensued.

2.2.3 Self-assessed mental health and report of symptoms commonly associated with depression

Most respondents reported somewhat good (30.9%) or average (37.8%) mental health status, although differ-



ences between EU/EEA and non-EU/EEA respondents were observed. In the EU/EEA 38.4% of respondents self-assessed their mental health as good, whereas 18.9% of people living with HIV from Eastern European countries report the same. Similarly, while 3.3% of EU/EEA respondents and 14.1% of non-EU/EEA reported poor mental health, whereas 12.3% (EU/EEA) and 19.4% (non-EU/EEA) reported somewhat poor mental health. Respondents were additionally asked to report on the occurrence of symptoms commonly associated with depression, which was generally more frequent in those reporting poorer mental health status. The proportion of respondents reporting some of the symptoms ranges from over 50% in both samples for those reporting sleep disturbances and reduced quality of concentration, as well as loss of memory (61.4%/65.6% for non-EU/EEA; 80%; 91.7% in EU/EEA), to over 90% reporting of anhedonia (91% and 91.7% in EU/EEA; 81.8% and 93.8% in non-EU/EEA).

Direct reports of feeling particularly low, down or depressed for over two weeks in a row were observed in 73.3% (EU/EEA) and 59.1% (non-EU/EEA) of those reporting “somewhat poor” mental health, and in 100% (EU/EEA) and 78.1% (non-EU/EEA) of those reporting “poor” mental health. Similarly, reports of suicidal ideation or self-harm were observed in 68.9% (EU/EEA) and 54.5% (non-EU/EEA) of those reporting “somewhat poor” mental health, and in 91.7% (EU/EEA) and 75% (non-EU/EEA) of those reporting “poor” mental health.

These findings support the existence of an extremely high burden of mental health issues among people living with HIV across the European Region, far superior to the documented burden of mental health among the general public in Europe, which was estimated at 17.3% in 2018.²

Despite the high levels of reported symptoms, 63.7% of the sample reported not visiting a specialist in the last 6 months for psychological help or support (**Table 3**). Of those who had reported visiting one, 14.7% report a peer consultant (24.3% non-EU/EEA; 8.9% EU/EEA), while 11.8% report a private therapist (14.7% EU/EEA; 7.1% non-EU/EEA) and 6.5% a therapist through an HIV organization (8.1% non-EU/EEA; 5.5% EU/EEA).

Additionally, over half (51.5%) of the sample of people living with HIV reported feeling bad about their HIV status and consider that HIV has had a negative impact on their ability to engage in relationships and social activities (55.9%), and in their sex life (56%). 63.4% consider HIV stigma to have had a negative role on their mental well-being (**Table 4**).

EU/EEA respondents reported that HIV had an impact in these dimensions more frequently than non-EU/EEA respondents.

2.2.4 Availability of mental health services for people living with HIV in city of residence

Overall, 42.7% of the sample reported some type of psycho-emotional service being available in their place of residence (40.3% EU/EEA; 46.7% non-EU/EEA), whereas 22.7% report these not to be available, and 34.5% did not know.

We highlight that despite the seemingly high percentage of persons reporting service availability, still over half the sample either reported that services were not available or did not know if services existed. If we consider that the sample is composed mostly of persons living in the capital city or other big cities, as well as generally well-educated persons, it is likely that these percentages would decrease in the most vulnerable among those living with HIV.

Table 5 shows reported availability of mental health services in their city of residence (reported by people living with HIV) and services provided by HIV organizations (reported by OW). Reported data hints at low levels of knowledge from people living with HIV regarding available services with 43.6% of respondents reporting

2 https://www.oecd-ilibrary.org/docserver/health_glance_eur-2018-en.pdf?expires=1612482538&id=id&accname=guest&checksum=7993A9D86557E11D6CE3450336F48968



they do not know (50% of EU/EEA people living with HIV; 33.5% of non-EU/EEA people living with HIV) if mental health services are available.

Psychological support was known to be available by 29.6% of respondents (37.9% non-EU/EEA; 24.4% EU/EEA), whereas it is reported by 52% of persons working in HIV organizations (53.5% EU/EEA; 49.8% non-EU/EEA).

Therapy was reported to be available by 9.4% of respondents (8.9% EU/EEA; 10.1% non-EU/EEA), while over half of OW report this service to be available in their organizations (50% EU/EEA; 57.6% non-EU/EEA), whereas help groups are reportedly available by 31% of people living with HIV (25.3% EU/EEA; 40.1% non-EU/EEA), while being reported as available by 40.1% of OW (38.9% EU/EEA; 41.9% non-EU/EEA).

2.2.5 Impact of COVID-19 in mental health

Almost half of EU/EEA (50%) and non-EU/EEA (46.4%) respondents reported a negative impact of lockdown due to COVID-19 on their mental health, whereas 39.2% of EU/EEA respondents and 35.7% of non-EU/EEA respondents stated that lockdown due to COVID-19 did not negatively impact their mental health. Additionally, 29.5% of EU/EEA people living with HIV and 28.2% of non-EU/EEA people living with HIV reported that the lockdown period reactivated or worsened previous mental health issues.

There is no way to assess if this impact was higher than that of other population groups (including the general population) without a comparator, but from the point of view of accessing support services for these situations of worsening mental health, 67.1% of people living with HIV from EU/EEA countries and 63.2% of people living with HIV from non-EU/EEA countries reported not having received any type of support. 34.1% reported that they received support from family or friends only, whereas 21.2% reported receiving support from HIV organizations alone, and 7.1% only from their HIV clinic.

3. Closing remarks

Data from the survey suggests the burden of mental health among people living with HIV in the WHO European Region is much higher than that of the general population. If we factor in stigma and discrimination, which are still reported in high percentages, it seems clear that these topics should remain key priority areas in the work of EATG and other organizations and individuals working in the field of HIV.

While the survey was successful in reaching people living with HIV from different countries, its online format and the pathways of dissemination will have left out segments of people living with HIV, particularly those with less access to information, less contact with HIV organizations, low access to internet and likely less financial capacity and/or formal education. This means that the most underserved people living with HIV will have likely not been captured in this sample.

Knowledge of existing mental health support services and their reported availability by people living with HIV differs substantially from the reported availability by OW. With the concerning levels of reported symptoms and diagnoses reported in multiple questions throughout the survey, it seems clear - and a relatively straightforward effort - that investing in mapping and extensively disseminating available services is a relatively simple intervention that can contribute to rapidly bridging this knowledge gap.

This should be accompanied by a clear definition, both internal and at the level of external communication, of what specific types of support services are available.

While the role of peer led and community led support services in mental health is no doubt extremely important, as is the role of social support networks (family and friends), terminology regarding mental health and related services throughout the questionnaire varies, and there is a lack of clear definitions of the different types of services, which makes the task of clearly identifying gaps much harder (psychological support, psycho-emotional services, etc.).



With general health systems already overburdened pre-COVID, the added strain from the ongoing pandemic at the level of mental health responses has demonstrated that available services are not only lacking in dissemination, but also in scale.

Many individuals have experienced a deterioration in mental health status during the pandemic, which for some has been compounded by the pre-existing lived experiences of stigma and discrimination related to both HIV and mental health. Consequently, efforts to increase availability of services and willingness to fund these services, relying solely on highly differentiated responses delivered by mental health professionals is not sustainable. Furthermore, many persons will not require long lasting therapies or lifelong psychiatric medication to improve their mental health, which means that there is opportunity for less demanding interventions, both technically and financially.

As a result, community interventions have a key role to play in the response to mental health, but this will require much more structure and articulation than has existed so far.

Stepped care models, starting with low threshold interventions, delivered by trained lay workers, who have been provided with tools to perform “first line” triage, and with access to working referral networks to progressively more differentiated responses, all the way to psychiatric treatment for those who require it are, conceptually, easier to scale, cheaper to implement, and capable of providing a quality response to persons with varying mental health issues, from mild symptoms to diagnosed pathologies.

This will require, however, a redesign of existing systems, and a shift in the way we look at mental health and at how we should respond to mental health issues that arise. Additionally, this requires structured collaboration with both mental health professionals and their regulatory associations, policy makers, agencies, and donors; with the purpose of raising the priority of mental health in the overall health discussion, selecting, training and implementing adequate tools and service delivery models at a national and local scale and, of course, ensure adequate funding and sustainability.

While community organizations have the will to play a meaningful role in this response, it is necessary that they acknowledge their existing limitations, and do not conflate the role they can play in triaging and providing emotional support, with the need to provide professional mental health support to a wide range of persons.



Tables

Table 1 – Self reported diagnosis of mental health disorder or experience of symptoms of mental health disorders before and after HIV diagnosis

		Before HIV diagnosis				After HIV diagnosis			
		Sub-region		Total	Missing	Sub-region		Total	Missing
		EU/EEA	European Non-EU/EEA			EU/EEA	European Non-EU/EEA		
Yes	Count	142	118	260	40	215	150	365	39
	% within Sub-region	37.6%	47.8%	41.6%		56.6%	61.0%	58.3%	
No	Count	228	117	345		153	91	244	
	% within Sub-region	60.3%	47.4%	55.2%		40.3%	37.0%	39.0%	
I do not remember	Count	8	12	20		12	5	17	
	% within Sub-region	2.1%	4.9%	3.2%		3.2%	2.0%	2.7%	
Total	Count	378	247	625		380	246	626	
	% within Sub-region	100.0%	100.0%	100.0%		100.0%	100.0%	100.0%	

Table 2 – Self reported sources of support for mental health issues

		Sub-region		Total	Missing
		EU/EEA	European Non-EU/EEA		
Family/relatives	Count	98	92	190	80
	% within region	27.1%	41.1%	32.5%	
Friends	Count	207	92	299	
	% within region	57.3%	41.1%	51.1%	
HIV organisations	Count	47	36	83	
	% within region	13.0%	16.1%	14.2%	
General practitioner	Count	43	7	50	
	% within region	11.9%	3.1%	8.5%	
HIV clinician/Nurse at the HIV clinic	Count	44	21	65	
	% within region	12.2%	9.4%	11.1%	
Social worker / Psychologist	Count	82	49	131	
	% within region	22.7%	21.9%	22.4%	
Other	Count	60	43	103	
	% within region	16.6%	19.2%	17.6%	



Table 3 – Visits to specialists regarding mental health issues in the last 6 months

		Sub-region		Total	Missing
		EU/EEA	European Non-EU/EEA		
Private therapist	Count	51	15	66	108
	% within region	14.7%	7.1%	11.8%	
Mental health consultant at the HIV clinic	Count	22	7	29	108
	% within region	6.3%	3.3%	5.2%	
Peer consultant (through HIV community organisations)	Count	31	51	82	108
	% within region	8.9%	24.3%	14.7%	
Therapist (through HIV organisations)	Count	19	17	36	108
	% within region	5.5%	8.1%	6.5%	
Other	Count	14	14	28	108
	% within region	4.0%	6.7%	5.0%	
None	Count	228	127	355	108

Table 4 - Perceived impact of HIV in social and emotional well being

			Sub-region		Total	Missing
			EU/EEA	European Non-EU/EEA		
Do you feel bad about yourself or your HIV status or that you are a failure or have let yourself or your family down?	Yes	Count	201	113	314	55
		% within Sub-region	53.9%	47.7%	51.5%	
Do you think your HIV status has had a negative impact on your ability to engage in relationships and social activities?	Yes	Count	242	100	342	53
		% within Sub-region	64.5%	42.2%	55.9%	
	I do not know	Count	34	28	62	
		% within Sub-region	9.1%	11.8%	10.1%	
Do you think your HIV status has had an impact on your sexual life?	Yes	Count	215	128	343	53
		% within Sub-region	57.3%	54.0%	56.0%	
	I do not know	Count	27	8	35	
		% within Sub-region	7.2%	3.4%	5.7%	
Do you think that HIV stigma and discrimination has played a negative role on your mental well-being?	Yes	Count	251	133	384	59
		% within Sub-region	67.7%	56.6%	63.4%	



Table 5 - Mental health services provided by local/regional organizations (reported by people living with HIV) and self-report of services provided by respondents from HIV organizations

PLHIV: Are MH services provided to PLHIV by your local/regional organization		Sub-region		Total	Missing	OW: Services provided by organization		Sub-region		Total	Missing	
		EU/EEA	European Non-EU/EEA					EU/EEA	European Non-EU/EEA			
Psychological support	Count	88	86	174	78	Psychological support	Count	169	101	270	146	
	% within Sub-region	24.4%	37.9%	29.6%			% within Sub-region	53.5%	49.8%	52.0%		
Therapy	Count	32	23	55		Therapy sessions	Count	158	117	275		
	% within Sub-region	8.9%	10.1%	9.4%			% within Sub-region	50.0%	57.6%	53.0%		
Peer support	Count	95	105	200		A referral system	Count	91	50	141		
	% within Sub-region	26.4%	46.3%	34.1%			% within Sub-region	28.8%	24.6%	27.2%		
Help groups	Count	91	91	182		Help groups	Count	123	85	208		
	% within Sub-region	25.3%	40.1%	31.0%			% within Sub-region	38.9%	41.9%	40.1%		
None	Count	25	16	41		Other	Count	27	14	41		
	% within Sub-region	6.9%	7.0%	7.0%			% within Sub-region	8.5%	6.9%	7.9%		
I do not know	Count	180	76	256								
	% within Sub-region	50.0%	33.5%	43.6%								



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 150 members from 45 countries in Europe. Our members are people living with HIV 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