HIV &
Mental Health

SURVEY REPORT

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

ENGLISH | РУССКИЙ

EA
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European
AIDS Treatment
Group

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.

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a. Executive Summary

This report presents findings of an exploratory, cross-sectional study which focuses on the mental health of People Living with HIV (PLHIV), as well as services provided by community and civil society organizations in the field of HIV in the WHO European Region.

A total of 389 people living with HIV from 13 EU/EEA countries and 257 people living with HIV from 13 non-EU/EEA countries, as well as 359 staff members of organizations working in HIV and/or with people living with HIV from Europe (187 EU/EEA, 14 countries; 172 non-EU/EEA, 13 countries) responded to the survey.

Questions for persons working in community organizations included services provided, main mental health issues reported in their organizations, services considered missing and both variation in reporting of mental health issues and types of support services provided during the COVID-19 pandemic.

For people living with HIV, questions included 6 main categories:

1. Demographics (gender, age, sexual identification, type of location of residence, employment and housing status, difficulty facing daily expenses)
2. Time since HIV diagnosis, treatment status and treatments missed in last month
3. 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
4. Self-rated mental health and report of symptoms commonly associated with depression
5. Perceived impact of HIV and HIV stigma in social and emotional well being
6. Impact of COVID-19 in perceived mental health and mental health support received during COVID-19 pandemic

Our results indicate an overall greater availability of several types of mental health support services provided by non-mental health professionals in organizations from the non-EU/EEA countries (71.4% psychological support, 77.4% peer support, 60.7% help groups compared to 50.8% psychological support, 55.0% peer support and 43.5% help groups in EU/EEA respondents), as well as generally higher frequency of reported mental health issues in non-EU/EEA countries (69.8% depression, 71% anxiety, 45.5% sleep problems, compared to 58.6% depression, 66% anxiety, 32.1% sleep problems). The only exception is isolation, more frequently reported in the EU/EEA (59.5%, compared to 58.5% in non-EU/EEA). Suicidal feelings were reported twice as frequently in the non-EU/EEA sample (28.5%, compared to 14% in the EU).

This matched self-reported mental health status, generally poorer among people living with HIV from non-EU/EEA countries.

Respondents from non-EU/EEA countries also reported more difficulties in accessing treatment: 22.9% non-EU/EEA compared to 12% EU/EEA. This percentage increases to 32.73% in non-EU/EEA and 19.49% in EU/EEA respondents when analysing only those who reported to have ever been in treatment.

Coupled with the reported difficulties in accessing treatment, low percentages of ever having had a professional mental health examination were also found, with 64.8% of non-EU/EEA respondents and 47% of EU/EEA respondents reporting never to have had a mental health examination.

Despite this, only 22.4% of participants assess their mental health as “poor” or “somewhat poor”, again with higher percentages among non-EU/EEA people living with HIV (19.4% somewhat poor, 14.1% poor, compared to 12.3% somewhat poor and 3.3% poor among EU/EEA people living with HIV).

Additionally, 41.6% of the sample self-reported symptoms or diagnosis of mental health disorders prior to their HIV diagnosis, whereas 58.3% reported the same after the diagnosis.

Only 11.8% of respondents reported to have visited a private therapist and 6.5% a therapist through an HIV organization in the last 6 months, an extremely low proportion when compared to the percentage of persons reporting symptoms associated with mental health conditions, particularly depression (including suicidal ideation/thoughts of self-harm). Between 50.9% and 53.26% of all people living with HIV responding self-reported at least 3 out of 5 symptoms commonly associated with depression, including suicidal ideation and thoughts of self-harm.

While no doubt there will be multiple factors contributing to these results, both HIV associated stigma and mental health associated stigma have a relevant role in both mental health itself, as well as help seeking.

Over half of the sample of people living with HIV reported to feel bad about their HIV status (51.5%) and consider that HIV had a negative impact in 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 in their mental wellbeing.

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

The COVID-19 pandemic seems to have affected mental health of responding people living with HIV, with 48.6% of the sample reporting a negative impact of the pandemic in their mental health, and 29% reporting the COVID-19 pandemic to have re-activated or worsened previously existing mental health conditions. However, only 34.3%. of those reporting that COVID-19 worsened their mental health have received support.

Despite reporting of several support services available during the COVID-19 pandemic by staff of HIV organizations, people living with HIV seem to have little knowledge of the different services available to them in their cities. As the majority of respondents reside in capital cities (32%) or other big cities (24%) this may indicate that more communication on existing mental health support services for people living with HIV is required.

Despite limitations in the data, results clearly show the need for further research into the mental health of people living with HIV, as well as into the availability and use of mental health services for people living with HIV in the WHO European Region.

Additionally, they underline the importance of better defining the range of existing mental health responses in the Region, and expand access to these responses, as well as increase their availability and use.

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1. Foreword

> ***"Help!"***
> Respondent comment to Q48: Additional comments

Mental health is not only an extremely serious global health concern overall, it is also one that has largely been overlooked until very recently, both in the general population, and in specific groups.

Our health response systems tend to focus on suppressing symptoms, and our mental health response has historically replicated this pattern, with an overfocus on psychiatric/pharmacological treatment for both severe and mild mental health symptoms or disturbances.

Although pharmacological treatment is useful and desirable to many, it is not - by any means - the only response available. And even those who are not trained in mental health can have a determinant role in promoting it, and be a part of its response system, although until we reach that goal, there will be many steps to climb.

Mental health is also largely determined by our environment, where prejudice and stigma have a key role. For people living with HIV, given the double stigma of the infection and of mental health itself, often accumulating with other forms of stigma, discrimination, or marginalization, this is an even more important aspect.

It is a professional and personal pleasure to see EATG embarking on what will most likely be a very long journey into the improvement of the mental health of people living with HIV, and I am privileged for having the opportunity to play a role in this work, hoping that it remains a strategic priority for as long as necessary, until people living with HIV have access to a range of mental health services that is adequate to their needs.

As in many other fields of research, there are many gaps and unknowns. In this field particularly, there are also issues around definitions and terminologies that are not yet clear and will be refined over time.

There is a long road ahead, but every step counts, and this is - in my mind - a particularly important one, as it not only confirms that there is great need for research and interventions focusing on mental health of people living with HIV, but also brings to light some of the frailties of our own preparation to tackle this subject, which we will no doubt improve upon in the near future.

Daniel Simões

2. Introduction and objective

This report is part of a wider effort, undertaken by EATG, developed as a follow up to a previous project, "Ageing with HIV"[1] Project (2016-2018), which identified mental health as a key neglected area, and its importance for the quality of life for people living with HIV. This finding is also supported by scientific evidence, which suggests that mental health problems are one of the most significant areas of comorbidity for people living with HIV worldwide and are more prevalent among people living with HIV than the general population.[2]

As a follow up to this work, EATG initiated the "Mental Health, Well-being and HIV" 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.

These recommendations will advise on how to develop a supportive and integrated framework within the HIV care setting, which provides people living with HIV with access to prevention, screening, treatment and care for mental health problems.

It is its objective to contribute to the creation of a European network bringing together the different stakeholders in the field of mental health and HIV and establish a platform for them to interact.

The project is mainly addressed to:

1) community, people living with HIV as well as persons working in community HIV organisations at the local, regional or international level in the European context

and

2) healthcare professionals who provide prevention, treatment and care services for people living with HIV.

Other key stakeholders are national/EU-level decision-makers and agencies in the health sector and international organisations working in the mental health field.

Researchers/academia and industry working in HIV field will also be closely linked to during the project.

The main activities of the project are:

1. Literature review on HIV and mental health;
2. Survey on community perspective on the role of mental health in HIV prevention, treatment adherence, quality of life and retention in care;
3. Workshop to define recommendations for practical interventions in community and healthcare settings to improve access to and quality of HIV prevention, treatment and care services for people living with HIV who face mental health problems;
4. Multi-stakeholder event to present findings and recommendations to community, healthcare sector, policy, industry, research and international organisations;
5. Development of a briefing paper on mental health and promising approaches;
6. Dialogue with EACS on better integration of the mental health dimension in the HIV guidelines;
7. Meeting bringing together members of community and representatives of industry partners about mental health related endpoints in research and drug development;
8. Dissemination of information via website and social media, webinars, publications, translated materials;

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[1] https://www.ageingwithhiv.com/

[2] http://bit.ly/eatg_hivmentalhealth_reports

9. Creating a European Platform to allow continuous and sustainable collaboration and experience exchange of the stakeholders involved in the project beyond the project duration;
10. Development of concept for a recurring bi-annual European conference on interplay of mental health, well-being and HIV.

The expected specific outcomes of the project are:

- Increased knowledge of the interplay of mental health, well-being and HIV among community organizations, healthcare professionals and other stakeholders in the HIV field at the European level, through broad dissemination of the knowledge generated through this project.
- European stakeholders from community, healthcare sector, policy, industry, research, and international organisations are considering this interplay of mental health, well-being and HIV in their respective areas of work, based on the findings and recommendations of the project.

This specific survey was designed with the intent of providing on the one hand an overview of the existing landscape of mental health services available in HIV organizations in the WHO European Region, as well of commonly reported mental health issues in the organizational context, and on the other hand to 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 in the WHO European Region.

The present report aims to provide a descriptive analysis of the data, to inform next steps in the project, as well as pave the way for future work in this field.

3. Methodology

> *"It's good that working with people living with HIV in the field of psychology is being started. This was sorely lacking"*
>
> Respondent comment to Q48: Additional comments

The development of the survey was based on the findings of a literature review, conducted between February and August 2020.[3] The initial version of the survey was developed by Maryan Said and Miran Šolinc.

Four local community consultants (Mario Cascio, Mihai Lixandru, Viktor Tretiakov, Willian Gomes) were hired to revise proposed survey questions and finalise survey through two online meetings, and in collaboration with the EATG secretariat and the HIV & Mental health Project Advisory Group, as well as translate and disseminate survey in local communities in Italy, Romania, Russia and Ukraine, Portugal, France, and French-speaking Belgium from October to November 2020.

This exploratory, cross-sectional survey targeted two groups: people living with HIV (people living with HIV) and persons working in HIV organisations at the local, regional, or international level in the WHO European Region **(OW)**, and is therefore divided in two parts:

- A first part with 8 questions focused on OW and inquiring about availability of services focused on mental health issues for people living with HIV.
- A second part (Q9 and onward) focused on people living with HIV, with an additional 40 questions covering:
  - Demographics (gender, age, sexual identification, 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
  - Self-rated mental health and report of symptoms commonly associated with depression
  - Perceived impact of HIV and HIV stigma in social and emotional well being
  - Impact of COVID-19 in perceived mental health and mental health support received during COVID-19 pandemic

Full survey can be found in Appendix (Appendix 1)

The survey was launched on International Mental Health day 2020 (10 October), and remained open to respondents for 3 weeks, until November 3, 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.

As questions differed across the two samples (people living with HIV and OW), all data analysis was conducted for each of these two samples individually. Data below is presented separately for people living with HIV and OW for all variables, except where stated otherwise.

All questionnaires without a response in the question of country of residence (Q1) were excluded from the analysis. A total of 53 people living with HIV questionnaires and 87 questionnaires from persons working in HIV organizations with no response to country of residence were excluded from the corresponding analysis. Prior to exclusion, responses to this question were revised case by case and recategorized when possible.

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[3] http://bit.ly/eatg_hivmentalhealth_reports

For all data analysis except Table 1, respondents reporting to reside outside of Europe were also excluded.

In Table 1 (below), the number and percentage of people living with HIV who also work in a community organization, and the number and percentage of OW reporting to live with HIV are shown. Due to the small numbers, not many specific analyses with these sub-groups were performed.

Data below is presented in two sections, one for Community workers, and one for people living with HIV. In order to assess differences between EU/EEA countries and non-EU/EEA countries, data is shown divided in those two categories in the majority of the data Tables.

Data was analysed in SPSS v25.0.

Venn diagram lists were created through a unique numeric sequential ID, assigned randomly to each questionnaire. ID lists relevant to each question were input into Venny.[4]

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[4] Oliveros, J.C. (2007-2015) Venny. An interactive tool for comparing lists with Venn's diagrams. https://bioinfogp.cnb.csic.es/tools/venny/index.html

4. Results and discussion

4.1 - Country of residence and Sub-regional division of respondents

As shown in Table 1, the survey reached people living with HIV from both EU/EEA countries (389 respondents), and non-EU/EEA countries in the Region (257 respondents). Similarly, individuals working in HIV organizations from both parts of the WHO European Region responded (187 EU/EEA; 172 non-EU/EEA countries).

The number of respondents by country was varied, and despite the high variety of countries reported (14 EU/EEA; 13 non-EU/EEA), a few countries represent most respondents in both sides of the Region (Italy, Portugal and Romania for the EU countries; Russia and Ukraine for the non-EU countries).

Logically the data is not representative (due to multiple factors) and should be interpreted with caution.

More detailed analysis of data from the countries mentioned above and looking into country specific availability of and access to mental health services could be envisaged in the near future (*cf.* Section 4 - Final remarks).

Table 1 - Distribution of respondents by Sub-region (EU/EEA and non-EU/EEA) country of residence, reporting to live with HIV and reporting to work in an HIV organization.

PLHIV (a)					OW (a)				
Sub-region	**Country of residence**	**Total**	**Are you part of an HIV community organization in Europe or Central Asia?**		**Sub-region**	**Country of residence**	**Total**	**Living with HIV?**	
			Yes	**No**				**Yes**	**No**
EU/EEA					**EU/EEA**	Belgium	8	3	5
	Belgium	17	3	14		Bulgaria	1	1	0
	Bulgaria	2	1	1		Croatia	2	0	2
	France	21	6	15		Czechia	1	0	1
	Germany	6	1	5		France	15	6	9
	Greece	1	1	0		Germany	2	1	1
	Hungary	1	0	1		Greece	1	1	0
	Italy	222	52	170		Italy	73	52	21
	Latvia	1	1	0		Latvia	1	1	0
	Netherlands	1	1	0		Netherlands	1	1	0
	Portugal	63	16	47		Portugal	46	16	30
	Romania	50	19	31		Romania	32	19	13
	Slovenia	1	1	0		Slovenia	3	1	2
	Spain	3	1	2		Spain	1	1	0
	Total	**389**	**103**	**286**		**Total**	**187**	**103**	**84**

European Non-EU/ EEA	Albania	3	1	2
	Azerbaijan	1	0	1
	Belarus	2	1	1
	Israel	7	1	6
	Kazakhstan	9	6	3
	Moldova	2	1	1
	North Macedonia	1	1	0
	Russia	127	52	75
	Switzerland	1	0	1
	Tajikistan	8	8	0
	Ukraine	91	65	26
	United Kingdom	4	1	3
	Uzbekistan	1	1	0
	Total	257	138	119
Total (Europe)		646	241	405
Non-European (1)		10		
French ultramarine territories (1)		1		
Missing		53		
Total		710		

European Non-EU/ EEA	Albania	2	1	1
	Belarus	1	1	0
	Israel	1	1	0
	Kazakhstan	6	6	0
	Kyrgyzstan	2	0	2
	Moldova	2	1	1
	North Macedonia	1	1	0
	Russia	55	52	3
	Serbia	1	0	1
	Tajikistan	9	8	1
	Ukraine	89	65	24
	United Kingdom	2	1	1
	Uzbekistan	1	1	0
	Total	172	138	34
Total (Europe)		359	241	118
Non-European (1)		2	2	0
French ultramarine territories (1)		2	1	1
Missing		87		
Total		450	244	119

(1) Excluded from analysis

a. Responses are not mutually exclusive. The same respondent can be in both categories.

In Figure 1 we can see the overlap of respondents living with HIV, and those working in HIV related organizations. As shown, 28.2% of all respondents both lived with HIV, and worked in an HIV organization.

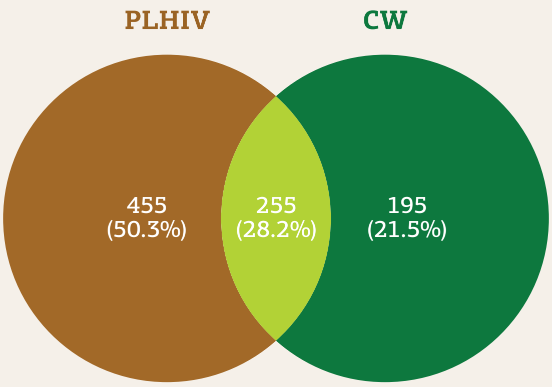


Figure 1 - Overlap in survey respondents among those living with HIV (PLHIV) and working in HIV related organizations (CW)

4.2 Persons working in HIV organizations in the WHO European Region (OW)

Most respondents among those providing an affiliation reported to belong to key population or community led organizations, or civil society organizations (87,7% of all affiliations reported in the EU/EEA; 89% of all affiliations reported outside the EU/EEA) (Table 2).

This shows that on the one hand the survey was efficient in reaching its target segment, and on the other hand that the survey results in this section will reflect the reality of a specific group of persons working in the HIV response: those working in community based, key population led or civil society organizations.

Table 2 - Type of organization respondents belong to (self-reported)

Are you part of an HIV community organization in Europe or Central Asia?	Sub-region		Total (valid responses)
	EU/EEA	European Non-EU/EEA	
Yes	220	206	**426**
Key Population-led Organisation/ Community-led or -based Organisation or Network	116	69	**185**
Civil Society Organisation/ NGO	77	96	**173**
Donor/ Funder	1	3	**4**
UN agency/Technical partner	1	0	**1**
Prefer not to share	12	9	**21**
Other	13	8	**21**
Total affiliations	220	185	**405**
I have no organizational affiliation	16	35	**51**
Total	**236**	**220**	**456**

Table 3 (below) shows the distribution of reported issues commonly mentioned in a work setting, among those working in HIV organizations.

The most reported issues are Depression (64%), Anxiety (68.4%), isolation/loneliness (59%) and shame (51.3%), all reported by over half the participants. These are followed by self-blame (46.3%) and sleep disturbances (38.6%). Harmful and regular use of drugs and alcohol is reported frequently as well (39.5%), although this question mixes “harmful” and “regular”, as well as represents the reality of those working in HIV organizations (including working with key populations), where use of drugs and alcohol will be mentioned frequently, particularly if not necessarily harmful.

Table 3 - Reported commonly raised issues related to HIV and mental health in work context

Issue		Sub-region		Total (1)	Missing
		EU/EEA	European Non-EU/EEA		
Depression	Count	126	139	**265**	12
	% within region	58.6%	69.8%	**64.0%**	
Anxiety	Count	142	142	**284**	11
	% within region	66.0%	71.0%	**68.4%**	
Low self-esteem	Count	101	122	**223**	11
	% within region	47.0%	61.0%	**53.7%**	
Isolation/loneliness	Count	128	117	**245**	11
	% within region	59.5%	58.5%	**59.0%**	
Post-traumatic stress disorder	Count	32	58	**90**	11
	% within region	14.9%	29.0%	**21.7%**	
Sleep problems/sleep disturbance/ Insomnia	Count	69	91	**160**	11
	% within region	32.1%	45.5%	**38.6%**	
Harmful and regular use of drugs and/or alcohol	Count	83	81	**164**	11
	% within region	38.6%	40.5%	**39.5%**	
Self-harm	Count	9	12	**21**	11
	% within region	4.2%	6.0%	**5.1%**	
Suicidal feelings	Count	30	57	**87**	11
	% within region	14.0%	28.5%	**21.0%**	
Shame	Count	108	105	**213**	11
	% within region	50.2%	52.5%	**51.3%**	
Self-blame	Count	93	99	**192**	11
	% within region	43.3%	49.5%	**46.3%**	
Body image issues	Count	45	29	**74**	11
	% within region	20.9%	14.5%	**17.8%**	
Other issues	Count	11	10	**21**	11
	% within region	5.1%	5.0%	**5.1%**	

(1) Percentages do not include missing responses on the denominator

A note for the high percentage of reports of suicidal feelings which even considering that those reporting will not have the necessary knowledge to assess this in all situations, remains extremely high, particularly in Eastern countries (14% EU/EEA; 28.5% non-EU/EEA). In fact, although mostly comparable in percentages, all these issues - except for isolation/loneliness - are proportionally more reported in non-EU/EEA countries. Again, assessing country specific results may provide more insight on local specificities.

Other issues mentioned by respondents (n=21) included difficulties in accessing work (*"I can't find work because of HIV."*); stigma, discrimination, self-discrimination, psychological pressure of bullying, social issues, economic difficulties, and fear in disclosing one's status, among others.

These link to other issues touched by this survey (*cf.* Section 3.3.6 - impact of HIV and HIV stigma in social and emotional wellbeing), and hint at the continuous relevance of working on HIV related stigma, including internalized stigma.

Table 4 shows the services provided by respondents' organizations, to persons living with HIV. As one could expect from the respondent characteristics (Table 2), peer support (65.5%) and psychological support (60.4%) as well as help groups (51.5%) are the most reported services.

To note that 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.

Table 4 - Does your organization provide any specific mental health services to people living with HIV?

Service		Sub-region		Total (1)	Missing
		EU/EEA	European Non-EU/EEA		
Peer support	Count	105	130	**235**	67
	% within Sub-region	55.0%	77.4%	**65.5%**	
Psychological support	Count	97	120	**217**	
	% within Sub-region	50.8%	71.4%	**60.4%**	
Therapy sessions	Count	34	30	**64**	
	% within Sub-region	17.8%	17.9%	**17.8%**	
Help groups	Count	83	102	**185**	
	% within Sub-region	43.5%	60.7%	**51.5%**	
Other	Count	20	8	**28**	
	% within Sub-region	10.5%	4.8%	**7.8%**	
None	Count	22	15	**37**	
	% within Sub-region	11.5%	8.9%	**10.3%**	

(1) Percentages do not include missing responses on the denominator

A word of caution regarding the interpretation of this question, and regarding wording. Due to its nature, Psychological support (as the name points out) is support conducted by a trained Psychologist. However, in the field of HIV the same word is used to refer to psycho-social support, which although has positive effects in mental health if delivered correctly, is not a professional mental health intervention, and like peer counselling is a common component in the work of HIV organizations.

This category would benefit from being better defined in future surveys, separating mental health interventions conducted by trained professionals, and support interventions conducted by other trained staff, including peers, which are an extremely important part of the overall mental health response model in place (and any other in the future).

Although discussions on the matter occurred during questionnaire development, further refinement of the terminology and adding definitions of key terms alongside survey questions would be beneficial in future activities/surveys, as psychological support and therapy sessions lack clear definitions, and can be interpreted in multiple ways (ultimately as the same thing).

Other mental health services offered by organizations, reported by respondents, included referrals to mental health professionals, psychosocial support by staff; self-esteem workshops, online help, body therapy and Information on the role of psychological assessment as useful in starting a therapy.

Regarding services lacking, and as shown in Table 5, 41.2% of respondents consider psychological support is missing, and 59.5% claim more therapy sessions. The percentages are similar among Sub-regions, although a bit lower in the Eastern respondents, and in agreement with higher reported existence of mental health services in that part of the Region (Table 4). Existence of referral systems for mental health responses, although mentioned less frequently, was also considered necessary by 35% of respondents.

Table 5 - Are there any mental health resources, tools or services that lack in your organisation and which you think would be of benefit for people living with HIV?

Missing resources, tools or services		Sub-region		Total (1)	Missing
		EU/EEA	European Non-EU/EEA		
Psychological support	Count	70	58	**128**	115
	% within region	42.9%	39.2%	**41.2%**	
Therapy sessions	Count	84	101	**185**	115
	% within region	51.5%	68.2%	**59.5%**	
Referral system	Count	63	46	**109**	115
	% within region	38.7%	31.1%	**35.0%**	
Other	Count	25	20	**45**	115
	% within region	15.3%	13.5%	**14.5%**	

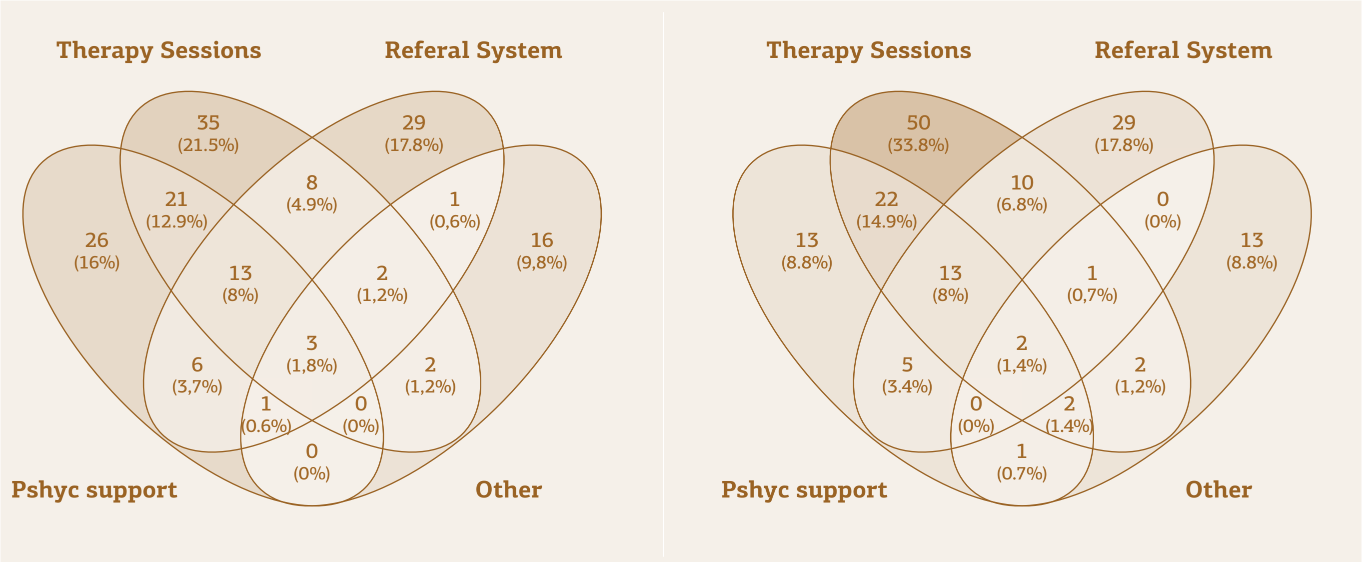
(1) Percentages do not include missing responses on the denominator

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

Overall, 14.5% (45 persons) reported other missing resources or services, which included physical exercise (also beneficial for mental health), relaxation and wellness services (massages for example), specific projects on psychological health, and problematic chemsex support, among others.

The intersection of services reported to be lacking by the different respondents is shown below, in Figure 2.

Figure 2 - Intersection of services considered to be lacking in their organizations, reported by OW



Left - EU/EEA countries; Right - non-EU/EEA countries

21.5% of EU/EEA and 33.8% of non-EU/EEA respondents report that only therapy sessions are missing, the highest parcel reported in both subsamples. This further underlines an apparent gap in the offer of professional mental health support, whereas non-professional mental health support (by other trained professionals or trained peers and here represented by the "psychological support" option) is reported in exclusive by 16% of the EU/EEA respondents, and 8.8% of the non-EU/EEA ones.

Referral systems are however more reported in exclusive (17.8% EU/EEA; 10.1% non-EU/EEA), than psychological support, and many respondents (38.8% of non-EU/EEA and 34.9% of EU/EEA respondents) report that two or three of these services are required.

As in the previous question, a clearer definition of "Therapy sessions" and "psychological support" would be beneficial for a more trustworthy interpretation of the question, and to guarantee scientific validity of data.

4.2.1 - Mental health issues and mental health services provided during the COVID-19 pandemic

Over half of respondents reported increases in mental health issues in their work context during the COVID-19 pandemic, 53.5% of the EU/EEA respondents and 54.8% of the non-EU/EEA respondents (Table 6).

It seems clear that the mental health condition of persons using the respondents' HIV organizations has deteriorated during the course of the pandemic, which fits the profile of respondents, who will likely be working not only with people living with HIV, who still face stigma and discrimination,[5] [6] but also with key populations, frequently marginalized and living in vulnerable social and economic conditions, which may have worsened during the pandemic.

Table 6 - Have you in your work experienced an increase of mental health issues during the Covid-19 pandemic and lockdown period?

Increased MH issues during COVID?		**Sub-region**		**Total**	**Missing**
		EU/EEA	**European Non-EU/EEA**		
Yes	Count	99	91	**190**	75
	% within Sub-region	53.5%	54.8%	**54.1%**	
No	Count	39	41	**80**	75
	% within Sub-region	21.1%	24.7%	**22.8%**	
Not sure	Count	47	35	**82**	75
	% within Sub-region	25.4%	21.1%	**23.4%**	

Table 7 shows the type of psycho-social support delivered by responding individuals' organizations during the COVID-19 pandemic.

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[5] https://www.stigmaindex.org/country-reports/

[6] https://www.unaids.org/en/keywords/stigma-and-discrimination

Table 7 - What kind of psychosocial-support has your organisation provided to people living with HIV during Covid-19 lockdown?

Increased MH issues during COVID?		Sub-region		Total	Missing
		EU/EEA	European Non-EU/EEA		
Usual psychological support	Count	39	95	**134**	70
	% within Sub-region	20.9%	56.2%	**37.6%**	
Online Psychological support	Count	69	105	**174**	70
	% within Sub-region	36.9%	62.1%	**48.9%**	
Online therapy sessions	Count	22	19	**41**	70
	% within Sub-region	11.8%	11.2%	**11.5%**	
Online peer support	Count	62	94	**156**	70
	% within Sub-region	33.2%	55.6%	**43.8%**	
Webinars on mental health and wellbeing	Count	14	29	**43**	70
	% within Sub-region				
Referrals	Count	44	66	**110**	70
	% within Sub-region	23.5%	39.1%	**30.9%**	
Other	Count	22	7	**29**	70
	% within Sub-region	11.8%	4.1%	**8.1%**	
None	Count	32	15	**47**	70
	% within Sub-region	17.1%	8.9%	**13.2%**	

56.6% of non-EU/EEA and 20.9% of EU/EEA respondents report to have provided their usual psychological support services. The difference is considerable, and hints at greater baseline availability of some sort of mental health support in HIV organizations outside EU/EEA countries.

Online psychological and peer support are 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. Clearly organizations from the non-EU/EEA countries seem to have some sort of support service implemented more consistently, although it is not possible to assess the real number of organizations who responded, given the anonymity of the questionnaire, which limits conclusions from this data.

Online therapy sessions were provided by 11.8% (EU/EEA) and 11.2% (non-EU/EEA) of respondents' organizations, less than half of those who reported providing referrals (23.5% EU/EEA; 39.1% non-EU/EEA). Again, respondents from outside the EU/EEA countries reported over twice the availability of Referral services, as was the case with online psychological and peer support.

As mentioned previously, clear definitions of the terms/response options used would be beneficial, as would harmonization of response options regarding types of services, across the questionnaire.

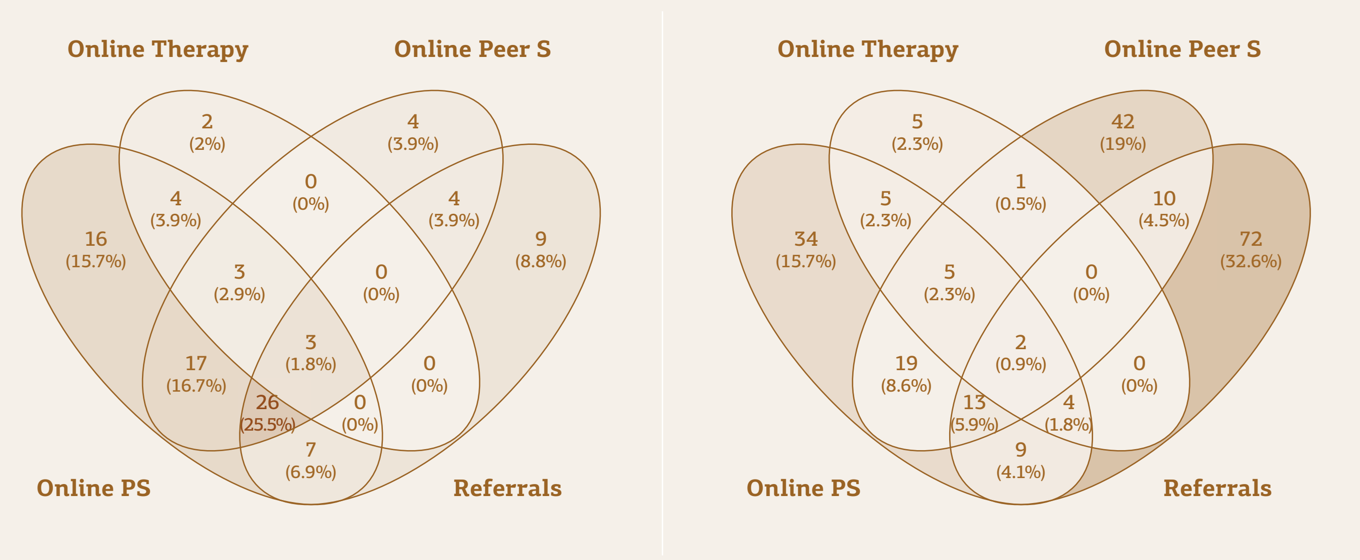
Additionally, in this question separating "usual support services" and adding a question on newly implemented ones could have given a more accurate picture of what was happening prior to COVID, and what was implemented post-COVID, as this is a multiple response question.

In order to assess any differences in services provided between those providing their usual support services, and those not, the sample was stratified according to this variable, and overlaps in reported services provided are shown in Figure 3.

Figure 3 - Overlaps in reported services provided during COVID-19

Left - Distribution of reported services provided during COVID-19 lockdown among OW reporting to provide their usual psychosocial services

Right - Distribution of reported services provided during COVID-19 lockdown among OW not reporting to provide their usual psychosocial services



Those providing their usual services seemingly have available mostly online psychological support and peer support (both non-professional support), followed by referral systems to other services, while those not providing their usual support appear to have set up referral systems in the majority of cases, having them alongside online psychological and peer support.

Online therapy is scarcely available, although seemingly more available among organizations implementing new services.

A deeper exploration of referral circuits in place may be desirable in order to understand response circuits already set up, and attempt to identify and scale up good practices in service integration. As setting up professional mental health responses is both complex and expensive, community organizations could likely rapidly benefit from establishing partnerships or referral systems with existing mental health services, if any available. Examples in this domain could potentially support new efforts to increase availability of professional mental health support.

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

4.3 People living with HIV (PLHIV)

4.3.1 - Demographics

Table 8 shows the distribution of respondents' gender, and Table 9 shows the distribution of their sexual identification, as well as the self-report of where they live.

The survey reached mostly cisgender men and women (57% and 37% respectively). 9 trans persons responded (5 transgender women, 4 transgender men) as well as 5 gender non-binary and 4 gender fluid individuals. 2% (14 persons) preferred not to respond, and 11 persons identified as "other" genders.

Regarding sexuality, respondents self-identified mostly as heterosexual (52%) or gay/lesbian (41%), followed by bisexual/pansexual (6%).

Respondents live mostly in capital cities (32%) or other big cities (24%), followed by middle sized cities (19%) and small cities (16%). Only 8% of respondents report to live in a village/countryside. This reflects on the one hand the higher capacity and access of those living in busier urban environments, but also the lower number of people living with HIV living outside urban areas in Europe.[7]

Table 8 - Social and demographic characteristics of responding people living with HIV

	Total	% of total respondents	Sub-region	
			EU/EEA	European Non-EU/EEA
Gender identity				
Cisgender woman	232	37%	87	145
Cisgender man	358	57%	280	78
Transgender woman	5	1%	3	2
Transgender man	4	1%	1	3
Gender non-binary	5	1%	4	1
Gender fluid	4	1%	2	2
Prefer not to answer	14	2%	4	10
Other:(please specify)	11	2%	4	7
Total	**633**	**100%**	**385**	**248**
Missing	32			

Table 9 - Sexual self-identification and self-reported degree of urbanization of place of residence

How do you identify yourself?				
Heterosexual	328	52%	135	193
Gay/Lesbian	260	41%	227	33
Bisexual/Pansexual	37	6%	20	17
Asexual	2	0%	1	1
Other	6	1%	1	5
Total	**633**	**100%**	**384**	**249**
Missing	32			

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[7] https://www.unaids.org/sites/default/files/media_asset/20150918_Ending_urban_AIDS_epidemic_en.pdf

Where do you live?				
In the capital city	205	32%	142	63
Other Big city	155	24%	89	66
Middle size city	122	19%	58	64
Small city	102	16%	60	42
Village, countryside	52	8%	35	17
Total	**636**	**100%**	**384**	**252**
Missing	29			

Table 10 - Distribution of people living with HIV by age, education level and employment status

Which age group are you in?				
20-29	59	9.25%	40	19
30-39	218	34.17%	109	109
40-49	193	30.25%	95	98
50-59	123	19.28%	98	25
60 or more	45	7.05%	43	2
Total	**638**	**100.00%**	**385**	**253**
Missing	29			
What is the highest level of education you have attained?				
Primary school	22	3.45%	21	1
Some high school	48	7.52%	32	16
High school diploma	165	25.86%	136	29
College degree	135	21.16%	54	81
University degree	243	38.09%	128	115
Other	25	3.92%	13	12
Total	**638**	**100.00%**	**384**	**254**
Missing	27			
What is your current employment status?				
Employed/self employed	426	66.88%	235	191
Unemployed	90	14.13%	54	36
Student	16	2.51%	13	3
Sick or disabled	40	6.28%	26	14
Retired	35	5.49%	33	2
Other	30	4.71%	22	8
Total	**637**	**100.00%**	**383**	**254**
Missing	28			

Age distribution is varied from 20 years of age onward, concentrated on the 30-49 age ranges, which represent over 60% of the total sample. The percentage of those older than 50 is much higher in the EU/EEA respondents, than in the sample from those outside the EU, reflecting epidemiological and demographic factors in both sides of Europe, and highlighting some of its regional differences (Table 10).

Education wise most respondents have completed high school level or higher education (85.11%), most frequently University (38.09%) or College (21.16%) level (Table 10).

The majority (66.88%) of respondents are employed, with 14.13% unemployed. Other employment statuses include students (2.51%), sick or disabled (6.28%) and retired (5.49%). “Other” employment statuses mentioned (n=30) were not analysed here and will be subject to recategorization in the future (Table 10).

Finally, regarding housing status, the majority rents (34.74%) or owns (45.38%) their house, with 17.84% living with family or friends. 4 homeless people living with HIV responded to the questionnaire (Table 11).

Regarding the difficulty in dealing with daily expenses (Table 11), most respondents replied “neutral” (41.69%), which is not an analysable category and does not fit the rest of the metric options selected. Revising the wording in this - and similar - questions may contribute to improve information quality in future surveys.

22.41% of participants reported that it was difficult to cover living expenses, 15.83% reported it was easy, 10.82% reported it was very difficult and 6.11% reported it was very easy.

Table 11 - Self reported housing status and difficulty in covering living costs

What is your current housing status?				
I rent a place	222	34.74%	158	64
I own my own house/apartment/home	290	45.38%	167	123
I live with family/friends	114	17.84%	56	58
I am homeless	4	0.63%	0	4
Other	9	1.41%	4	5
Total	**639**	**100.00%**	**385**	**254**
Missing	26			
In a typical month, how difficult is it for you to cover your living expenses (including food, all your bills, and other personal costs)?				
Very difficult	69	10.82%	37	32
Difficult	143	22.41%	63	80
Neutral	266	41.69%	154	112
Easy	101	15.83%	78	23
Very easy	39	6.11%	38	1
I do not know	6	0.94%	4	2
Prefer not to answer	14	2.19%	11	3
Total	**638**	**100.00%**	**385**	**253**
Missing	27			

4.3.2 - Time since HIV diagnosis, treatment status and treatments missed in last month

> *"Having lived with HIV for many years, I have developed strategies for avoiding to be overwhelmed by my depression, first with the help of medications and psychological support and help groups, then on my own. I believe support is needed during the first years after diagnosis."*
>
> Respondent comment to Q48: Additional comments

Table 12 shows the distribution of respondents according to the time since their HIV diagnosis, as well as their current self-reported treatment status, and the number of treatments skipped or missed in the last month.

Table 12 - Time since HIV diagnosis and current treatment status

	Total (1)	% of total respondents	Sub-region	
			EU/EEA	European Non-EU/EEA
Years since HIV diagnosis				
Less than 1 year	35	5.51%	25	10
1 – 5 years	153	24.09%	83	70
5 – 10 years	150	23.62%	91	59
10 – 20 years	150	23.62%	74	76
Over 20 years	147	23.15%	112	35
Total	**635**	**100.00%**	**385**	**250**
Missing	30			
What is your HIV treatment status?				
On ART, undetectable	551	87.18%	351	200
On ART	64	10.13%	23	41
Stopped ART	6	0.95%	3	3
Never taken ART	2	0.32%	0	2
Other	9	1.42%	6	3
Total	**632**	**100.00%**	**383**	**249**
Missing	33			
Have you in the past month skipped or missed any of your HIV treatment?				
Missed no HIV treatment	384	60.47%	220	164
Missed 1 dose	121	19.06%	87	34
Missed 2 doses	65	10.24%	39	26
Missed 3 or more doses	50	7.87%	33	17
Not relevant / not applicable	15	2.36%	6	9
Total	**635**	**100.00%**	**385**	**250**
Missing	30			

As visible, the sample has a similar distribution in the percentage of respondents diagnosed in all categories (23.15%-24.09%), except those diagnosed less than one year ago (5.51%). This may be due to the lack of contact with HIV community/support organizations shortly after diagnosis, who were the main dissemination points of this survey.

This also highlights the survey's reach into diverse subgroups of people living with HIV and opens the possibility for more in-depth analysis by time since diagnosis to be conducted in the future, with the current data.

Regarding HIV treatment status, 87,18% report being on ART and undetectable, which roughly matches the 89,77% who report to not have missed any treatment doses in the last month or have missed only 1 or 2.

Social desirability bias may have an influence in the high report of no missed treatment doses, although overall the sample seems to represent mostly highly adherent people living with HIV throughout the Region. This also makes sense as the most compliant would be the most probable to respond to a survey of any kind, particularly one regarding their mental health.

10.13% of the sample reports being on ART, but not undetectable, with a higher weight in the sub sample from Eastern Europe. Under 1% report having stopped ART (6 persons) and 2 persons reported to have never taken ART.

4.3.3 - Self assessed mental health knowledge, previous diagnosis of mental health condition or experience of symptoms before and after HIV diagnosis, current or previous use professional of mental health treatment

> *"I am a member of an organization which works both at local and national level, but unfortunately at local level we are at the moment lacking psychological support services, we used to have a psychologist providing short term support when needed. Personally, the fact that I'm working in an organization which does a lot of prevention work, provides information on HIV and fights against stigma, makes me feel better, but I must admit that I myself would need support and that both the healthcare system and community organizations are lacking support services in my area"*
>
> Respondent comment to Q48: Additional comments

Table 13 shows the self-reported level of knowledge regarding mental health issues of people living with HIV responding to the survey.

Reports are similar across both parts of the Region, with 40.1% of all people living with HIV reporting to be knowledgeable, and 32.2% reporting to be "neutral".

Due to the lack of a consistent definition, or criteria to accompany this assessment, the responses to this question reflect only a personal evaluation with no comparator, or base concept.

As there are also no follow up questions regarding previous training or experience working in mental health, or even a definition of what "issues" are, it is suggested that the question is removed from any analysis and reformulated for any subsequent surveys.

Table 13 - Self reported mental health knowledge and previous experience of mental health issues

How knowledgeable are you about mental health related issues?		**Sub-region**		**Total**	**Missing**
		EU/EEA	**European Non-EU/EEA**		
Very knowledgeable	Count	49	26	75	41
	% within Sub-region	12.9%	10.6%	12.0%	
Knowledgeable	Count	148	102	250	
	% within Sub-region	39.1%	41.6%	40.1%	
Neutral	Count	130	71	201	
	% within Sub-region	34.3%	29.0%	32.2%	
Not knowledgeable	Count	37	36	73	
	% within Sub-region	9.8%	14.7%	11.7%	
Not knowledgeable at all	Count	15	10	25	
	% within Sub-region	4.0%	4.1%	4.0%	
Total	**Count**	**379**	**245**	**624**	
	% within Sub-region	**100.0%**	**100.0%**	**100.0%**	

Table 14 shows the number and percentage of people living with HIV who reported to have been diagnosed or experienced symptoms of mental health disorders before and after their HIV diagnosis.

Although validity of the responses to assess prevalence of mental health conditions or symptoms is limited since the question mixes professional diagnosis (*i.e.* by a mental health professional - psychiatrist or psychologist) with self-reported symptoms, most of which nonspecific and can have multiple causes, including side effects of ART, daily stress and events, personal moods, etc. - and are not a diagnosis-, the overall number and percentage of persons reporting diagnosis or symptoms increases by over 15% in both regions when looking at the period before and after an HIV diagnosis (37.6% to 56.6% for the EU/EEA respondents; 47.8% to 61% for the non-EU/EEA respondents).

This is much higher than the average disease burden of mental health in Europe,[8] estimated at 17.3%, and consistent with other research which places the prevalence of depressive disorders among people living with HIV close to 50%.[9]

Table 14 - 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%**	

The situation becomes even more concerning when we look at effective treatment for mental health problems or conditions.

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[8] https://www.oecd-ilibrary.org/docserver/health_glance_eur-2018-en.pdf?expires=1612481941&id=id&accname=guest&checksum=C613314B836A1CD9CCBE0AAA8B6355DC

[9] https://drive.google.com/drive/folders/1Zodzv02eE41xMDVhlprR1fCy6Vgo165N?usp=sharing

Table 15 - Use of Mental Health services, help seeking and availability of Mental Health services

When did you last get your mental health examination done?		Sub-region		Total	Missing
		EU/EEA	European Non-EU/EEA		
Less than 6 months ago	Count	60	24	**84**	72
	% within Sub-region	16.4%	10.6%	**14.2%**	
More than 6 months ago	Count	134	56	**190**	
	% within Sub-region	36.6%	24.7%	**32.0%**	
I have never had a mental health examination	Count	172	147	**319**	
	% within Sub-region	47.0%	64.8%	**53.8%**	
Total	Count	**366**	**227**	**593**	
	% within Sub-region	**100.0%**	**100.0%**	**100.0%**	

Have you visited a specialist in the last 6 months for Psi help or support		Sub-region		Total	Missing
		EU/EEA	European Non-EU/EEA		
Private therapist	Count	51	15	**66**	108
	% within Sub-region	14.7%	7.1%	**11.8%**	
Mental health consultant at the HIV clinic	Count	22	7	**29**	108
	% within Sub-region	6.3%	3.3%	**5.2%**	
Peer consultant (through HIV community organisations)	Count	31	51	**82**	108
	% within Sub-region	8.9%	24.3%	**14.7%**	
Therapist (through HIV organisations)	Count	19	17	**36**	109
	% within Sub-region	5.5%	8.1%	**6.5%**	
Other	Count	14	14	**28**	108
	% within Sub-region	4.0%	6.7%	**5.0%**	
None	Count	228	127	**355**	108
	% within Sub-region	65.7%	60.5%	**63.7%**	

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

The majority of respondents (53.8%) reported never to have had a mental health examination, with a higher percentage in the non-EU/EEA countries (64.8%, compared to 47% in the EU/EEA). This confirms that the greater availability and use of mental health support services in this part of the Region will be mostly with resort to non-professional mental health interventions, such as peer support or emotional support by lay providers (persons with no formal training in mental health).

This is further supported when looking at who respondents ask for help, where social workers and psychologists (unfortunately grouped together instead of separately) account for only 22.4% of responses (22.7% EU/EEA; 21.9% non-EU/EEA).

The most reported sources of help are 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 organizations (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. 17.6% of participants reported “others”, which included mutual help or self-help groups, religion/pastor in church, Psychiatrist or Psychotherapist, but also more concerning testimonies such as:

> *“Cry into the pillow, I can’t afford to ask for help, because I’m afraid that they can cling on and take away the children, which have no one but me. That’s why I don’t allow myself to get too hung up on negative circumstances in my life, I cried into / trust to my pillow and that’s enough. I have too much responsibility.”*
>
> *“I handle myself, nobody, I worry inside myself. I don’t ask anyone. No one needs me with my problems.”*
>
> *“I do not ask anyone because in our region it makes no sense to go to the hospital. No one needs people living with HIV in my area.”*
>
> Comments to Q42: Who do you ask for help when you have psycho-emotional difficulties?

Additionally, despite the high levels of reported mental health symptoms (sections 3.3.3 and 3.3.4), 63.7% of the sample reports to not have visited a specialist in the last 6 months for psychological help or support.

Of those reporting to have visited 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).

This further underlines the low effective access to mental health support, particularly professional mental health support.

Although reasons to resort specifically to these sources of support, for not visiting a specialist, as well as the specific type of support being referred were sadly not explored, comments on other questions allude to issues of availability of mental health services, as well financial constraints and fear of stigma and discrimination, which is also in line with the results found in section 3.3.5 (Perceived impact of HIV in and HIV stigma in social and emotional well-being).

Table 16 - Availability of mental health services for people living with HIV in city of residence

> *"I have a lot of questions regarding my status, I have no available information on it and just can't ask or find out more with anyone"*
>
> *"Once there was a wider range of services for people living with HIV and there was a facility where we could undergo any treatment without fear of stigma and discrimination. Now there is nothing more except peer-to-peer and self-help groups for women with HIV."*
>
> Respondent comment to Q48: Additional comments

Are there any psycho-emotional services for people living with HIV available in your city?		Sub-region		Total	Missing
		EU/EEA	European Non-EU/EEA		
Yes	Count	145	105	**250**	80
	% within Sub-region	40.3%	46.7%	**42.7%**	
No	Count	77	56	**133**	
	% within Sub-region	21.4%	24.9%	**22.7%**	
I do not know	Count	138	64	**202**	
	% within Sub-region	38.3%	28.4%	**34.5%**	
Total	Count	**360**	**225**	**585**	
	% within Sub-region	**100.0%**	**100.0%**	**100.0%**	

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

The percentage of persons not knowing if services are available or not reinforce a possible need for better overall communication of existing support services, although it is not clear what is a "psycho-emotional service", and services available were not explored in a direct follow up question, although people living with HIV were asked about services available in their local or regional organizations, which provides a good complementary metric to these results (Table 17).

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

Table 17 - People living with HIV self-reported mental health services provided by local/regional organizations and self-report of services provided by OW's organizations

PLHIV: Are MH services provided to PLHIV by your local/regional organization		**Sub-region**		**Total**	**Missing**
		EU/EEA	**European Non-EU/EEA**		
Psychological support	Count	88	86	**174**	78
	% within Sub-region	24.4%	37.9%	**29.6%**	
Therapy	Count	32	23	**55**	
	% within Sub-region	8.9%	10.1%	**9.4%**	
Peer support	Count	95	105	**200**	
	% within Sub-region	26.4%	46.3%	**34.1%**	
Help groups	Count	91	91	**182**	
	% within Sub-region	25.3%	40.1%	**31.0%**	
None	Count	25	16	**41**	
	% within Sub-region	6.9%	7.0%	**7.0%**	
I do not know	Count	180	76	**256**	
	% within Sub-region	50.0%	33.5%	**43.6%**	

OW: Services provided by organization		**Sub-region**		**Total**	**Missing**
		EU/EEA	**European Non-EU/EEA**		
Psychological support	Count	169	101	**270**	146
	% within Sub-region	53.5%	49.8%	**52.0%**	
Therapy sessions	Count	158	117	**275**	
	% within Sub-region	50.0%	57.6%	**53.0%**	
A referral system	Count	91	50	**141**	
	% within Sub-region	28.8%	24.6%	**27.2%**	
Help groups	Count	123	85	**208**	
	% within Sub-region	38.9%	41.9%	**40.1%**	
Other	Count	27	14	**41**	
	% within Sub-region	8.5%	6.9%	**7.9%**	

When comparing reported availability of mental health services in their city of residence, reported by people living with HIV, with services provided by HIV organizations, reported by responding OW, we observe relevant differences. Although these responses cannot be directly comparable, due to limitations in available data (specific number and location of organizations; type of services reported - different terminology; and no possibility to match responses from people living with HIV to responses of organizations providing services in the same cities), reported data on both questions hints at low levels of knowledge from people living with HIV regarding available services with 43.6% of respondents reporting they do not know (50% of EU/EEA people living with HIV; 33.5% of non-EU/EEA people living with HIV).

Psychological support is 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 OW (53.5% EU/EEA; 49.8% non-EU/EEA). This may be further influenced by the personal definition of what constitutes psychological support, as mentioned previously, which limits the validity of these responses.

Therapy is 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). Again, direct comparisons are not scientifically valid, but these results show a perceived availability of services by people living with HIV which is far lower than the reported availability of services in HIV organizations. More information would be welcome to better understand this situation, but overall an investment in increasing visibility of available services could be beneficial to further promote their use by people living with HIV.

Table 18 looks at reported treatment for mental health problems, which can be looked at as a proxy of the use of mental health services by people living with HIV.

Table 18 - Number and percentage of people living with HIV who have been treated (medical or psychological) for mental health problems

Have you taken or are you currently taking any treatment or getting psychological support for mental health problems?		**Sub-region**		**Total**	**Missing**
		EU/EEA	**European Non-EU/EEA**		
Yes	Count	120	57	**177**	40
	% within Sub-region	31.7%	23.2%	**28.3%**	
No	Count	249	184	**433**	
	% within Sub-region	65.7%	74.8%	**69.3%**	
Not relevant	Count	10	5	**15**	
	% within Sub-region	2.6%	2.0%	**2.4%**	
Total	Count	**379**	**246**	**625**	
	% within Sub-region	**100.0%**	**100.0%**	**100.0%**	

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 report to have ever been treated for mental health problems (Table 18), despite 55% of the overall sample mentioning symptoms or diagnosis of a mental health condition after their HIV diagnosis (Table 14).

Although these are not necessarily persons with mental health conditions or pathology, this data means that resorting to mental health services is still not a common practice among responding people living with HIV, regardless of the existence of symptoms or diagnosis.

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, as shown in Table 19 (below), people living with HIV from non-EU/EEA countries report difficulties in accessing treatment in 22,9% of responses (55 persons), whereas this percentage is 12% in the EU/EEA respondents.

Table 19 - Number and percentage of people living with HIV experiencing difficulties accessing treatment for mental health conditions

Q25. Do you experience difficulties accessing treatment for mental health conditions?		Sub-region		Total	Missing
		EU/EEA	European Non-EU/EEA		
Yes	Count	45	55	**100**	49
	% within Sub-region	12.0%	22.9%	**16.2%**	
No	Count	222	155	**377**	
	% within Sub-region	59.0%	64.6%	**61.2%**	
Not relevant	Count	109	30	**139**	
	% within Sub-region	29.0%	12.5%	**22.6%**	
Total	Count	**376**	**240**	**616**	
	% within Sub-region	**100.0%**	**100.0%**	**100.0%**	

Although respondents were not inquired regarding having ever tried to access treatment, which limits the analysis that can be done with this data, responses were analysed among only those who reported to have undergone/are undergoing treatment, and those who have not (Table 20).

Table 20 - Number and percentage of people living with HIV experiencing difficulties accessing treatment for mental health conditions, according to self-report of undergoing psychological treatment and region.

	Do you experience difficulties accessing treatment for mental health conditions?									
	Reported to be or have been in treatment/therapy					Reported not to be or have been in treatment/therapy				
	Sub-region				Total	Sub-region				Total
	EU/EEA	%	European Non-EU/EEA	%		EU/EEA	%	European Non-EU/EEA	%	
Yes	23	19.49%	18	32.73%	**41**	21	8.50%	36	20.00%	**57**
No	86	72.88%	33	60.00%	**119**	132	53.44%	119	66.11%	**251**
Not relevant	9	7.63%	4	7.27%	**13**	94	38.06%	25	13.89%	**119**
Total	**118**	**100.00%**	**55**	**100.00%**	**173**	**247**	**100.00%**	**180**	**100.00%**	**427**

Among those to have ever been in treatment/therapy, the percentage reporting difficulties in accessing them increases to 19.49% in EU/EEA respondents, and 32.73% in non-EU/EEA respondents. Further insight into the type of access difficulties would be welcome in future research, as these percentages are considerable, especially when considering the already reduced percentage of persons undergoing mental health treatment, despite the high reported symptomatology and mental health status.

These percentages decrease among those who have never been treated, to 8.5% among the EU/EEA respondents, and 20% among the non-EU/EEA respondents. Although it is possible that several of these persons have not looked for treatment (including the 38% in EU/EEA and 13.9% in non-EU/EEA who reported this not to be relevant), existence of difficulties remains at a concerning level in the non-EU/EEA countries among those never having been treated.

4.3.4 - Self rated mental health and report of symptoms commonly associated with depression

> *"How can I live a normal life? It is difficult for me to be the way I am, at times I have bad thoughts about not wanting to live any longer"*
>
> *"I am diagnosed with depression. Working is very difficult for me, my emotional state is bad, I can't concentrate and have panic attacks, this is unacceptable in my work. I went to a private psychotherapist and psychiatrist, but I am in troubles due to the difficult life circumstances, can not buy prescribed medicines and pay for psychotherapy sessions. All this very scared me, I don't know what will happen to me next."*
>
> Respondent comments to Q48: Additional comments

Table 21 shows the self-assessed mental health status of responding people living with HIV, by Sub-region. Most respondents report somewhat good (30.9%) or average (37.8% mental health status), although differences between EU/EEA and non-EU/EEA respondents are visible.

In the EU/EEA 38.4% of respondents self-assess 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 report poor mental health, 14.1% of non-EU/EEA respondents report the same. 6% (EU/EEA) and 6.6% (non-EU/EEA) reported excellent mental health, whereas 12.3% (EU/EEA) and 19.4% (non-EU/EEA) reported somewhat poor mental health.

This is in line with results shown in Table 14 and continues to hint at a greater burden of mental health conditions among people living with HIV in non-EU/EEA countries.

Table 21 - Self reported mental health status

Overall, how would you rate your mental health? (Q47)		**Sub-region**		**Total**	**Missing**
		EU/EEA	**European Non-EU/EEA**		
Excellent	Count	22	15	**37**	73
	% within Sub-region	6.0%	6.6%	**6.3%**	
Somewhat good	Count	140	43	**183**	
	% within Sub-region	38.4%	18.9%	**30.9%**	
Average	Count	138	86	**224**	
	% within Sub-region	37.8%	37.9%	**37.8%**	
Somewhat poor	Count	45	44	**89**	
	% within Sub-region	12.3%	19.4%	**15.0%**	
Poor	Count	12	32	**44**	
	% within Sub-region	3.3%	14.1%	**7.4%**	
Not sure	Count	8	7	**15**	
	% within Sub-region	2.2%	3.1%	**2.5%**	
Total	Count	**365**	**227**	**592**	
	% within Sub-region	**100.0%**	**100.0%**	**100.0%**	

Participants were additionally asked to self-report the occurrence of a series of symptoms associated with mental health conditions. Although several of the questions asked were adapted from a validated depression symptoms' triage scale (PHQ-9),[10,11] the metrics of some of the questions were changed in the current questionnaire (i.e., response options), which compromises conclusions drawn from these questions. Similarly, not all questions were included, which makes it difficult to use these questions as a proxy for depression, since they are not validated in the form they were used here.

Additionally, PHQ-9 is a "first line" triage tool, designed to refer persons to a more specific mental health evaluation, as its sensitivity and specificity, even when correctly applied, have their own limitations. This means that the data collected cannot be used to rank the severity of depressive symptoms, as the original scale is intended to do, but they can provide a proxy for the prevalence of symptoms commonly associated with depression.

In order to attempt to demonstrate some internal validity in the self-reporting of these questions, and to assess potential burden of symptoms commonly associated with depression in people living with HIV, Table 22 shows reported factors and symptoms according to participants' self-assessed mental health status.

Table 22 - Reported factors and symptoms according to participants' self-assessed mental health status

		Overall, how would you rate your mental health?													
		EU/EEA							**non-EU/EEA**						
		Excellent	**Somewhat good**	**Average**	**Somewhat poor**	**Poor**	**Not sure**	**Total**	**Excellent**	**Somewhat good**	**Average**	**Somewhat poor**	**Poor**	**Not sure**	**Total**
How is your quality of sleep in the past 2 weeks?															
Very bad	Count	1	10	16	10	3	4	44	1	0	5	6	10	3	**25**
	% within self-rating	4,5%	7,1%	11,7%	22,7%	25,0%	50,0%	12,1%	6,7%	0,0%	5,8%	13,6%	31,3%	42,9%	**11,0%**
Bad	Count	2	21	47	21	5	1	97	0	11	28	15	12	0	**66**
	% within self-rating	9,1%	15,0%	34,3%	47,7%	41,7%	12,5%	26,7%	0,0%	25,6%	32,6%	34,1%	37,5%	0,0%	**29,1%**
Normal	Count	8	55	57	11	3	3	137	5	16	41	22	9	3	**96**
	% within self-rating	36,4%	39,3%	41,6%	25,0%	25,0%	37,5%	37,7%	33,3%	37,2%	47,7%	50,0%	28,1%	42,9%	**42,3%**
Good	Count	8	43	15	2	1	0	69	7	12	11	1	0	1	**32**
	% within self-rating	36,4%	30,7%	10,9%	4,5%	8,3%	0,0%	19,0%	46,7%	27,9%	12,8%	2,3%	0,0%	14,3%	**14,1%**
Very good	Count	3	11	2	0	0	0	16	2	4	1	0	1	0	**8**
	% within self-rating	13,6%	7,9%	1,5%	0,0%	0,0%	0,0%	4,4%	13,3%	9,3%	1,2%	0,0%	3,1%	0,0%	**3,5%**

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[10] https://patient.info/doctor/patient-health-questionnaire-phq-9

[11] https://pubmed.ncbi.nlm.nih.gov/11556941/

Quality of your concentration in the past 2 weeks?															
Very bad	Count	0	4	8	13	6	4	35	0	0	0	2	4	4	**10**
	% within self-rating	0,0%	2,9%	5,8%	28,9%	50,0%	50,0%	9,6%	0,0%	0,0%	0,0%	4,5%	12,5%	57,1%	**4,4%**
Bad	Count	1	18	54	25	6	1	105	0	4	23	15	18	1	**61**
	% within self-rating	4,5%	13,0%	39,1%	55,6%	50,0%	12,5%	28,9%	0,0%	9,3%	26,7%	34,1%	56,3%	14,3%	**26,9%**
Normal	Count	7	54	68	6	0	3	138	2	23	53	25	9	2	**114**
	% within self-rating	31,8%	39,1%	49,3%	13,3%	0,0%	37,5%	38,0%	13,3%	53,5%	61,6%	56,8%	28,1%	28,6%	**50,2%**
Good	Count	9	51	8	1	0	0	69	7	12	10	2	1	0	**32**
	% within self-rating	40,9%	37,0%	5,8%	2,2%	0,0%	0,0%	19,0%	46,7%	27,9%	11,6%	4,5%	3,1%	0,0%	**14,1%**
Very good	Count	5	11	0	0	0	0	16	6	4	0	0	0	0	**10**
	% within self-rating	22,7%	8,0%	0,0%	0,0%	0,0%	0,0%	4,4%	40,0%	9,3%	0,0%	0,0%	0,0%	0,0%	**4,4%**
Loss of memory or difficulty remembering things experienced in the last weeks															
Yes	Count	3	39	75	36	11	6	170	2	12	50	27	21	5	**117**
	% within self-rating	13,6%	28,1%	54,3%	80,0%	91,7%	75,0%	46,7%	13,3%	27,9%	58,1%	61,4%	65,6%	71,4%	**51,5%**
Little interest or pleasure in doing things over the last weeks?															
Yes	Count	3	47	87	41	11	6	195	1	19	59	36	30	7	**152**
	% within self-rating	13,6%	33,6%	63,0%	91,1%	91,7%	75,0%	53,4%	6,7%	44,2%	68,6%	81,8%	93,8%	100,0%	**67,0%**
Self-rated level of energy in performing daily activities the past weeks															
Excellent	Count	8	9	3	0	0	0	20	9	2	1	1	0	1	**14**
	% within self-rating	36,4%	6,4%	2,2%	0,0%	0,0%	0,0%	5,5%	60,0%	4,7%	1,2%	2,3%	0,0%	14,3%	**6,2%**
Somewhat good	Count	9	57	25	2	0	0	93	2	14	10	4	1	0	**31**
	% within self-rating	40,9%	40,7%	18,1%	4,4%	0,0%	0,0%	25,5%	13,3%	32,6%	11,6%	9,1%	3,1%	0,0%	**13,7%**
Average	Count	3	61	58	14	0	3	139	1	15	42	6	5	2	**71**
	% within self-rating	13,6%	43,6%	42,0%	31,1%	0,0%	37,5%	38,1%	6,7%	34,9%	48,8%	13,6%	15,6%	28,6%	**31,3%**
Somewhat poor	Count	1	10	38	17	6	2	74	1	9	25	16	5	1	**57**
	% within self-rating	4,5%	7,1%	27,5%	37,8%	50,0%	25,0%	20,3%	6,7%	20,9%	29,1%	36,4%	15,6%	14,3%	**25,1%**
Poor	Count	1	3	13	12	6	2	37	2	3	8	17	21	1	**52**
	% within self-rating	4,5%	2,1%	9,4%	26,7%	50,0%	25,0%	10,1%	13,3%	7,0%	9,3%	38,6%	65,6%	14,3%	**22,9%**
Not sure	Count	0	0	1	0	0	1	2	0	0	0	0	0	2	**2**
	% within self-rating	0,0%	0,0%	0,7%	0,0%	0,0%	12,5%	0,5%	0,0%	0,0%	0,0%	0,0%	0,0%	28,6%	**0,9%**
Felt particularly low, down, depressed or hopeless for more than 2 weeks in a row															
Yes	Count	2	41	75	33	12	6	169	1	11	39	26	25	4	**106**
	% within self-rating	9,1%	29,3%	54,3%	73,3%	100,0%	75,0%	46,3%	6,7%	25,6%	45,3%	59,1%	78,1%	57,1%	**46,7%**

Have you at any time had any thoughts that you would be better off dead or thoughts of hurting yourself in some way?															
Yes	Count	4	41	66	31	11	3	156	3	17	46	24	24	5	**119**
	% within self-rating	18,2%	29,3%	47,8%	68,9%	91,7%	37,5%	42,7%	20,0%	39,5%	53,5%	54,5%	75,0%	71,4%	**52,4%**
Regularly use drugs and/or alcohol?															
Yes, both	Count	0	7	9	8	1	0	25	1	0	7	2	3	0	**13**
	% within self-rating	0,0%	5,1%	6,6%	17,8%	8,3%	0,0%	6,9%	6,7%	0,0%	8,2%	4,5%	9,4%	0,0%	**5,8%**
Only drugs	Count	0	6	11	3	1	0	21	1	0	8	6	4	2	**21**
	% within self-rating	0,0%	4,3%	8,1%	6,7%	8,3%	0,0%	5,8%	6,7%	0,0%	9,4%	13,6%	12,5%	28,6%	**9,3%**
Only alcohol	Count	6	22	30	11	3	2	74	0	3	21	5	10	1	**40**
	% within self-rating	27,3%	15,9%	22,1%	24,4%	25,0%	25,0%	20,5%	0,0%	7,0%	24,7%	11,4%	31,3%	14,3%	**17,7%**
I do not regularly use either	Count	16	103	86	23	7	6	241	13	40	49	31	15	4	**152**
	% within self-rating	72,7%	74,6%	63,2%	51,1%	58,3%	75,0%	66,8%	86,7%	93,0%	57,6%	70,5%	46,9%	57,1%	**67,3%**

Generally, symptom reporting is more frequent in those reporting poorer mental health status, which provides some level of confidence in the quality of the data collected and the veracity of self-report. In all categories those reporting "somewhat poor" or "poor" mental health status consistently report high levels of all symptoms. Percentage 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% for 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 are 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 are 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 show not only internal concordance in self reporting, increasing the presumed reliability of the responses provided, but also reinforce remaining data in this survey, supporting a very high burden of mental health among people living with HIV in all the European Region.

Additionally, Figure 4 shows the overlaps among reports of selected symptoms of depression. Five symptoms typically associated with depression were selected, divided into two groups of four, with the prioritization of more direct symptoms associated with depression, as well as dichotomic factors, to avoid further recategorization - memory loss, sleep disorders, anhedonia, depressive symptomatology and suicidal ideation. Both groups include the following set of questions:

- How is your quality of sleep in the past 2 weeks? (Trouble falling asleep, staying asleep or sleeping too much) (sleep quality)
- Have you in the past weeks had little interest or pleasure in doing things? (Little interest)
- Have you felt particularly low, down, depressed or hopeless for more than 2 weeks in a row? (Low, down, dep)

The left side diagram also includes “Have you in the last weeks experienced loss of memory or difficulty remembering things?” (Loss of memory), whereas the right side one includes the more direct question on suicidal ideation and self-harm (“Have you at any time had any thoughts that you would be better off dead or thoughts of hurting yourself in some way?” (SI)

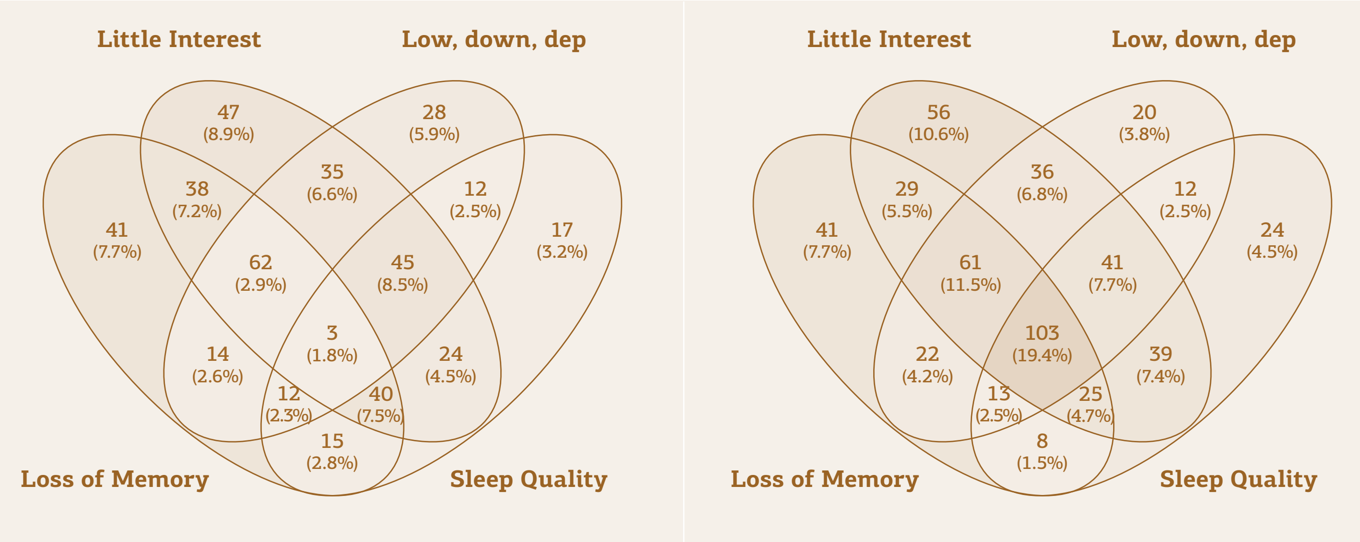
Questions on symptoms not used for this analysis were:

- How is the quality of your concentration in the past 2 weeks?
- How would you rate your level of energy in performing daily activities in the past weeks?
- Do you regularly use drugs and/or alcohol?

Figure 4 - Overlaps among selected self-reported symptoms associated with depression

Left: Inclusion of loss of memory

Right: Inclusion of Suicidal ideation/self-harm



Despite the differences to the original PHQ--9 scale mentioned above, if we consider that those reporting at least 3 of the four selected factors in each diagram would benefit from a second step mental health assessment, we verify that *ad minima* 50.9% of respondents (using the 4 factors on the left diagram, which do not include suicidal ideation/self-harm) and 53.2% of respondents (using the 4 factors on the right diagram, which include suicidal ideation/self-harm) would benefit from a more thorough mental health assessment, a percentage far superior to the general burden of mental health in Europe, which was estimated at 17.3% in 2018.[12]

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

Combining this with the low percentage of people living with HIV who have undergone or are undergoing some type of treatment for mental health conditions, it seems clear that there is a wide space to fill in terms of providing mental health support services to this group.

4.3.5 - Perceived impact of HIV and HIV stigma in social and emotional well being

> *"It is very difficult to cope with this disease especially when everyone stigmatizes you and no one wants to hire you"*
>
> *"I have no idea what kind of support I can get. I always received only kicks in the back like: do you have credits, do you have mental problems? You have a job, you have to manage, you are on your own. If you liked taking it in the ass now suffer. No one can help me :) I'm alone."*
>
> *"I feel fear of stigma and discrimination based on my belonging to the drug addicts. That is why I can not seek professional psychological and psychotherapeutic help. The help that is offered and accessible does not take into account my huge experience of addictive behaviour, therefore, the prescribed medicines are incorrect and have no therapeutic effect."*
>
> Respondent comments to Q48: Additional comments

Table 23 - Perceived impact of HIV in social and emotional well being

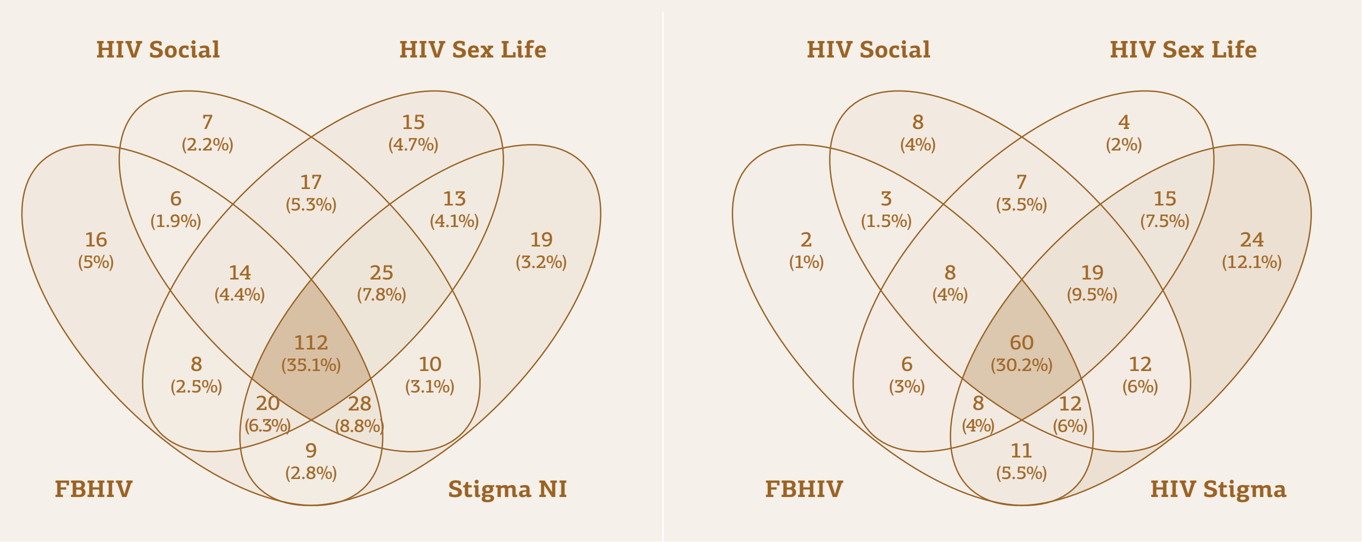
			Sub-region		Total	Missing
			EU/EEA	European Non-EU/EEA		
Do you feel bad about yourself or your HIV status or that you are a failure or have let yourself or your family down?	Yes	Count	201	113	**314**	55
		% within Sub-region	53.9%	47.7%	**51.5%**	
Do you think your HIV status has had a negative impact 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 20 shows the perceived impact of HIV in four dimensions of respondents' personal lives.

Over half of the overall sample reports that HIV and HIV stigma had an impact on all four dimensions (51.5% for "self-worth" up to 63.4% for the impact of HIV stigma in their mental health). The percentages vary slightly by Sub-region, with respondents from the non-EU/EEA countries reporting a lesser impact on all factors.

In order to better understand the distribution of this perceived impact, and the potential protective factor of working in an HIV organization, Figure 5 shows the overlap of persons responding "yes" to each of these four questions.

Figure 5 - Overlaps of reported impact of HIV and stigma in social and emotional well being



Left - people living with HIV not working in community organizations

Right - people living with HIV working in HIV organizations

Overall, OW report lower perceived effects of HIV, but a higher effect of HIV stigma. Those working in HIV organizations will also most likely be aware and informed of HIV stigma, and thus will be more likely to report its effect. Despite this, the percentage of those reporting impact of HIV and HIV stigma on all assessed dimensions is similar (35.1% on those not working in HIV organizations, 30.2% of those working in HIV organizations).

This underlines the relevance of intensifying work around HIV stigma (including self-stigma) and discrimination.

An additional analysis by time since diagnosis could be added, but likely results will not add much to the current picture.

4.3.6 - Impact of COVID-19 in perceived mental health and mental health support received during COVID-19 pandemic

Respondents were asked about the impact of lockdown due to the COVID-19 pandemic in their mental health, and responses are summarized in the table below:

Table 24 - Impact of COVID-19 in perceived mental health

Do you think that the period of lockdown due to Covid-19 has had a negative impact on your mental well-being?		**Sub-region**		**Total**	**Missing**
		EU/EEA	**European Non-EU/ EEA**		
Yes	Count	186	109	**295**	58
	% within Sub-region	50.0%	46.4%	**48.6%**	
No	Count	146	84	**230**	
	% within Sub-region	39.2%	35.7%	**37.9%**	
I am not sure	Count	40	42	**82**	
	% within Sub-region	10.8%	17.9%	**13.5%**	
Total	Count	**372**	**235**	**607**	
	% within Sub-region	**100.0%**	**100.0%**	**100.0%**	
Has the lockdown period due to Covid-19 re-activated or worsened any mental issues or traumas that you had previously?		**Sub-region**		**Total**	**Missing**
		EU/EEA	**European Non-EU/ EEA**		
Yes	Count	110	66	**176**	58
	% within Sub-region	29.5%	28.2%	**29.0%**	
No	Count	208	122	**330**	
	% within Sub-region	55.8%	52.1%	**54.4%**	
I am not sure	Count	55	46	**101**	
	% within Sub-region	14.7%	19.7%	**16.6%**	
Total	Count	**373**	**234**	**607**	
	% within Sub-region	**100.0%**	**100.0%**	**100.0%**	

Almost half of respondents report a negative impact of lockdown due to COVID-19 in their mental health (50% of EU/EEA respondents; 46.4% of non-EU/EEA respondents), whereas 39.2% of EU/EEA respondents and 35.7% of non-EU/EEA respondents state 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. Although these questions are of hard interpretation without further knowledge of individual situations, it seems safe to say that, as expected, lockdown due to COVID-19 had a considerable impact on the perceived mental health of responding people living with HIV, on all the Region.

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 report not to have received any type of support (Table 25).

Table 25 - Self reported support received by respondents during COVID-19 pandemic

If yes, have you received support?		Sub-region		Total	Missing
		EU/EEA	European Non-EU/EEA		
Yes, through HIV organisation(s)	Count	28	24	**52**	274
	% within Sub-region	11.0%	17.6%	**13.3%**	
Yes, through the HIV clinic	Count	17	4	**21**	
	% within Sub-region	6.7%	2.9%	**5.4%**	
Yes, through family and friends	Count	40	28	**68**	
	% within Sub-region	15.7%	20.6%	**17.4%**	
Other	Count	20	7	**27**	
	% within Sub-region	7.8%	5.1%	**6.9%**	
None	Count	**171**	**86**	**257**	
	% within Sub-region	**67.1%**	**63.2%**	**65.7%**	

Figure 6 - Overlap of types of support received by persons reporting the COVID-19 pandemic re-activated or worsened previous mental health issues or traumas

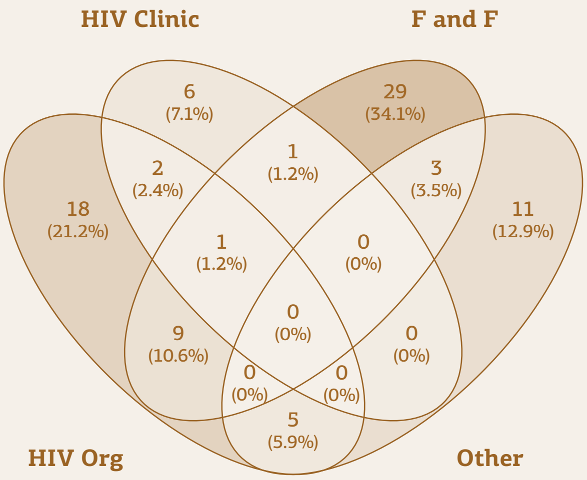


Figure 6 also shows the overlap of support received from different sources, among those reporting that COVID-19 reactivated or worsened previous mental health issues.

34.1% report that they received support from family or friends only, whereas 21.2% report receiving support from HIV organizations alone, and 7.1% only from their HIV clinic.

Those reporting support received from more than one source represent 24.5% of all respondents, with the biggest slice being the 10.6% reporting support from family and friends, as well as an HIV organization.

Even though response options did not include any professional mental health service type, it seems clear that there is a gap to fill in terms of ensuring access to mental health support services among persons identifying as having a mental health issue that would benefit from support.

Finally, when asked about missing mental health tools or mental health services in their local/regional HIV community organisation which would be of benefit to them or other people living with HIV, a variety of options were reported, including:

Mentions to increased availability/scale-up of professional mental health services:

- Psychiatrist, therapy groups
- More professionals
- Face-to-face counselling
- More attention for psychological issues at consultation with the HIV doctors
- Individual case-based long term psycho support
- Psychologists not working in the field of HIV, because of fear of confidentiality breach.

Other types of services/tools:

- Online forums
- Yoga
- Economic help

And more general considerations:

- A bit of all is the answer
- There is nothing for children with HIV
- Need HIV organisation in small towns.
- Services exist but they are very limited and hard to access.

5. Closing remarks

The purpose of this report was to provide an overview of survey results, alongside a first reflection surrounding both availability and use of mental health services, and on the general mental health of people living with HIV in the WHO European Region.

Our purpose was not to extensively compare current results with existing literature, particularly since a literature review has been conducted in parallel, within the scope of the project.

A more scientific oriented approach to the analysis of these results, focused on their publication, is both possible and desirable, as are country specific analysis. Both these options are being discussed and will likely constitute future deliverables within the project.

Following the preparation of the first draft of this report, a presentation of the data and two workshops were organized, aiming to collect insight from members and partners of EATG, with the purpose of formulating recommendations and next steps, deriving from the literature review and the results presented, and thus this concluding section will not include neither recommendations nor a detailed overview of possible next steps, as they will be included in a separate document, to be produced in the coming weeks.

We would however like to highlight some key points from the data presented here, and some specific suggestions stemming from this first analysis.

The burden of mental health among people living with HIV in WHO Europe seems to be much higher than that of the general population, according to available data. If we factor in stigma and discrimination, which are still reported in high percentages, it seems clear that these topics should remain as 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, raising two critical follow up points:

- On the one hand, if the burden of mental health issues is this high among those with most access and education, and help seeking behaviour is reported to be this low, we would expect that both mental health and access to support services among the most vulnerable people living with HIV to be worse than the one reported here, which flags important possibilities for further work.
- On the other hand, our results already highlight a concerning burden of mental health issues, and reduced access to support services, and while part of this may be due to COVID, which has had negative effects in the mental health of persons at a global level, they confirm the relevance of this endeavour, and a need to push mental health high up in the advocacy agenda of organizations working in the field of HIV.

Knowledge of the existence of 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 diagnosis 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 low hanging fruit and can contribute to rapidly bridge a part of this knowledge gap.

However, this should be associated with 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 mental health 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.).

As mental health is a complex field, and the majority of people living with HIV and those working in HIV organizations do not have training in mental health, several concepts are blurred and the role of each actor in the mental health response, as well as their added value and articulation amongst actors and services, seems to be unclear.

This means that we - both organizations and communities - would benefit from greater clarity, and further discussions regarding how we classify and define support services for mental health. Additionally, evaluations of responses in place at a CBO/NGO level by lay providers could also be beneficial in order to understand their current and envisaged role in a mental health response system. The same could be said regarding training and intervention needs and models.

If in general health systems were already overburdened pre-COVID and will be even more under stress during the ongoing pandemic, at the level of mental health responses it seems clear that available services are not just lacking in dissemination, but also in scale.

With many persons experiencing deterioration of their mental health during the pandemic, and the interplay with stigma and discrimination related to both HIV and mental health also influencing availability of services and willingness to fund these services, it seems clear that relying solely on highly differentiated responses delivered by mental health professionals is not realistic. Furthermore, many persons will not require long lasting therapies or lifelong psychiatric medication to improve their mental health, which means that there is space for less demanding interventions, both technically and financially.

This means that, and according to existing guidance, 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 up 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, which in turn requires structured collaboration with both mental health professionals and their 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 models at a national and local scale and, of course, ensure their 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 mix 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.

It is similarly paramount to work with mental health professionals in the development of tools that can be used in the “front line”, to ensure adequate referral of persons, many of which have been already developed and are known to psychologists and psychiatrists, having the potential to be used by lay workers with adequate training.

It cannot be expected that CBO/NGO can provide all services to all persons, and thus it is paramount that links with multiple types of responses are developed. When speaking about mental health, not only the links with mental health professionals, but also with other services that provide support in areas of our lives which have a direct impact on mental health need to be taken into consideration, including housing, food, employment, among many others.

A final note not directly related to the survey results themselves, but an important one nonetheless - with a mix of a personal and professional reflection. As shown by some of the quotes used here, the survey was successful in reaching a wide array of persons, including some who shared not only personal information, but concerning one, including several - and very clear - requests for help. This underlines an important aspect of balance between research and action which I feel a need to clearly add for our reflection, which can be summarized in a need to provide links or referrals to support services alongside any survey or questionnaire.

As a community network EATG has an added responsibility at this level and should consider - and promote in its future research and activities - that all surveys or studies in topics as sensitive as mental health, or even others such as violence or stigma and discrimination for example, should always be accompanied by a contact or referral system to a support organization or service, where respondents can resort to if they require support/help or more information.

As a mental health professional, let me underline that exploring emotional experiences and symptoms who are often uncomfortable, difficult to manage and that many persons do not possess the tools to deal with should never be done unless we are prepared to provide persons with some sort of response or pathway to support.

We were - proudly I would add - successful in earning persons' trust and in obtaining their responses; it is my conviction that we must also be successful in properly addressing their needs, even in a survey. Asking people to share these difficulties and not providing them with any type of support or solution is - in my mind - unethical, and places us at the same level as the classic research institutions we so often - and rightly - criticize, who address communities to gather data, and leave without providing them with anything in return, and ignoring the needs expressed, here in the first person.

If we aim to be better and promote good practices, they should begin ”in-house”, and thus as a professional and personal recommendation, the creation of a mechanism that can provide persons with referral to adequate support (even if an email and a note clearly stating that this is possible) should be a priority step for EATG, and it should be made available as quickly as possible, and disseminated through the same channels as this report, and in the same organizations, attempting to reach as wide of an audience as possible.

Although we know we will never be able to support everyone, it is our mission to at least provide a contact point to persons who - as the results have shown - are unaware of responses or support services available to them. It is, after all, the ultimate objective of EATG - to act as a network of support to people living with HIV in Europe, regardless of what the need is.

6. Appendixes

6.1 – Survey Questionnaire

SURVEY ON MENTAL HEALTH OF PEOPLE LIVING WITH HIV

Reports

Survey short title:	Kopija
Question number:	48
Number of variables:	122
Status:	Survey was not activated yet
Author:	Miran Šolinc, 10.11.2020
Edited:	Miran Šolinc, 10.11.2020

Dear participant, this survey is addressed to the community, people living with HIV as well as persons working in HIV organisations at the local, regional or international level in Europe and Central Asia. Our survey is part of the European Aids Treatment Group – EATG and 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.The recommendations will advise on how to develop a supportive and integrated framework within the HIV care setting, which provides people living with HIV with access to prevention, screening, treatment and care for mental health problems. It is completely anonymous and it will not take more than 10 minutes of your time. Please help us gather this relevant and useful data to learn about the current needs for better mental health care services across the region. EATG always take in consideration all ethical norms and standards, in line with GDPR, respecting individuals personal rights like confidentiality and anonymity. Filling out this survey you agree to give this data for research purposes. This survey will end on 31/10/20.

Q1 What is your country of residence?

....

Q2 Are you part of an HIV community organization in Europe or Central Asia?

☐ *Yes*

☐ *No*

IF (1) Q2 = [1] (Yes)

Q3 Which best describes your organisational affiliation?
(Multiple answers are possible)

☐ *Key Population-led Organisation/ Community-led or -based Organisation or Network*

☐ *Donor / Funder*

☐ *UN agency / Technical partner*

☐ *I have no organizational affiliation*

☐ *Prefer not to share*

☐ *Other: (please specify):* ....

IF (1) Q2 = [1] (Yes)

Q4 What are commonly raised issues related to HIV and mental health in your work?
(Multiple answers are possible)

☐ *Depression*

☐ *Anxiety*

☐ *Low self-esteem*

☐ *Isolation / loneliness*

☐ *Post-traumatic stress disorder*

☐ *Harmful and regular use of drugs and/or alcohol*

☐ *Self-harm*

☐ *Suicidal feelings*

☐ *Shame*

☐ *Self-blame*

☐ *Body image issues*

☐ *Other: (please specify):* ....

(1) Q2 = [1] (Yes)

Q5 Does your organization provide any specific mental health services to people living with HIV?

(Multiple answers are possible)

☐ *Peer support*

☐ *Help groups*

☐ *Other: (please specify):* ....

☐ *None*

IF (1) Q2 = [1] (Yes)

Q6 What kind of psychosocial-support has your organisation provided to people living with HIV during Covid-19 lockdown?

(Multiple answers are possible)

☐ *Usual psychological support*

☐ *Online psychological support*

☐ *Online peer support*

☐ *Webinars on mental health and wellbeing*

☐ *Refferals*

☐ *Other: (please specify):* ....

☐ *None*

IF (1) Q2 = [1] (Yes)

Q7 Are there any mental health resources, tools or services that lack in your organisation and which you think would be of benefit for people living with HIV?

(Multiple answers are possible)

☐ *Psychological support*

☐ *Refferals*

☐ *Other: (please specify):* ....

IF (1) Q2 = [1] (Yes)

Q8 Have you in your work experienced an increase of mental health issues during the Covid-19 pandemic and lockdown period?

☐ *Yes*

☐ *No*

☐ *I am not sure*

Q9 -

☐ *Yes*

☐ *No*

(2) Q9 = [1] (Yes)

Q10 What is your gender identity?

☐ *Cisgender woman*

☐ *Cisgender man*

☐ *Transgender woman*

☐ *Transgender man*

☐ *Gender non-binary*

☐ *Gender fluid*

☐ *Prefer not to answer*

☐ *Other: (please specify):* ....

IF (2) Q9 = [1] (Yes)

Q11 How do you identify yourself?

☐ *Heterosexual*

☐ *Gay / Lesbian*

☐ *Bisexual / Pansexual*

☐ *Asexual*

☐ *Other: (please specify):* ....

IF (2) Q9 = [1] (Yes)

Q12 Where do you live?

☐ *In the capital city*

☐ *Middle size city*

☐ *Small city*

☐ *Village, countryside*

IF (2) Q9 = [1] (Yes)

Q13 Which age group are you in?

☐ *Less than 20*

☐ *20-29*

☐ *30-39*

☐ *40-49*

☐ *50-59*

☐ *60 or more*

IF (2) Q9 = [1] (Yes)

Q14 What is the highest level of education you have attained?

☐ *Primary school*

☐ *Some high school*

☐ *High school diploma*

☐ *College degree*

☐ *University degree*

☐ *Other:* ....

IF (2) Q9 = [1] (Yes)

Q15 What is your current employment status?

☐ *Employed / self employed*

☐ *Student*

☐ *Sick or disabled*

☐ *College degree*

☐ *Retired*

☐ *Other: (please specify):* ....

IF (2) Q9 = [1] (Yes)

Q16 What is your current housing status?

☐ *I rent a place*

☐ *I live with family / friends*

☐ *I am homeless*

☐ *Other:* ....

IF (2) Q9 = [1] (Yes)

Q17 In a typical month, how difficult is it for you to cover your living expenses (including food, all your bills, and other personal costs)?

☐ *Very difficult*

☐ *Neutral*

☐ *Easy*

☐ *Very easy*

☐ *I do not know*

☐ *Prefer not to answer*

(2) Q9 = [1] (Yes)

Q18 Years since HIV diagnosis

☐ *Less than 1 year*

☐ *1 – 5 years*

☐ *5 – 10 years*

☐ *10 – 20 years*

☐ *Over 20 years*

IF (2) Q9 = [1] (Yes)

Q19 What is your HIV treatment status?

☐ *On ART, undetectable*

☐ *Stopped ART*

☐ *Never taken ART*

☐ *Other: (please specify):* ....

IF (2) Q9 = [1] (Yes)

Q20 Have you in the past month skipped or missed any of your HIV treatment?

☐ *Missed no HIV treatment*

☐ *Missed 2 doses*

☐ *Missed 3 or more doses*

☐ *Not relevant / not applicable*

IF (2) Q9 = [1] (Yes)

Q21 How knowledgeable are you about mental health related issues?

☐ *Very knowledgeable*

☐ *Neutral*

☐ *Not knowledgeable*

☐ *Not knowledgeable at all*

IF (2) Q9 = [1] (Yes)

Q22 Have you ever been diagnosed with a mental disorder or experienced any symptoms of mental disorders before you got your HIV diagnosis? (For example, depression, anxiety, low self-esteem, sleeping problems, self-harm, regular and harmful use of drugs and/or alcohol, suicidal feelings, social isolation, other issues)

☐ *Yes*

☐ *No*

☐ *I do not remember*

IF (2) Q9 = [1] (Yes)

Q23 Have you ever been diagnosed with a mental disorder or experienced any symptoms of mental disorders after you got your HIV diagnosis? (For example, depression, anxiety, low self-esteem, sleeping problems, self-harm, regular and harmful use of drugs and/or alcohol, suicidal feelings, social isolation, other issues)

☐ *Yes*

☐ *No*

☐ *I do not remember*

IF (2) Q9 = [1] (Yes)

Q24 Have you taken or are you currently taking any treatment or getting psychological support for mental health problems?

☐ *Yes*

☐ *No*

☐ *Not relevant*

(2) Q9 = [1] (Yes)

Q25 Do you experience difficulties accessing treatment for mental health conditions (For example accessing antidepressants, etc.?)

☐ *Yes*

☐ *No*

☐ *Not relevant*

IF (2) Q9 = [1] (Yes)

Q26 How is your quality of sleep in the past 2 weeks? (Trouble falling asleep, staying asleep or sleeping too much)

☐ *Very bad*

☐ *Normal*

☐ *Good*

☐ *Very good*

IF (2) Q9 = [1] (Yes)

Q27 How is the quality of your concentration in the past 2 weeks?

☐ *Very bad*

☐ *Normal*

☐ *Good*

☐ *Very good*

IF (2) Q9 = [1] (Yes)

Q28 Have you in the last weeks experienced loss of memory or difficulty remembering things?

☐ *Yes*

☐ *No*

IF (2) Q9 = [1] (Yes)

Q29 Have you in the past weeks had little interest or pleasure in doing things?

☐ *Yes*

☐ *No*

(2) Q9 = [1] (Yes)

Q30 How would you rate your level of energy in performing daily activities the past weeks?

☐ *Excellent*

☐ *Somewhat good*

☐ *Average*

☐ *Somewhat poor*

☐ *Poor*

☐ *Not sure*

IF (2) Q9 = [1] (Yes)

Q31 Have you felt particularly low, down, depressed or hopeless for more than 2 weeks in a row?

☐ *Yes*

☐ *No*

IF (2) Q9 = [1] (Yes)

Q32 Have you at any time had any thoughts that you would be better off dead or thoughts of hurting yourself in some way?

☐ *Yes*

☐ *No*

IF (2) Q9 = [1] (Yes)

Q33 Do you regularly use drugs and/or alcohol?

☐ *Yes, both*

☐ *Only alcohol*

☐ *I do not regularly use either*

(2) Q9 = [1] (Yes)

Q34 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*

☐ *No*

IF (2) Q9 = [1] (Yes)

Q35 Do you think your HIV status has had a negative impact on your ability to engage in relationships and social activities?

☐ *Yes*

☐ *No*

☐ *I do not know*

IF (2) Q9 = [1] (Yes)

Q36 Do you think your HIV status has had an impact on your sexual life?

☐ *Yes*

☐ *No*

☐ *I do not know*

IF (2) Q9 = [1] (Yes)

Q37 Do you think that HIV stigma and discrimination has played a negative role on your mental well-being?

☐ *Yes*

☐ *No*

IF (2) Q9 = [1] (Yes)

Q38 Do you think that the period of lockdown due to Covid-19 has had a negative impact on your mental well-being?

☐ *Yes*

☐ *No*

☐ *I am not sure*

IF (2) Q9 = [1] (Yes)

Q39 Has the lockdown period due to Covid-19 re-activated or worsened any mental issues or traumas that you had previously?

☐ *Yes*

☐ *No*

☐ *I am not sure*

IF (2) Q9 = [1] (Yes)

Q40 If yes, have you received any kind of psycho-social support?
(Multiple answers are possible)

☐ *Yes, through HIV organisation(s)*

☐ *Yes, through the HIV clinic*

☐ *Yes, through family and friends*

☐ *Other:* ....

☐ *None*

(2) Q9 = [1] (Yes)

Q41 When did you last get your mental health examination done?

☐ *Less than 6 months ago*

☐ *I have never had a mental health examination*

IF (2) Q9 = [1] (Yes)

Q42 Who do you ask for help when you have psycho-emotional difficulties?
(Multiple answers are possible)

☐ *Family / relatives*

☐ *Friends*

☐ *HIV organisations*

☐ *General practitioner*

☐ *HIV clinician/Nurse at the HIV clinic*

☐ *Social worker / Pscyhologist*

☐ *Other:* ....

IF (2) Q9 = [1] (Yes)

Q43 Are there any psycho-emotional services for people living with HIV available in your city?

☐ *Yes*

☐ *No*

☐ *I do not know*

IF (2) Q9 = [1] (Yes)

Q44 Have you visited a specialist, consultant, or peer consultant to receive psychological help and support for the past 6 months? If yes, where.

(Multiple answers are possible)

☐ *Private therapist*

☐ *Peer consultant (through HIV community organisations)*

☐ *Therapist (through HIV organisations)*

☐ *General practitioner*

☐ *Other:* ....

☐ *None*

IF (2) Q9 = [1] (Yes)

Q45 Does your local or regional HIV organization(s) provide any specific mental health services to people living with HIV?

(Multiple answers are possible)

☐ *Peer support*

☐ *Therapy*

☐ *Help groups*

☐ *None*

☐ *I do not know*

IF (2) Q9 = [1] (Yes)

Q46 Which mental health resources, mental health tools or mental health services you lack in your local / regional HIV community organisation and which you think would be of benefit to you or other people living with HIV?

(Multiple answers are possible)

☐ *Psychological support*

☐ *Therapy sessions*

☐ *A referral system*

☐ *Help groups*

☐ *Other:* ....

IF (2) Q9 = [1] (Yes)

Q47 -

☐ *Excellent*

☐ *Somewhat good*

☐ *Average*

☐ *Somewhat poor*

☐ *Poor*

☐ *Not sure*

Q48 **If you have any additional comments/ information relevant to this questionnaire, please use the box below:**

EA
TG
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AIDS Treatment
Group

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 160 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