EXPLORATORY SURVEY REPORT
August 2020

Mental Health and YPLHIV

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Newcastle University
GLOBAL NETWORK OF YOUNG PEOPLE LIVING WITH HIV
CHILE POSITIVO FUNDACIÓN
TEENERGIZER!

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Definitions

Undetectable = Untransmittable (U=U): when HIV medication suppresses the virus to undetectable levels, a person with HIV is untransmittable and cannot spread the virus sexually.

Pre-exposure prophylaxis (PrEP): A drug taken by HIV-negative people before and after sex that reduces the risk of getting HIV

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Acronyms

(Y)PLHIV	(Young) people/person living with HIV
WHO	World Health organisation
U=U	Undetectable equals untransmittable is the simplest way to convey the message that when a person living with HIV has a suppressed viral load, they cannot pass on HIV sexually.
ART	Antiretroviral treatment

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Foreword

Young people in today's world face a plethora of challenges. For those living with HIV, there are many intersecting factors that impact on their health and wellbeing. Youth Stop AIDS is a UK based organisation campaigning to end AIDS by 2030 in line with Sustainable Development Goal 3. With a specific focus on youth leadership and impact, we seek to champion young people and provide a platform for them to use their power to make change in the world around them.

As a consequence of being a youth-led organisation, we know the challenges that young people face regarding mental health. We are excited to partner with the researchers and sponsors of this report in an attempt to better understand the key factors impacting the mental health of young people living with HIV (YPLHIV) and to work towards evidence-based recommendations for how to improve this. As this report demonstrates, YPLHIV across the globe report significant challenges to maintaining their mental health. This includes lack of trust, lack of training or knowledge, ongoing stigma – both regarding one's HIV status and one's mental health – and lack of available and accessible mental health services.

We partnered with the researchers on this research project because we are passionate about championing young people. We believe that young people are often referred to as a token gesture and that a disaggregated focus on young people has been lacking in other research. In undertaking this research, we were interested to learn what changes young people themselves believed would make a difference. To understand this, it was important that we listened to what young people had to say. This report has been a crucial opportunity to hear the voices and experiences of YPLHIV in order to understand how best we can address the issues that they face. The report also recognises that young people are not a homogenous category and seeks to encourage reflection of how differences such as region, occupation, gender identity, or socioeconomic background may impact individuals differently.

YPLHIV face many interconnected barriers to health and wellbeing; de-prioritisation of HIV services, a lack of focus on mental health, and a severe gap in specialist services for youth and young adults. This report signals key actions and policy changes that we can adopt to ensure better services, health, and wellbeing of YPLHIV. However, to adequately represent the lives of young people we must take seriously their experiences and knowledge.

Going forward, we hope that what we have to say in this report not only addresses key knowledge gaps but also inspires action. We *can* improve the mental health of YPLHIV if we work together and engage with what young people have to say. Youth Stop AIDS are committed to this, and to ending AIDS by 2030. We will draw on this report to understand what needs to change and to inspire our campaigns, and hope to encourage others to do so too.

Finally, many thanks to Nadege, the lead researcher, and the sponsors of this research, Newcastle University's Social Justice Fund, for their hard work and support

(Molly Pugh-Jones, London and Southern England Co-ordinator)

- **Youth Stop AIDS**

Acknowledgements

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Thanks go to people who supported the development of the survey, including those who helped to translate the survey into Spanish and Russian, and those who helped to pilot the survey and provided feedback at different stages of the research process.

This report would not have been possible without the young people and stakeholders who took part. We are ever grateful to participants for taking the time to complete the survey.

We would also like to extend many thanks to the organisations and individuals that supported the survey dissemination effort by sharing information about the survey on their social media platforms.

Disclaimer

All quotes used in this report are direct quotes. Author’s notes within quotes are demarcated by square brackets. For a global survey such as this, it is inevitable that some statements or phrases or words will be problematic in some contexts than others. We encourage readers to maintain a tolerant attitude towards quotes within this publication.

Introduction

Mental health is a major disease burden globally (1). The threat posed by the rising levels of mental ill-health is so serious that it constitutes a *"global health crisis"*, according to the commission on global mental health and sustainable development (2). The commission's assessment of the mental health agenda embedded within the sustainable development goals (SDGs) identified a lack of real-world effects of existing knowledge on prevention and treatment of mental health disorders and promotion of mental wellbeing. A significant issue is the lack of investment in mental health globally; only 1% of total health budgets in low and middle-income countries and only 4-5% in high -income countries are spent on preventing mental illness and promoting mental health (3).

COVID-19 has added new levels of stress, anxiety and loss to be grappled with in the coming years, which further emphasises the importance of effective and accessible mental health services (4, 5).

Young people are more vulnerable to poor mental health due to the demanding dynamics of transitioning from childhood through adolescence into adulthood (6). Adolescence and young adulthood is a difficult time when young people build their social, cultural, emotional, educational, and economic foundations to sustain their health and wellbeing throughout their lives (Ibid.). A quarter of all mental health disorders like anxiety and depression begin before age 24 (7). Poor mental health early on in life can lead to adverse knock-on effects on health, education, livelihoods and the formation of positive relationships (8, 9).

Defining mental health

It is noted throughout literature that the term "mental health" lacks a clear and consistent meaning and definition (10). A distinction is made between "Mental health" and "mental disorder" whereby the former represents mental wellbeing while the latter stands for abnormality.

The domain of psychology operates with the "mental disorder" dichotomy by focusing on those who manifest symptoms of mental ill health. Highly developed definitions and theories for various forms of mental ill health are used to measure/assess mental health. The underlying dysfunctions for many mental disorders, such as depression, anxiety and eating disorders, involve stressful socioeconomic and environmental stressors (11).

The “wellness” aspect of the "mental health" dichotomy is also referred to as "mental wellbeing" and conveys the understanding that we are not merely dealing with the presence of measurable disorders. Mental wellbeing incorporates aspects of self-esteem, mastery and ability to maintain meaningful relationships. It is the viewpoint adopted in most public health settings, and the definition of mental health by the World Health Organisation is a good example:

> *"Mental health is a state of wellbeing in which an individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community."* (12)

Mental health in this broad and positive sense can mean different things to different people and in different geographical, cultural and temporal contexts (13). The UK Government's "No Health without Mental Health" strategy employs an understanding of mental health as:

> *"The foundation for wellbeing and effective functioning both for individuals and for their communities" and "a positive state of mind and body, feeling safe and able to cope, with a sense of connection with people, communities and the wider environment."* (UK Government, 2011).

The Public Health Agency of Canada defines good mental health as:

> *"The capacity of each and all of us to feel, think, and act in ways that enhance our ability to enjoy life and deal with the challenges we face. It is a positive sense of emotional and spiritual wellbeing that respects the importance of culture, equity, social justice, interconnections and personal dignity."* (14)

The list of customised mental health definitions is long, and definitions change over time. However, it is not clear in existing literature what mental health means to PLHIV and YPLHIV in particular. What is clear is that it might mean different things in different contexts.

Mental health and HIV

This report is situated somewhere between the two dichotomies, but with a bias towards the public health perspective, which is concerned with promoting mental wellbeing.

HIV is distinct from other long-term conditions in that it is also highly stigmatised. This stigma exposes PLHIV to emotional and psychological distress which might not lead to diagnosable mental disorders but may limit the ability of those affected to enjoy life and achieve their full potential. However, HIV-related stigma combined with the burden of living with a chronic illness can lead to both depression and anxiety, which are common mental disorders (15, 16). Additionally, PLHIV may experience socioeconomic and environmental stressors that may trigger or exacerbate pre-existing mental health problems (Ibid).

PLHIV suffer from a double burden of stigma since poor mental health is also highly stigmatised (17). Therefore, it is not surprising that PLHIV are more likely to have a mental health condition (15) resulting in reduced quality of life (18, 19). Exacerbating the situation is the fact that some mental disorders like depression and anxiety affect adherence to ART treatment (20-22). At the same time, some antiretroviral medications are known to contribute to mental health disorders such as depression (23).

Mental health challenges faced by PLHIV have evolved together with the dynamics of the epidemic. During the initial years of the HIV and AIDS epidemic, and before treatment was available, a person contracted HIV and died of AIDS-related illnesses. The mental health challenges associated with being HIV-positive included psychological responses to illness, including end-of-life contemplations and coping with the stigmatising public attitudes.

In the era of ART, mental health challenges revolve around issues pertaining to living with HIV as a chronic condition. The necessity of adherence to a lifelong treatment regimen has made health system issues salient determinants of mental health among PLHIV. While treatment is available free of charge in many parts of the world, there are still countries with poor treatment provision. An association was found between poor mental health and poor quality services or the inability to access services (24).

Fear of onward transmission of HIV also constitutes a significant mental health challenge and compromises the ability of PLHIV to engage in quality intimate relationships. However, innovations in the HIV response such as pre-exposure prophylaxis (PrEP) and the evidence that Undetectable=Untransmittable (U=U) make it easier to navigate sexual relations. U=U is a simple and clear way of communicating the robust research evidence showing that a person on effective treatment and a suppressed viral load cannot transmit HIV sexually, even without the use of protection (25, 26). Viral suppression refers to the state when the HIV virus is undetectable in blood samples of a person living with HIV.

Aims and objectives

This report builds on what is already known about the adverse effects that HIV can have on the mental health of PLHIV but directs focus on YPLHIV between the ages of 10-29 years. This focus addresses the fact that the impact of HIV on the mental health of young people is under-researched.

The research was exploratory and aimed to provide an overarching picture of mental health among YPLHIV and to explore to what extent mental health challenges are prevented and mitigated. The report is based on the results of an exploratory global survey that was undertaken between 17th April and 11th June 2020 among YPLHIV and stakeholders working directly with YPLHIV. The objectives of the survey were to:

- Assess mental health challenges faced by YPLHIV
- Explore existing responses to mental health challenges experienced by YPLHIV
- Identify barriers which hinder efforts to improve mental health among YPLHIV
- Identify gaps and highlight neglected areas in need of prioritisation
- Develop a bespoke definition of mental health relevant to the needs of YPLHIV.

Methodology

Scope

The survey had a global scope and targeted all WHO regions: Africa, Americas, Eastern Mediterranean, Europe, South-East Asia, and Western Pacific.

Inclusion criteria

The survey was conducted among two populations: YPLHIV and stakeholders working in the HIV and AIDS response in the fields of health service delivery, research, and advocacy.

For ethical reasons, the age group of interest for YPLHIV was 18 to 29 years. Eighteen is the age of consent to participate in research according to the WHO.

The higher age limit was set to account for the fact that the definition of youth in some regions, such as Africa, a person is considered a youth up to the age of 35 (the African Youth Charter). However, we did not want too wide an age range, and so 29 was selected.

Inclusion was restricted to stakeholders working specifically with the 10-24-year-old age group. The lower age bracket of 10 was included to account for the transitional and continuous nature of development from early adolescence;10-14 years through youth; 15-19 years and early adulthood; 20-24 years. Including these age groups enabled the assessment of stakeholders' perspectives on mental health barriers and facilitators during transitions from paediatric to adolescent and from adolescent to adult care.

Questionnaire development process

The questionnaire was developed using online surveys (www.onlinesurveys.ac.uk), which is a web-based form building platform for creating, administering and analysing surveys. We took an iterative approach to questionnaire development. Initially, the questionnaire was designed to explore challenges and opportunities for addressing mental health challenges faced by YPLHIV globally. Specifically, the survey explored the availability of mental health policies, guidelines, and interventions or programmes and the extent to which they meet the needs of YPLHIV. The initial survey was developed by the lead researcher using knowledge from the field and insights from Oxfam on the type and forms of evidence needed to influence policy successfully (27). The questionnaire was refined through discussion and feedback from some members of the YSA community, YSA's national coordinator and the research supervisor, who reviewed the survey several times. YSA campaigners and others who participated in this process were asked to give a general assessment of their experiences of piloting the survey, including their understanding of key questions and terms used. A series of changes were made to the questionnaire based on the recommendations arising from this exercise. This stage of development also involved a review of mental health definitions. Thus, a significant change made was the addition of a question to assess the preferred definition of mental health following the suggestions in the literature, that the meaning of the term 'mental health' is different in different contexts -both conceptual and geographical. It seemed imperative to ensure that the survey could generate an understanding of what mental health means to and for YPLHIV.

In the next stage of the survey development process, the survey was piloted among nine YPLHIV from the UK, Tanzania, Eswatini, Kenya and Malawi. In addition, a scoping review of the literature was undertaken to further develop the questionnaire. The mini-pilot and literature review indicated that it would be beneficial to assess the mental health challenges faced by young people as well as their position in relation to known drivers of poor mental health among PLHIV, such as stigma as well as other social and behavioural factors such as unemployment poverty and alcohol intake. A set of questions to assess the availability of mental health services and the level of integration of HIV and mental health services were also added. The survey was also extended to assess youth involvement in the design and delivery of mental health interventions and services, which was a major grievance in the initial pilot. The pilot study led to other minor changes in the survey, including the wording of questions to improve consistency and clarity.

The revised questionnaire was reviewed by the YSA steering committee, and it was completed by two Malawians, a young person living with HIV and a health provider, who provided feedback. The survey was then finalised before dissemination.

Approach to translation

We translated the survey into two other global languages; Spanish and Russian, through consultation with Y+ global. We envisioned that Spanish would reduce barriers to participation for many Latin American countries which are immensely underrepresented in HIV-related research. We chose Russian because of the perceived value of investigating mental health in Eastern European countries where new HIV infection rates are on the rise. Also, treatment coverage in Eastern Europe and Central Asia (EECA) region remains alarmingly low (28).

We adapted the WHO's process of translation and adaptation of instruments to fit the premises of this research (29). Young people from two organisations working with YPLHIV in Chile and Ukraine translated the questionnaire. The two young people were familiar with the terminology used in the questionnaire and knowledgeable of the English culture despite their mother tongues being Spanish and Russian, respectively. We instructed them to produce translations that emphasised conceptual rather than actual meaning. As young people themselves, translators were mindful of using language appropriate for a young audience. We did not engage an expert panel, and instead of a full backward translation, we engaged two bi-lingual researchers with Spanish and Russian as their mother tongue to validate the forward translated versions of the questionnaire by comparing them with the original English version. The two validators had no prior knowledge of the questionnaire. We sent issues identified by the two validators back to the translators who assessed them and decided which changes to adopt. In both cases, the translators adopted all the changes proposed by the validators. We then tested both questionnaires with a couple of young people and stakeholders whom we asked to give feedback on their overall experience of responding to the survey, the ease of understanding and answering the questions, length and effect on their mood. Testers found the survey to be relevant and highlighted issues with some questions, many of which had to do with errors made when transferring the questions into the online survey builder form. Almost all testers felt that the survey was too long, but it was not possible to change the questions at that point because the English version of the survey was already in circulation. Table 1 depicted the feedback from one of the testers.

Table 1 Example of feedback from a survey tester

Tester 1-

What did you think of the survey?

Overall, they thought it was a good survey, it was interesting and thought that it was very relevant to our local context, as lots of YPLHIV struggle to access mental health services. They thought they understood the survey very well, with a few exceptions on a few questions.

2. Was there any question that they had trouble answering and why?

Question 3. Is in English (*If you selected more than one group above, select the viewpoint)*

Question 4. Is wrong (*what is your age?).* It should ask for the age of the participant but instead, repeats question 4.b.

Question 33. Is in English (*how often do you have an alcoholic drink?)*

Question 58 and 58.a. Duplicate. They are asked twice.

3. Was there any point at which they felt like leaving the survey due to fatigue or any other difficulty and if so, what can we do to make it easier for respondents to get through to the end?

They didn't think the survey was long. They enjoyed taking surveys, and it took them 34 minutes to complete. They also didn't have any privacy concerns nor any concerns about their mental wellbeing.

Sample size

We employed a convenience sampling approach (30) by sampling readily available eligible candidates through social media and the internet. The decision to use convenience sampling was based on pragmatic considerations due to restrictions imposed by COVID-19 (see page 2).

Pragmatic considerations informed sample size estimation due to the fact that this was an exploratory study with a conveniently sampled population and no ambition to achieve statistical inference. The estimated target sample size was based on predictions of the responses that we could expect to get from online dissemination, well knowing that our sample would be biased towards young people and stakeholders with internet access. We decided on sample sizes of 1000 young people and 1000 stakeholders.

We aimed for an equal distribution of the total sample sizes among the six WHO regions such that approximately 166 YPLHIV and 166 stakeholders would be sampled from each region. However, the sample sizes for the African region were increased by 50% to account for the significantly higher burden of HIV in terms of both HIV prevalence and death from AIDS-related illnesses. Thus, we aimed for a sample size of 249 young people and 249 stakeholders in the African region, and samples sizes of 150 young people and 150 stakeholders in each of the five remaining regions. We set out to achieve within region samples reflective of the burden of HIV and AIDS sampling half of the sample from countries above, and a half from countries below the median death rate from AIDS for each region. The following procedure was followed:

1. Sort the countries in each region in order of mortality rate
2. Calculate the median death rate from AIDS-related illness
3. Separate the countries into above & below the median
4. Sample half of the sample from countries above, and a half from countries below the median.

Find a sample of the sampling guidance table in **Appendix 1.**

Sampling procedure

The Global Network of YPLHIV (Y+ Global) facilitated survey dissemination together with Fundación Chile Positivo and Teenergiser and Youth Stop AIDS.

The survey was primarily disseminated through e-mail and social media: Instagram, Twitter and Facebook. We formulated short social media posts and an e-mail template that we used to share the survey. Social media posts were shared on the social media pages of the four organisations involved in the study and some of their partner organisations. The lead researcher searched for organisations working with HIV in different regions on Twitter and Facebook and tagged them in posts.

For e-mail dissemination, charities were identified through YSA and Y+ Global networks and through web-searches. We aimed to disseminate the survey through a variety of organisations that represented the fields of interest: health care delivery, research, advocacy and policy. An e-mail with the survey link was e-mailed to the identified organisations which were asked to share it with YPLHIV and relevant stakeholders through the channels that they normally used to communicate. For example, we asked the organisations to share a link to the survey through their social media accounts: Twitter, Facebook and Instagram. The expectation was that the survey would then circulate through chain referral to both target populations.

Expected limitations and attempts at mitigation

The research project was initiated at the onset of COVID-19, which led to changes to the original plan. The main change was that instead of administering the survey through a combination of online, e-mail and personal interviews in selected countries, we opted for internet dissemination through social media and e-mail only. Personal interviews were eliminated due to the risk that research assistants could contract and spread COVID-19. Relying on electronic dissemination of the survey only introduced a limitation in that young people and stakeholders without access to the internet and appropriate electronic devices would not have the opportunity to participate. Because of this, we expected most respondents to be from urban areas in low and middle-income countries. We strived for rural representation by making deliberate mention of the fact that we needed respondents from both urban and rural settings in social media posts and e-mail invitations.

We sought to mitigate bias by sampling varying types of organisations, including those working directly with different affected populations. We monitored responses so as to disseminate the survey strategically to ensure representative regional samples.

Literacy levels were also bound to influence participation in countries and regions with low literacy rates. We strived for simple and clear questions.

We sampled young people through HIV charities and expected that the majority would be working or volunteering with such organisations. Thus, we expect most young respondents to be young leaders and activists with strong opinions regarding the status quo relating to mental health service provision, research and policy.

Ethics

The ethics committee under the medical faculty at Newcastle University granted ethical approval. Approval reference number 1928/4312/2020.

Data analysis.

Quantitative data

Data were collected from a convenience sample. Thus, we could not use the data to draw statistical inferences. Moreover, advanced statistical analyses (including stratification of the analysis by region) were not possible due to the small sample sizes.

We employed descriptive statistics to analyse categorical data using frequencies and percentages. We analysed results for stakeholders and YPLHIV separately to understand differences in perceptions.

Qualitative data (Textual responses to open-ended questions)

Textual responses to questionnaires can be limited in their level of detail, which limits analysis possibilities. Of the different approaches to analysing qualitative data, content analysis is the most suited to questionnaire generated data (31). We employed the content analysis steps described by Krippendorf K. (32). The core features of the analytical process are coding, which entails a systematic process of classifying data into categories or themes (31).

The coding process:

Responses to one question or several related questions were read, and common units of meaning were identified and classified under the same category or cluster of meaning delineated by a code. Most of the open-ended questions were follow-up questions to categorical ones. Thus, we deliberately coded data with the intention of unveiling the processes underlying participants' answers to categorical questions and report complementary findings from the quantitative and qualitative data.

Each narrative response was read carefully, and a relevant category code(s) was/were assigned to it. Once all responses to a question or group of similar questions were coded, we assessed the accuracy of categories and corrected any misclassifications. Categories that were similar were grouped together into a theme. We then calculated the total number of times each code appeared in the responses and calculated the proportion of the total number of responses addressing each identified code or category. This was done in an iterative process with amendments where this was necessary, in the circular movement from data to category and code and back. Findings were presented visually using graphs and charts and reported with a narrative description of major categories. Where relevant, responses of stakeholders and young people were reported separately to highlight differences.

The coding process was mostly inductive and grounded in the data, but there were instances where deductive codes were drawn from inferences to the current body of knowledge and insights gleaned from other research questions in the study.

Results

Participant's health and social-economic characteristics

Table 2 presents information on the distribution of survey participants. In total, 214 people responded to the survey of which the majority, 84%, were YPLHIV. Around one-fifth of respondents self-identified as belonging to both respondent categories of YPLHIV and stakeholders. Primary identity signifies the category that respondents represented in the survey. Seventy-eight chose to participate in the survey as YPLHIV.

Table 2 Response categories

Variable	Number (%) of all 214 responses)
[a] Self-identification category (can be more than one)	
YPLHIV	179 (83.6)
Stakeholders:	
Health service employer/commissioner	6 (2.8)
Health workers/professionals	37 (17.3)
Researcher	15 (7.0)
Advocate/Activist	59 (27.6)
Other (e.g. programme manager)	6 (2.8)
Primary identity (Identity used for the survey)	
YPLHIV	166 (77.6)
Stakeholders*	48 (22.4)

[a] The total percentage is above 100 because some participants belonged to more than one group.

*The stakeholders category combines workers from different sectors involved in the HIV-response - the same as those listed under self-identification category.

Characteristics of YPLHIV

Table *3* summarises the participant socio-economic characteristics for YPLHIV, which provide a context for interpreting survey results and offers an approximate indication of the representativeness of the survey. In addition, this information describes the living conditions of survey participants, which can have mental health implications.

More than two-thirds of the participants who responded to the survey as YPLHIV were from the WHO Region of the Americas, and they were all from Latin America. Of these, a little over half were from Chile, but there was also representation from ten other countries in the region, see (**Appendix 2**). Fifteen per cent of the young respondents were from the European region, and a majority of these were from Eastern Europe. Respondents from the African region accounted for just over one-tenth of the participants. There was a minimal representation of South-East Asia and Western-Pacific regions and no representation for the Eastern-Mediterranean region.

Four-fifths of respondents resided in urban settlements. The age group 25-29 years made up the majority of respondents at nearly three fifths. Sixty-eight per cent out identified as male (including transgender men).

The sample population was highly educated, with over three quarters having a college degree or above. Despite the high levels of education in the sample, poverty was still a problem, with over thirty-seven per cent describing current overall poverty.

Table 3 Participant characteristics for YPLHIV

	Number (%) of 166 responses from YPLHIV	
WHO Region		
Africa	19 (11)	
Americas (Latin America)	112 (68)	
Europe	25 (15)	
South-East Asia and Western Pacific	10 (6.)	
	% of 166 responses from YPLHIV	**% of 112 Latin American responses**
Residence		
Urban/peri urban/ city	91	91
Age		
18-19	5	2
20-24	38	28
25-29	60	71
Gender		

Male (including transgender men)	68	74
female (including transgender women)	16	8
Non-binary	13	14
Other or prefer not to say	3	4
Education		
Primary school	1	1
High school	14	16
College, undergraduate or Stakeholders' qualification	76	74
Postgraduate degree	8	9
Other	1	0
Employment		
Still at school (not University)	2	0
At University	33	38
In full-time or part-time formal employment	39	37
In full-time or part-time informal employment	9	7
Self-employed	8	9
Retired or unable to work due to disability	1	0
Homemaker or full-time parent	2	1
Unemployed and seeking work	27	31

Table 4 shows health-related participant characteristics and explores to what extent participants were involved in the HIV response either on a voluntary or employment basis. Nearly 70% were not involved in the HIV response, rising to over 80% in Latin America. A majority of those that were involved were volunteers. Of those who were involved, three out of ten worked or volunteered with civil society organisations.

Over half of participants reported having lived with HIV for between one and five years, with just less than one fifth being newly diagnosed. Twenty-eight per cent of respondents reported having a clinically diagnosed mental disorder alongside HIV, while twenty-two per cent had at least one other physical illness alongside HIV. Sixty participants, i.e. thirty-six per cent, had at least one physical health condition and at least one diagnosed mental condition alongside HIV.

Table 4 Participants' characteristics continued

	% of 166 responses from YPLHIV	**% of 112 Latin American responses)**
Involvement in the HIV response		
Volunteer	19	9
Paid Employment	7	4
No involvement	69	85
Other	4	4
Type of organisations (% of 66 & 31 responses)		
Civil society organisations or NGO	33	66
Research institution	2	10
Private health organisation	6	10
Policy-making organisation incl. Government institutions	5	14

Other	10	
Number of years living with HIV		
Less than 1 year	19	22
Between 1-5 years	56	62
Between 5-10 years	14	14
Over 10 years	11	2
Mode of HIV transmission		
Sex	80	95
Vertically/Mother to Child	14	2
Other, prefer not to say or 'don't know.'	6	4
On ART		
Not on ART	4	4
Comorbidities -physical and mental (can be more than one)		
Physical disorders	22	14
Clinically diagnosed mental disorder	28	33
None of the above	68	70
Current overall poverty (my household earns enough to keep us out of overall poverty):		
Disagree	35	38
Neither agree nor disagree	14	1
Agree	49	50
Long-term poverty (How often have you lived in poverty in the past):		
Never or rarely	30	34
Occasionally	31	30
Often or most of the time	36	35
Don't know	3	5

Stakeholder characteristics

Most respondents worked with YPLHIV between the ages of 20-24 years. Forty-four per cent had between one and five years of experience working with YPLHIV.

Table 5 displays the characteristics of Stakeholder participants. Contrary to young respondents, a majority of Stakeholders, three out of ten were from the African regions, while only sixteen per cent represented Latin America.

Health workers made up nearly two-fifths of the sample, while advocates accounted for one-fifth of the Stakeholder respondents. Researchers represented thirteen per cent. Of the stakeholders who were health workers, nearly three out of ten were community workers.

Most respondents worked with YPLHIV between the ages of 20-24 years. Forty-four per cent had between one and five years of experience working with YPLHIV.

Table 5 Participant characteristics for stakeholders

	% Of 48 responses
Region(s) which responses represent	
Africa	33
Americas (Latin America)	17
Europe	2
South-East Asia	6
Eastern Mediterranean	8
Western Pacific	2
Profession	
Researcher	13
Educator/trainer	11
Policy/administration	2
Student	4
Advocacy/activist	22
Other professions	9
Health worker	39
Type of organisation	
Academic (University, research institution, etc.)	17
Charitable Foundation	4
Faith-based organisation	4
Government	8
Grassroots community-based organisation	17
Hospital/clinic	17
NGO	48
PLHIV group/network	25
Private sector (other than a pharmaceutical company)	4
Other	4
Age group of YPLHIV that stakeholders work with (can be more than one)	
All regions	6
10-14	3
15-19	54
20-24	81
25-29	52
Number of years of experience working with YPLHIV	
Less than 1 year	14
Between 1-5 years	44
Between 6-10 years	26
Over 10 years	16

* Here, health worker is used as to denote all the participants who were involved in delivering treatment services.

*Social workers, pharmacist, mental health advocate, HIV adviser or testing, counselling provider.

Towards a bespoke definition of mental health for YPLHIV

Perceptions of existing mental health definitions

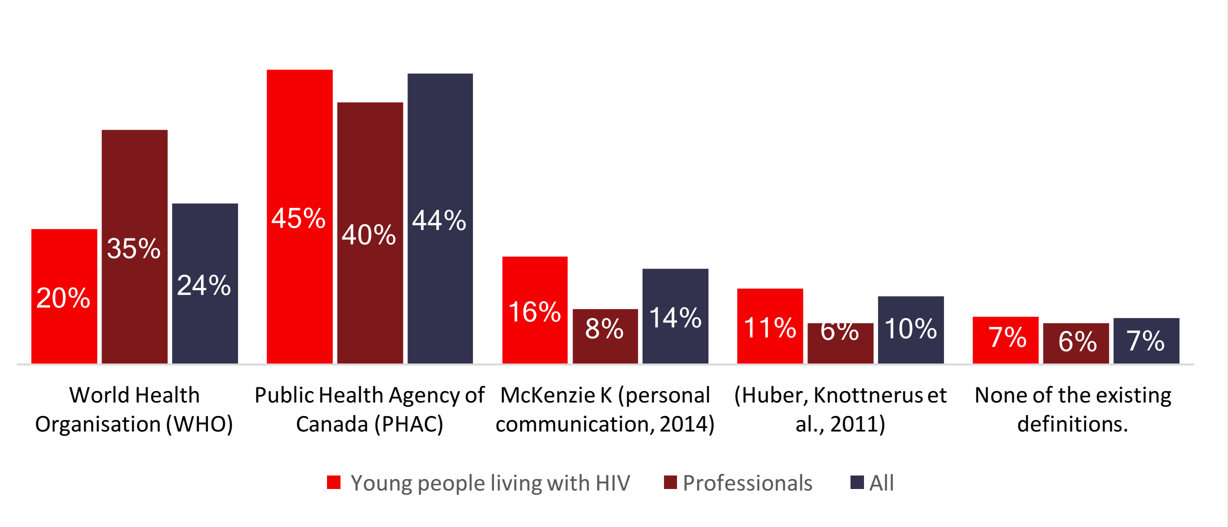
All participants were presented with four definitions of mental health and asked to select which one they found most compatible with the needs of YPLHIV. The four definitions were the same definitions presented to mental health practitioners in a survey that aimed to develop a consensus definition of *mental health* (13) – see **Table 6**. The proportion of respondents who preferred each of the definitions as well as the general descriptors used to describe them are also presented.

Table 6. The proportion of participants who preferred a given definition of mental health and overall descriptors assigned by participants.

Definition	Description	% of 214 participants who preferred the definition	Overall descriptors assigned by participants
Public Health Agency of Canada (PHAC)	Mental health is the capacity of each and all of us to feel, think, and act in ways that enhance our ability to enjoy life and deal with the challenges we face. It is a positive sense of emotional and spiritual wellbeing that respects the importance of culture, equity, social justice, interconnections, and personal dignity.	56.3	most holistic, specific, comprehensive, and inclusive
World Health Organisation (WHO)	Mental health is defined as a state of wellbeing in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community.	18.7	Generic, neutral, and broad (both in a positive and negative sense),
McKenzie K (personal communication, 2014)	A mentally healthy community offers people the ability to thrive. It is one in which people feel a sense of connectedness and there are also networks which link people from all walks of life to each other. There is a strong community identity but despite this the community is welcoming of diversity. People participate in their community, organise to combat common threats and offer support and aid for those in need.	19.5	Community-oriented with some mixed views. A few participants did not associate community-orientation with mental health.
(33)	Mental health is the "ability to adapt and self-manage".	16.1	Brief (perhaps too brief), and straight forward

Figure 1 shows that more stakeholders than young people appeared to prefer the WHO definition and slightly more young people than stakeholders appeared to prefer the definition by the PHAC. Compared with health workers, more young people preferred the short definition by Huber K. et al. (33).

Figure 1 The percentage of respondents who preferred different definitions of mental health by respondent group



One hundred and twenty-one of 214 participants shared the rationale underlying their preference. Eleven themes emerged from these data depicting participants' perceptions regarding key concepts within the four definitions. Figure 2 shows the identified themes of concepts and corresponding proportions of participants who expressed positive and or negative views.

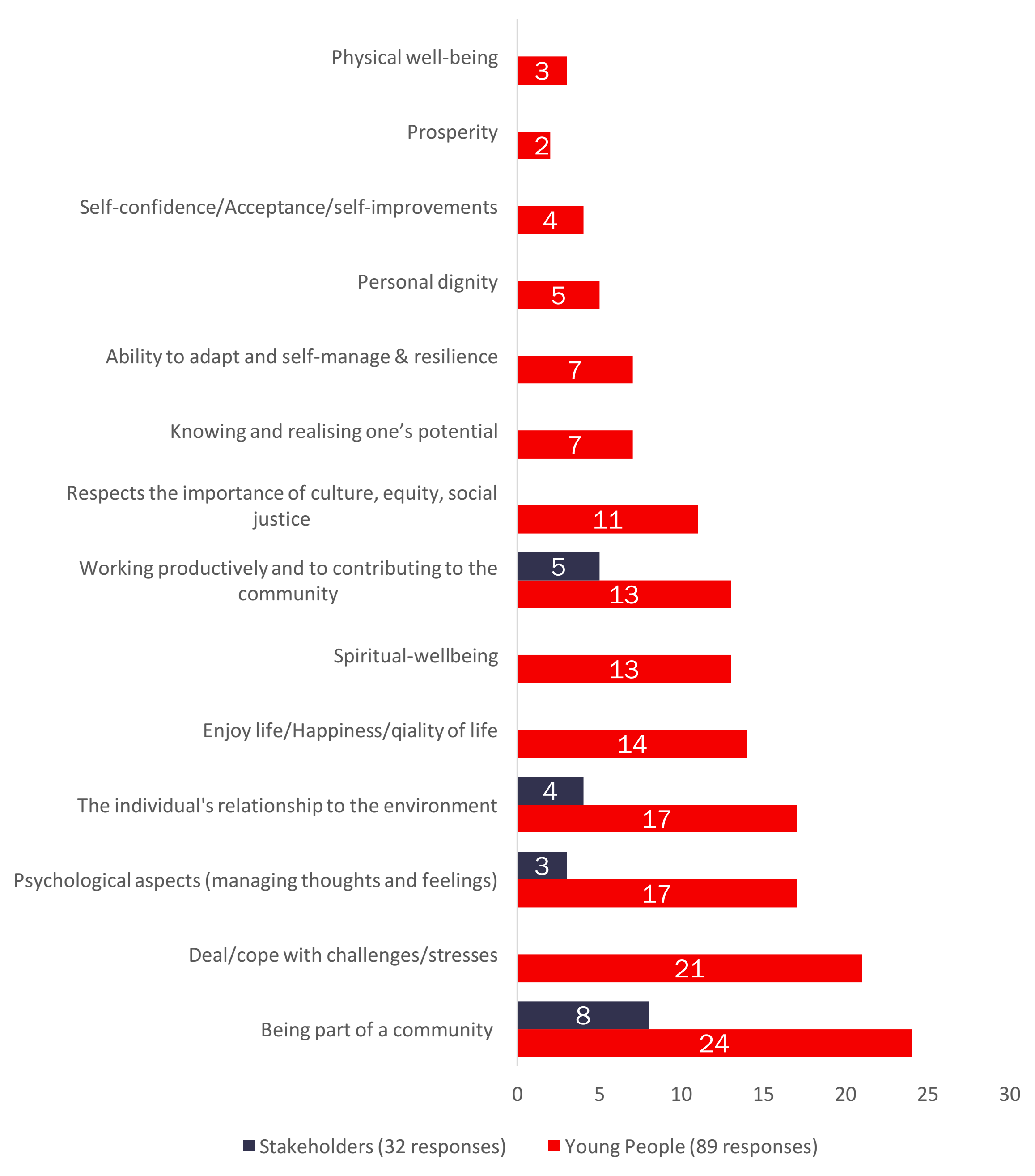
Many participants who preferred the **Public Health Agency of Canada (PHAC) definition** found it to be the most holistic, comprehensive, exhaustive, and specific of the four definitions.

Like the PHAC definition, many attributed their preference of the **WHO definition** to its comprehensiveness, and they assigned it the following descriptors: broad, exhaustive, generic, and neutral. However, a few respondents felt that the definition was too broad and thus more akin to a description of general rather than mental health.

The few respondents that preferred the **definition by McKenzie K** believed that belonging to a community is an important aspect of positive mental health for YPLHIV.

The few that preferred the **definition by Huber, Knottnerus (33)** valued its simplicity, but the definition was also criticised by those who considered mental health a much more complex phenomenon.

Figure 2 Participants' *opinions regarding concepts in existing mental health definitions*



Proportions are based on 121 respondents who expressed views about existing definitions.

Being part of a community

Participants held positive perceptions about most concepts included in existing mental health definitions. Only four concepts received mixed views, including ‘belonging to a community’, which was positively viewed in 24 responses and criticised in 8 responses.

The McKenzie definition has the strongest expression of the pertinence of community identity for mental health, and all the participants that preferred the McKenzie definition felt that belonging to a community constitutes an important aspect of mental health for YPLHIV.

> *“McKenzie K emphasises community and working together. In my opinion, I think that everyone can know what they are good at and what makes them happy, but if one fails to connect with the community around him/her, it may cause loneliness and depression, thus poor mental health.”* **Y+ African region**

The WHO and PHAC definitions also have aspects that emphasise community, but the PHAC definition used the term interconnections instead of ‘community’, and it received the fewest negative comments regarding referencing community/interconnections of the three definitions. Negative comments were mostly on the basis that mental health is not only about belonging to a community. This appeared to indicate the fact that although most YPLHIV were part of communities, they still experienced poor mental health due to stigma-induced secrecy and loneliness. The difference in opinion between those who endorsed the community emphasis and those who did not, appeared to be that the former perceived the definitions as idealistic positions while the later solicited more realistic definitions. The aspect of community was problematised as it did not reflect their lived reality.

Dealing or coping with challenges and stresses

Twenty-one of the 121 responses regarded the capacity to ‘deal with the challenges we face’ (PHAC) or ability to ‘cope with the normal stresses of life’ (WHO) as core components of mental health.

> *“It addresses the term of ‘challenge’, and among the options I consider this to be the most comprehensive.”* **Y+ Americas**

> *“It [the WHO definition] is quite straight forward and [I] appreciate the use of the word cope. The word cope for me defines what one may ask themselves if they are mentally unstable; 'am’ I coping?”*
> **Y+ Europe**

Psychological aspects (managing thoughts and feelings)

Seventeen responses agreed with the PHAC definition's inclusion of '*physical, emotional and psychological wellbeing'* in the definition. It was due to these components that participants thought it was the most explicit and specific of the definitions.

> *"It speaks on both emotional, physical and psychological and spiritual experience (…)"* **YPLHIV, Africa**

However physical wellbeing was not as salient in participants' responses (only addressed in three responses) as emotional and psychological wellbeing, whereas spiritual wellbeing (addressed in 11 responses) was considered important alongside emotional and psychological wellbeing by many respondents from Latin America and Africa.

> *"Exhaustively inclusive and explicit about mental health-related issues " capacity of each of us to feel, think and act in ways that enhance our ability to enjoy life……." Brings in critical elements of positive sense and spirituality issues."* **Stakeholder, Africa**

> *"Because it considers emotional and spiritual wellbeing"* **YPLHIV, America**

The individual and their relationship to the environment

Seventeen responses valued the PHAC definition for having a good balance between emphasis on the individual and their environment.

> *"I like that it does encompass not only the individual person and their wellbeing but also their environment and how it contributes to their emotional wellbeing."* **Y+ Americas**

The definition does not explicitly mention environment which could lead one to believe that environment was an interpretation of concepts such as *'respect for the importance of culture, equity and social justice'* as well as its reference to the importance of '*interpersonal connections*'.

> *"I like it because it is broader and intrinsic in nature; focusing on the individual and how they are connected to the others. The others [definitions] are good, but I feel they don't capture the full picture."* **Stakeholders, Africa**

Enjoying life, happiness, or quality of life

The concept 'enjoying life' was another contested topic. Fourteen respondents appreciated this concept in the PHAC definition, but four respondents indicated that enjoying life is neither a determinant of positive mental health nor a guaranteed consequence of it.

> *"While I disagree with others because the second definition talked about enjoying life, you can still enjoy life even if your mental health is weak because even* mad people *feel like they enjoy their condition."* **Y+ Africa**

> *"It* [the definition] *is very positive when it is not always like that in reality. It is not merely a state of happiness."* **Y+ Africa**

Working productively and contributing to the community

Thirteen respondents had positive views of the WHO definition's emphasis on the ability of individuals to work productively and contribute to the community.

> *"I liked wellbeing and also contributing to society. Other definitions look like somewhat selfish."* **YPLHIV, South-East Asia**

> *"It's more empowering and does not underestimate someone's abilities to do other things in life."* **Stakeholder, Africa**

However, five expressed mixed to negative views regarding the emphasis on productivity. Some felt that although productivity might contribute to good mental health, inability to realise one's potential or contribute to society does not equate to poor mental health. It was also highlighted that young people require support to realise their potential.

> *"Some are not able to work productively / fruitfully but may / not have mental health problems."* **YPLHIV, Europe**

> *"Not all individuals realise their potentials by themselves."*
> **Stakeholder, Africa**

In particular, participants from Eastern Europe and Latin America showed dissatisfaction over the emphasis on individual productivity because they linked this ideal to capitalism.

> *"The definition is too focused on individual productivity and does not consider the nature of connectedness and community."*
> **YPLHIV, Europe**

> *"I don't like that of the WHO because I find it with a very capitalist vision, where it focuses on the person as a producer. I like that of the Canadian public health agency because it focuses more on the person, their quality of life and their environment."* **YPLHIV, Americas**

A general critic of existing mental health definitions

A participant in one of the pilot rounds pointed out that existing definitions assume that a state of perfect mental health is an achievable goal. According to this participant, mental health is the ability to cope with psychological and emotional challenges throughout one's life. This understanding of mental health could be related to notions of resilience and the ability to adapt to changing circumstances both psychologically and emotionally.

> *"To me, mental health is not an 'endpoint' but rather varies widely throughout one's life and as such is rather just a 'measure' of how well they are able to psychologically and emotionally respond to life's challenges. Also, someone may be able to 'contribute to society' one day but then face a life stressor that makes them unable to deal with the problems that may face them. People's mental health can be worse than others, but to me, there is no 'goal' in which someone has perfect mental health, as there are always improvements that can be made."* **YPLHIV, Europe**

This overall critic appeared to underlie some of the views against considering individual components as predictive of mental health. This is because mental health is predicated on many domains of life: physical health, social support, romantic relationships, career, etc. Challenges in just one of these domains can have a disruptive effect on an individual's mental health, if they lack positive coping skills.

Bespoke mental health definitions suggested by participants

Participant preferences in relation to existing mental health definitions were insightful, but so were the bespoke definitions that were suggested by participants who wished to add to the existing definitions or found none of the existing definitions satisfactory.

Fifty-five bespoke definitions or understandings of what mental health means were provided. The suggestions varied greatly with some attempts at suggesting comprehensive definitions as well as suggestions of core concepts not included in the existing definitions.

Most attempts to provide generic and comprehensive definitions were by stakeholders from Latin America. Most of these definitions perceived mental health as involving a state of equilibrium among the biopsychosocial domains of wellbeing. This shows that these participants considered mental health as integral to overall or holistic wellbeing, which relates back to the notion of mental health being predicated on several domains of life.

> *"Mental health is being well in all aspects of life."* **Stakeholders, Americas**

> *"As a state of wellbeing influenced by the environment and lived experience, where biopsychosocial factors are important in both positive and negative development."* **Stakeholders, Americas**

> *"State in which biopsychosocial factors coexist in a balanced and harmonious way allowing the individual to maintain sustained wellbeing."* **Stakeholders, Americas**

A few emphasised the importance of one domain of wellbeing. For example, some gave importance to social and environmental factors while others focused on psychological wellbeing as the pillar of mental health with influences from the environment.

> *"Mental health is the state of how our psychological wellbeing is, impacting our emotions, behaviour, thoughts and our corporality, of how we perceive our being, our interactions and the world. It is related to external factors and stressors, but also to how well we feel about ourselves and our interpretations of what happens to us (this definition could be improved, but perhaps complements some aspects of the previous ones)."* **Stakeholders, Americas**

The majority of the suggested definitions were fragmented opinions about vital components of mental health by mostly young participants. These were categorised under three major themes: mental states/dispositions or abilities that characterise mental health, outlook on life and the world, and interactions with others and the environment. Most of the responses were provided by respondents from the Americas and Europe, which might indicate higher levels of mental health literacy. The themes and categories identified are presented in Table 7, which also displays illustrative quotes.

Table 7 Thematic categorisation of bespoke mental health definitions

Mental states and dispositions	
Living in the present moment	- *"As the state of living in the present, in the best possible way.* YPLHIV, Europe
Self-love and self-confidence	- *"Feeling good about who you are, believing that you can achieve and assert yourself as if you were the best human being."* YPLHIV, Americas - *"Mental health talks about personal feelings and self-confidence.*" PLHIV, Africa region
Inner peace or mental clarity through challenges and adversity.	- *"Mental health for me is the* ***adequate emotional state*** *that allows us to be well with oneself, in this way reaching an inner peace that allows us to deal with the problems and tests that life presents us with."* Y + Americas
Self-knowledge/awareness leading to the ability to recognise mental health challenges and seek help when needed	- *"I understand mental health as a mental state as the ability to recognise what affects our mental and mental potential and to convert that recognition into an effective therapy for healing our discomfort."* YPLHIV, Americas - *"Self-awareness: e.g., awareness of one's abilities and virtues."* YPLHIV, Americas
Ability to understand and accept why things happen	- *"Like the power to build a psychic mechanism that will counteract the bad penalties and actions that can be had in daily living, a mechanism that brings peace and harmony by understanding and accepting the why of things."* YPLHIV, Americas
General outlook on life	
Loving life and having goals and aspirations	- *"Mental health is an interest in life, aspiration, success and the goal at which we are aimed."* YPLHIV, Europe - *"Ability to resist stresses, love for life, mutual help."* Stakeholder, Europe

	• *“(…) to be able to realise themselves as a person, to study, to work, to feel that they really live and not only subsists with their context of everything that happened to them or for what has passed.”* YPLHIV, Americas • *“It is a type of health focused on people’s emotions, dreams, problems and self-knowledge*.” Y+ Americas
Interconnection with others and the environment	
Finding a meaning in life, being needed	• *“I would say, to be able to live together healthily, in such a way so that we can find meaning in life and be happy trying to achieve that goal.”* Y +, Americas • *“In my opinion, this is the ability to express oneself, earn money and be necessary.”* YPLHIV, Europe
Peaceful coexistence	• *“To be a part of the society and develop inside of it without harming oneself and people around.”* YPLHIV, Europe • *“A work in progress that lives making peace with itself and its environment (friends, family, community, etc.).”* YPLHIV, Americas
Community spirit	• “As the state of living in the present, in the best possible way, with community help to heal childhood wounds.” YPLHIV, Americas • *“Mental health is the social conditions that make all members of a community feel calm, listen, support and protect each other, where they face adversity in community.”* Y+ Americas

Summary of findings and implications

The analysis above illustrates that mental health is a complex phenomenon that means different things to different people and most likely, also at different times.

Participants found different components in the existing definitions useful, although some components were more preferred than others. These included being part of a community, ability to cope/deal with daily and situational challenges and stressors, and psychological factors, to mention just a few. Although most components were regarded positively, three also received negative comments. For two of the components, objections regarded their being value-laden and not always predictive of mental health. For instance, belonging to a community was thought to be important for mental health, but a few participants highlighted that one could be part of a community and still suffer from loneliness and depression. Critics considered belonging to a community as a factor that could enhance mental health in a conducive environment (e.g., an environment without stigma). It would appear from participants comments that access to social support is a more appropriate attribute of mental health than community. The negative comment also revealed geographical differences in perceptions. For example, it might not be a coincidence that young people from Latin America and Eastern Europe associated the WHO definition's reference to individual productivity and contribution to communist ideology.

All components from the included definitions were incorporated in a contextualised definition of mental health suitable for guiding mental health programs for YPLHIV globally. Component receiving negative comments were rephrased in ways that addressed participants' objections. In cases where two or more definitions addressed similar components, the phrasing from the most preferable definition was used. Our integration of components in existing definitions as described above produced the following definition, which also draws on insights from bespoke definitions suggested by participants.

> Mental health/wellbeing entails a state of harmony between one's inner and external self that is based on a sense of physical, social, emotional, and spiritual adaptation. It is the capacity to feel, think, and act in ways that enhance wellbeing while respecting the importance of culture, equity, social justice, interpersonal connections, and personal dignity. Mental health is variable; it exists on a continuum between extreme wellbeing and severe mental ill health, and an individual's mental health can vary and fluctuate along the continuum. Maintaining mental health across the lifespan relies on one's ability to cope with challenges and life's stressors, adapt to new situations, and self-manage. Mental health empowers us to thrive and flourish.

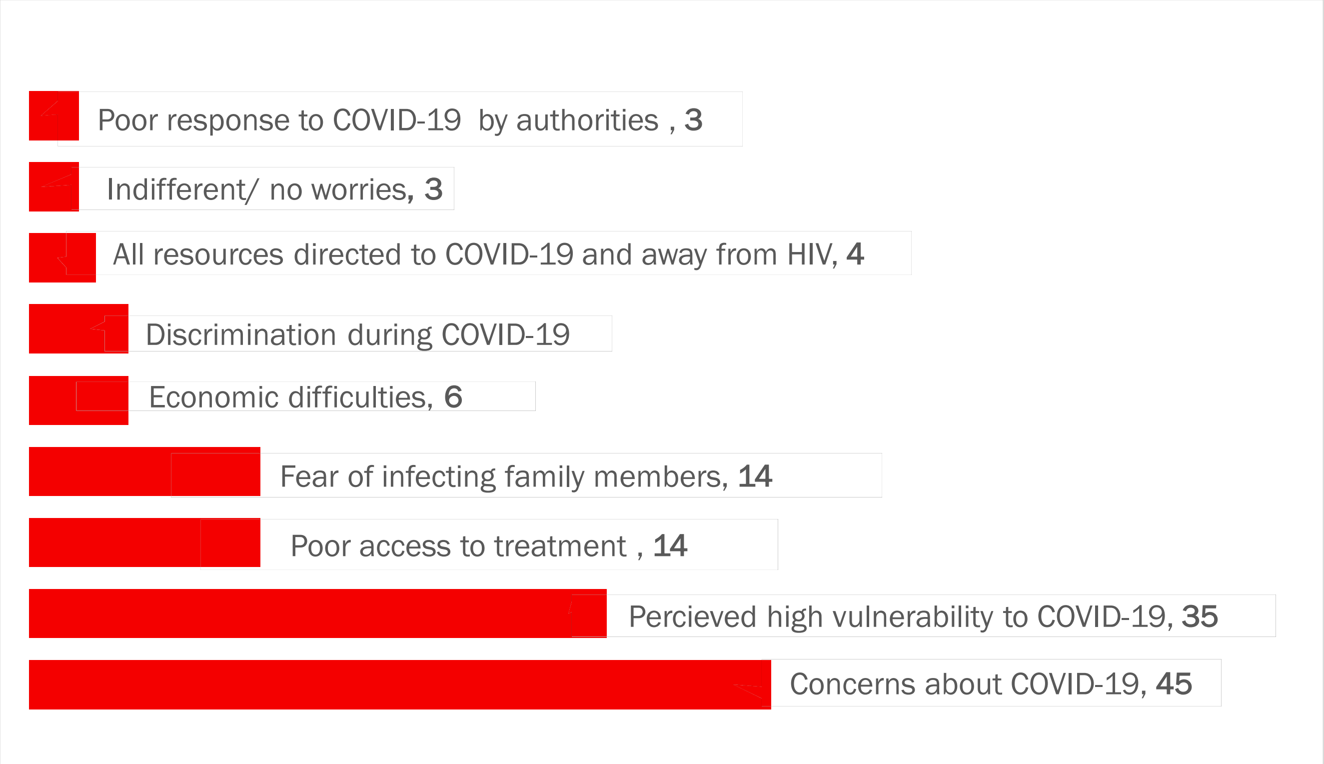
The definition is clear on what mental health is; the capacity for emotions, thoughts and actions that enhance inner wellbeing. Actions are further elaborated as the ability to deal with challenges and normal stresses of life and the ability to adapt and self-manage. The definition is also clear on the outcomes of mental health, namely, empowerment to thrive, which encompasses the ability to work productively and contribute to society and the ability to realise one's potential. The term *adapt* is used to suggest the understanding that mental health is not a static variable. It changes after biopsychosocial as well as socioeconomic conditions, which means that core to mental health is the ability to adapt to, i.e., resilience. Clarity on core attributes, contributing factors and outcomes were aspects we found lacking in existing definitions, and hence the attempt to clarify the roles of the components. It was also imperative to add a statement on the variable nature of mental health, which was a relevant point raised by one participant, the core of which resonated in the responses overall.

Like existing definitions, the generated definition is abstract like the ones suggested by stakeholders. In contrast, young people associated mental health with attributes such as a persons' self-image/self-confidence, general outlook on life and ability to manage emotions **Table 7**. These perspectives are represented in the bespoke definition by the reference to harmony between the inner and external self and self-management.

YPLHIV, mental health, and COVID-19

Around two-thirds of young participants (64%) agreed with the statement: *'I feel anxious about COVID-19 due to my HIV status*'. The results presented below are from an analysis of 109 in-text responses in which young participants explained their fears regarding COVID-19. **Figure 3** provides a summary of the themes emerging from the responses, and the number of responses that featured in each theme. Major themes are subsequently described narratively.

Figure 3. The ranking of reasons why YPLHIV are anxious about COVID-19



Based on 109 responses

Perceived high vulnerability to COVID-19

Thirty-five of the responses involved concerns that PLHIV have an increased risk of contracting COVID-19 and/or dying from it. Some had heard about the likelihood of an increased risk from undisclosed sources, and a few mentioned that COVID-19 was killing many PLHIV. For many of these responses, the worries were based on the participant's understanding of the link between a compromised immune system and a high risk of contracting COVID-19. The underlying fear was that since HIV weakens the immune system, they were susceptible to COVID-19. Those with other health conditions with a documented increased risk of contracting COVID-19 were concerned about the layering of risks.

> *"I feel that if the Covid-19 grabs me, I will not be able to overcome it, and I will easily die since HIV is supposed to attack my defences. One week ago, I had a crisis, and I thought I was getting sick from COVID-19, I was resigning myself to death, but luckily, I think it was only dengue with a cold."* **Y+ Americas**

A perceived '*lack of information* on the level of additional risk for PLHIV of contracting COVID-19 and having severe symptoms requiring hospitalisation was reported by two participants, which also relates to this theme.

Concerns about the body's reaction to COVID-19 based on treatment and adherence status

Forty-five of the respondents expressed a concern about how their bodies would react to COVID-19 based on their treatment or adherence status. A few of these participants found assurance in the fact that they were virally suppressed and not at an increased risk of contracting COVID-19. However, many were worried either because they were newly initiated on treatment and had a high viral load or because they did not know their viral load and were concerned about the state of their immune system. Those on treatment with suboptimal adherence and no recent viral load test feared the possibility that their immune systems were compromised.

> *"I hadn't been taking my meds properly (not taking at the same time each day) for a few months in the past year, so I have been worried that my HIV has become resistant to my medication and that I am detectable again which could make me more vulnerable to COVID-19. I have had to wait until the clinic is a bit safer to go to as well to get my blood checked."* **YPLHIV, Europe**

Concerns and uncertainties were also related to the fear of getting sick from yet another virus, which most respondents associated with the possibility of further compromising the immune system. In addition, most participants feared the worst if they contracted COVID-19 due to a generalised idea of an already weakened immune system due to HIV.

> *"Getting sick and falling into critical condition."* **YPLHIV, Americas**

Poor access to treatment

Participants were worried about accessing treatment because honouring refill appointments involved a risk of exposure to COVID-19. Some participants were also worried about the poor supply of medicines during the lockdown.

> *"In some way, being aware of medical appointments and having the medication on time, generates some anxiety due to contact with other people."* **YPLHIV, Americas**

> *"It makes me anxious to think that the stock of medications can run out, and they cannot guarantee treatment."* **YPLHIV, Americas**

Poor access to treatment also influenced concerns about the body's reaction to COVID-19, especially for Latin American respondents who reported poor access to CD4 count testing even before COVID-19.

Other fears were reported as showed in Figure 3, but the above were the most common fears. Most of the other themes were related to these three. For example, the fear of infecting family members was related to the fear of high vulnerability whereby some participants felt that they were the weak link in terms of spreading COVID-19 to family members. Economic difficulties were feared due to the lockdown and the need for shielding. For example, a few participants shared that they feared losing their jobs due to shielding. It is noteworthy that six participants in Latin America feared being denied COVID-19 treatment due to the rationing of COVID-19 treatment. Three participants who were indifferent about the situation shared the attitude that HIV was the worst that could happen to them, and that anything could end their existence, let alone COVID-19.

Summary of findings and implications

A few respondents with well managed HIV found assurance in the fact that they were virally suppressed and not at an increased risk of contracting COVID-19. Conversely, a few participants who were newly initiated on ART or with poorly managed HIV were concerned about their bodies' ability to cope with COVID-19. These respondents considered COVID-19 a threat to their already compromised immune systems. However, most respondents believed that HIV was a risk factor for contracting COVID-19 irrespective of their treatment status. COVID-19-related restrictions and the fear of contracting COVID was a barrier to accessing HIV treatment. The lack of trusted information about the vulnerability of PLHIV to contracting and dying from COVID-19 was a major contributor to these fears.

Mental health challenges and manifestations of poor mental health

Daily stressors and other stressful and potentially traumatic experiences

We presented young participants with a long list of statements describing typical stressful and traumatic events that can happen to anyone and asked them to indicate to what extent they had experienced what was described in each statement within 12 months before taking part in the survey. **Table 8** shows the disaggregated results, while **Figure 4** below presents the aggregated results.

The percentage of those who found the situations described in the statements as being ‘very stressful, stressful and somewhat stressful’ exceeded that of participants who found the experiences ‘*very unstressful*’, ‘*unstressful*” and ‘*somewhat unstressful*’. HIV-related stigma, accident or injury of loved ones, problems with parents and close relatives, problems at school or work and financial difficulties, were the stressors that were found very stressful, stressful or somewhat stressful by most participants.

Figure 4 Percentage of young participants (N=162) who experienced the described stressful 12 months before the survey and the extent to which they found them stressful or unstressful.

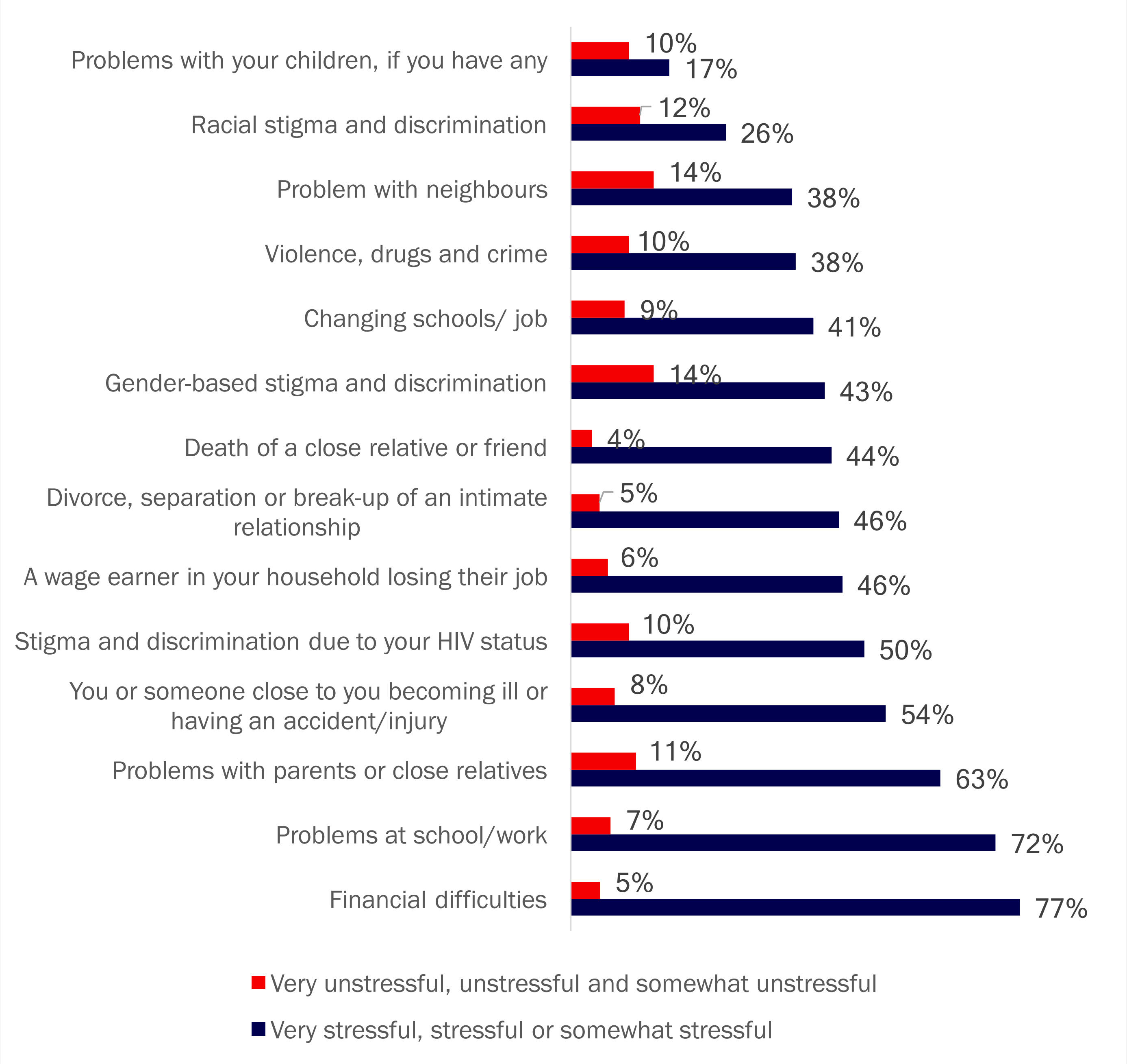


Table 8 The percentage of participants reporting on whether they have experienced stated potentially stressful or traumatic and ow stressful they had found the were

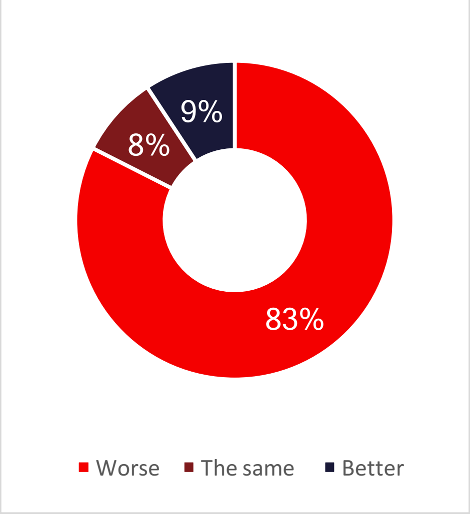
	% of young respondents (N =162 per statement)						
	Very stressful	Stressful	Somewhat stressful	Somewhat unstressful	Unstressful	Very Unstressful	Not experienced in the past 12 months
Death of a close relative or friend	21.6	10.5	12.3	1.2	1.2	0	53.1
Problems at school/work	35.3	17.3	19.8	3.7	3.1	0	21
Changing schools/ job	16.7	8.6	16	3.7	4.9	0.6	49.4
A wage earner in your household losing their job	26.5	9.9	9.9	1.9	2.5	1.9	47.5
Divorce, separation or break-up of an intimate relationship	23.5	10.5	11.7	4.3	0.6	0	49.4
Problems with your children, if you have any	5.6	5.6	5.6	3.7	4.3	1.9	73.5
Problems with parents or close relatives	21	21	21	4.3	2.5	4.3	25.9
You or someone close to you becoming ill or having an accident/injury	20.4	17.9	15.4	3.1	2.5	1.9	28.9
Financial difficulties	45.7	16	14.8	3.1	0	1.9	18.5
Problem with neighbours	10.5	10.5	16.7	4.3	4.9	4.9	48.1
Violence, drugs and crime	14.8	13.6	9.9	1.9	6.8	1.2	51.9
Stigma and discrimination due to your HIV status	23.5	12.3	14.2	3.7	4.3	1.9	40.1
Racial stigma and discrimination	11	7.4	8	3.1	6.2	2.5	61.7
Gender-based stigma and discrimination	19.8	10.5	13	4.9	4.9	4.3	42.6

The mental health of YPLHIV vis-a-vis that of their HIV negative counterparts

While the previous sub-section explored everyday stressors and traumatic events that could affect anyone regardless of their HIV status, this sub-section looks at HIV-related stressors and traumas.

Participants were asked how the mental health of YPLHIV compared to that of their HIV-negative counters and given options to indicate whether they thought it was better, worse or the same. One hundred and forty-three participants elaborated their response. **Figure 2** shows the aggregate results, and the disaggregate results are in **Table** 9.

Figure 5 Participants (N=214) perceptions of the mental health of YPLHIV in comparison to that of their HIV-negative counterparts. Table 9 Participants (N=214) perceptions of the mental health of YPLHIV



	Young people (N=166)	Stakeholders s (N=48)	all (N=214)
A lot worse	31.9	18.8	29.0
Worse	30.7	37.5	32.2
A little worse	20.5	27.1	22.0
There is no difference	7.2	8.3	7.5
A little better	6.0	4.2	5.6
Better	2.4	0.0	1.9
A lot better	1.2	4.2	1.9

Nine per cent of the 214 participants felt that the mental health of YPLHIV was better off than that of their HIV negative counterparts. They referred to the fact that YPLHIV had a more realistic and mature perspective on life, and that they could appreciate every living moment.

> *"After going through the processes involved in being a carrier of HIV, you have a different vision in many aspects; you go through a process of maturing that HIV-negative people may not have."* **YPLHIV, Americas**

Eight per cent believed that the mental health of the two groups was the same. Participants with this belief shared the view that both YPLHIV and their HIV negative counterparts experienced shared humanity (all people are equal), and that both had similar desires and aspirations -to be productive members of the community/society. This view appeared to be contingent on the fact that HIV has transformed into a manageable illness. A case in point is the quote below, which explains the temporary state of shock after learning about one's HIV-positive status. The shock was thought to disappear at the realisation that HIV is manageable, and that one can lead a long and productive life and contribute to society regardless of their HIV diagnosis.

> *"The life of an HIV+ person is not much different. Except for the period when a person is shocked by the news of his/her status, but it is a temporary state."* **YPLHIV, Europe**

> *"Because the negative one wishes to contribute to his or her community and have a life which is just like us."* **YPLHIV, Africa**

The only challenge to this view was the need for lifelong medication which, for some, acted as a daily reminder that one is HIV-positive.

> *"The shock of being diagnosed and the daily reminder of the pills can become overwhelming."* **YPLHIV, Americas**

The breakdown of mental health that some participants experienced right after their diagnosis was likened to grief, and psychological terms such as post-traumatic disorder (PTSD) were used to describe it. Participants solicited better support and care during this phase. It was, among other things, characterised by failure to accept the diagnosis and refusal of treatment.

> *"I feel that there is a big emotional breakdown at the time of receiving the diagnosis, it's like grieving, there is a before and after and I feel that everything is focused on treatment and the doctors are somewhat cold to treat us when it is a new world, and one has many doubts and fears, and nobody clarifies anything. I feel a great lack of psychological support and mental health concern."* **YPLHIV, Americas**

A majority (85%) thought that the mental health of YPLHIV was worse off than that of their HIV negative counterparts. The themes that emerged from the accounts of participants with this perception are presented below.

Experiences of trauma

A relatively common response was that YPLHIV had experiences of trauma from their childhood, such as sexual/physical/psychological abuse, poverty, or the loss of parents. These experiences had negative emotional effects that lasted long into adolescence, youth and adulthood.

> *"Because generally, young people who are HIV+ live acute stress and/or depression, abuse and other situations in our childhood."* **YPLHIV, Americas**

> *"Every young person has a history and behaviour that started when they were and also as they grow, poverty, GBV* [Gender-based violence]*, broken homes, illness and the words said to them while growing up affect them mentally."* **Stakeholder, Africa**

Concerns regarding romantic and sexual relationships

Participants also described YPLHIV's struggle to fit into existing social roles because of the need to keep their HIV status confidential. For example, a young person living with HIV expressed concerns regarding romantic relationships and marriage in the context of HIV-status non-disclosure. The cultural pressure to get married in South-East Asian societies was a source of emotional distress for YPLHIV.

> *"If your HIV status is unknown to others, then society pressures you to get married. Even if you get an HIV-positive Life partner, there is the incapability to understand each other. Choosing a life partner is just adjustment, not love. Difficulty to get a divorce as in court, your status can be disclosed by your*

> *partner. Even counsellors suggest that you marry. Is getting married that necessary?"* ***YPLHIV, Southeast Asia***

In Africa, the association of HIV with poor sexual morality compromised young people's dating and marriage prospects. This reality weighed heavily on young people's emotional wellbeing.

> *"YPLHIV are stigmatised because in community's HIV is a stigmatised condition, and most as they grow older, they are labelled as promiscuous, which affect their dating and marriages."* **Stakeholder, Africa**

Participants from Europe also faced fears of finding partners.

> *"YPLHIV are more susceptible to stresses and depression as they are forced to face various fears of their own (such as rejecting themselves, fear of not finding a partner) and public prejudice."* ***YPLHIV, Europe***

The mental health burden of managing HIV

Adherence to medication was identified as a contributor to positive mental health, but for some, the idea of lifelong treatment adherence, especially the daily ritual of taking medication and regular clinic attendance, compromised positive mental health. It was also evident that for some, the clinical encounters were associated with trauma.

> *"When we think about HIV status, it is a nightmare. I feel lost. Sometimes, I am even afraid to think about the clinic."* **YPLHIV, Southeast Asia**

In addition, young people felt like they were a burden to their families, as illustrated by this quote.

> *"You realise that your body is affected by a virus that forever will be inside of you, and you will die without civilisation and necessary measures, and it's hard. Also, this burden falls on relatives and friends, and they think about you not in a positive way."* **YPLHIV, Europe**

It was also noted that some HIV treatment regimens had mental health related-side effects.

> *"Especially in our ART wherein Efavirenz cause psychological effect for some who are taking it."* **Y+ Southeast Asia**

Limited opportunities to realise their potential

YPLHIV were believed to be disadvantaged in many areas related to self-realisation. Accessing and completing education was a challenge due to orphan-hood, stigma, and HIV-related cognitive deficits. Some participants referred to HIV-related physical limitations that affected their ability to work. For those who could work, work-related discrimination was feared, and some who had jobs found it difficult to fit their work schedule around health service appointments.

> *"Difficult to cope with working hours, especially in the IT field."* **YPLHIV, Southeast Asia**

A few participants were emotionally affected by the knowledge that there are places/ countries they could not visit because of their HIV-positive status.

> *"Limited country to get visa approval, can't choose desire profession."*
> **YPLHIV, Europe**

Stigma experiences and the resulting emotional loneliness

According to participants, the main difference in mental health between YPLHIV compared to their HIV negative counterparts was that the former had to deal with HIV-related stigma. Some participants reported that they experienced multiple stigmas–for instance, some experienced stigma because of being orphans or for their non-binary gender or sexual orientation.

> *"Cause they fight with double stigma and discrimination both from health facilities and also self-stigma. This also comes back to the political environment that criminalises same-sex relationship creates more depression and anxiety."* **YPLHIV, Africa**

One respondent from Southeast Asia reported that those who contracted HIV horizontally (i.e. through sexual transmission or intravenous drug use) were stigmatised by those who contracted HIV vertically (i.e. through mother to child transmission).

> *Stigma by HIV-positive people who contracted HIV vertically through mother to child transmission towards HIV-positive people who newly infected through sex (…) means a person is guilty.* **Y+ Southeast Asia**

Stigma led many of the young people to conceal their HIV status, and they became socially isolated. Isolation resulted in emotional loneliness whereby they struggled to find people to confide in.

> *Because you worry about HIV and how others will react when they find out, it is like having a secret always.* **Y+ Europe**

> *The stigma coming from HIV negative people is just so bad. People make jokes and laugh, as well as bashing. And it's everyone. At work, at home, friends. So you just keep it a secret, and you don't tell anyone anything. Which, in turn, means you create negative scenarios in your brain. You just think my life is very miserable because of a b c d etc. And worst of all you don't have anyone to confide in. In my case, I don't know anyone with HIV. I have stopped being friends with many because of subconscious bashing. So I just feel alone (which is ironic because there are millions living with it).* **Y+ Africa**

We presented statements describing negative experiences that can result from stigma and asked participants to indicate whether they had experienced them first-hand and if not, whether they personally knew others who had. Results are presented in **Table 10** and **Figure 6** below.

Twenty-eight per cent had experienced verbal abuse and ridicule, while twenty per cent had experienced rejection from a spouse or a romantic partner due to their HIV-positive status. Sixteen per cent had been rejected by family members, and twelve per cent had experienced being denied employment.

Figure 6 Parentage young respondents (N=162) who experienced HIV-stigma related stressors first-hand

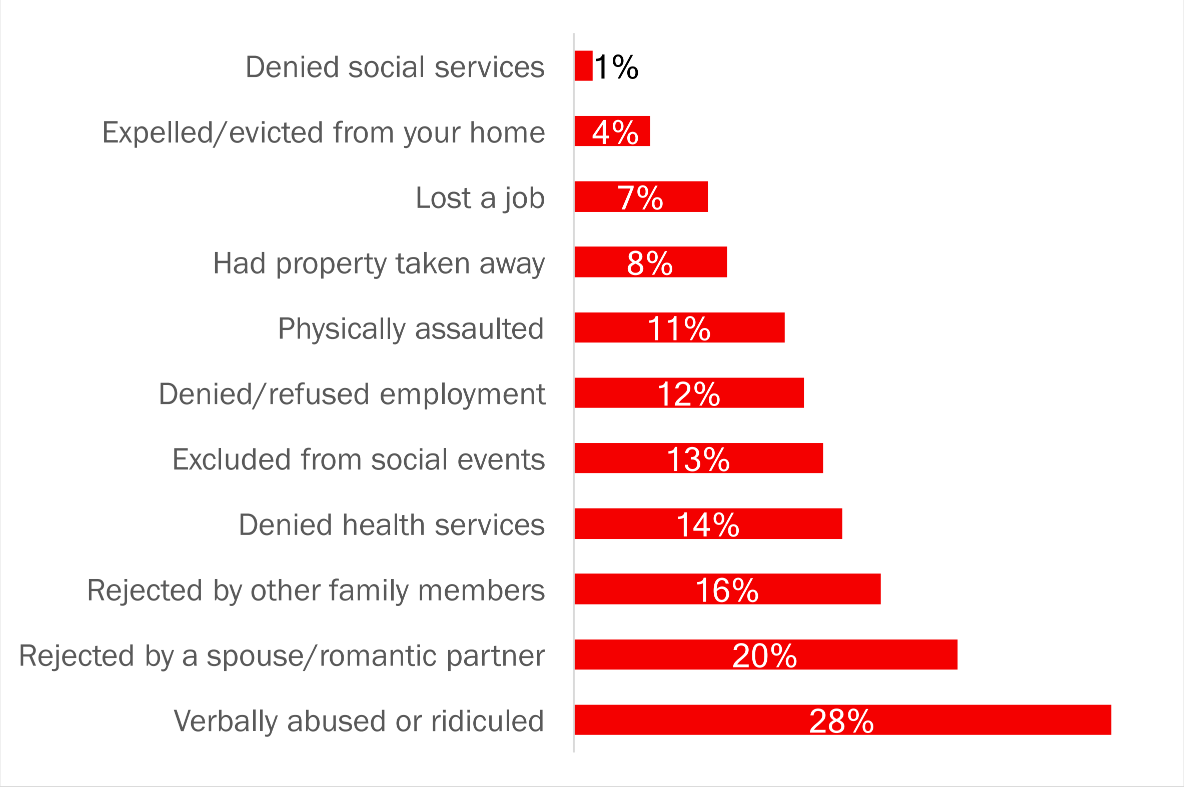


Table 10 Parentage who experienced HIV-stigma related stressors first-hand or knew someone close to them who had such experiences.

Have you experienced any of the following situations due to your HIV status?	Yes	No	I have not personally had such an experience, but someone close to me has
	% of young people (N =162 per statement)		
Excluded from social events	13	74	13.6
Rejected by a spouse/romantic partner	20	60	20
Rejected by other family members	16	67	17.4
Verbally abused or ridiculed	28	58	13.6
Physically assaulted	11	76	13.6
Denied/refused employment	12	73	14.8
Lost a job	6.8	78	15.4
Expelled/evicted from your home?	3.8	86	10
Had property taken away	7.5	85	8.1
Denied health services	14	76	10.5
Denied social services	11	78	10.5

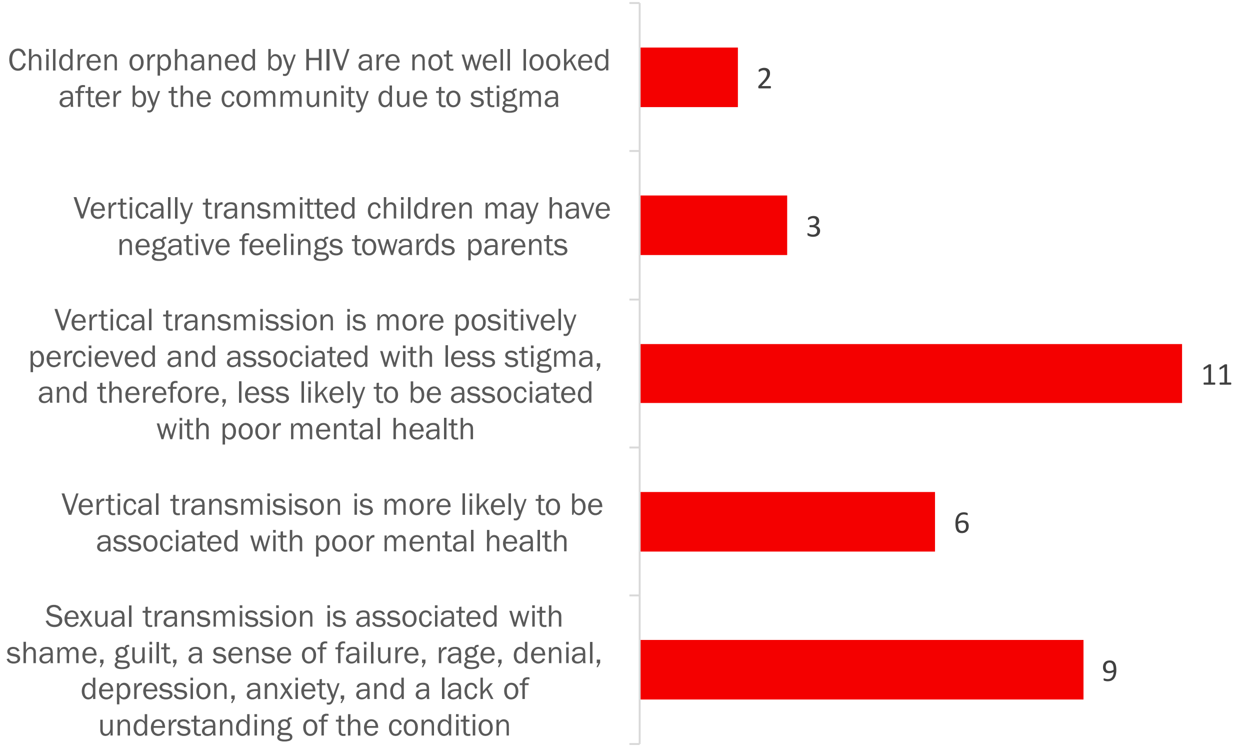
Summary and implications

In addition to other everyday stressors and traumatising events, such as problems at school or work, the mental health of YPLHIV who participated in the survey was influenced by traumatic experiences related to stigma and discrimination and managing HIV. Most respondents felt that the mental health of YPLHIV was worse than that of their HIV-negative counterparts due to HIV-related stigma and traumas. It was generally believed that mental health problems were pronounced in the period immediately following diagnosis, but the impact of HIV on mental health persisted long after diagnosis.

Perceived differences between mental health challenges faced by young people who acquired HIV vertically and horizontally.

We also asked stakeholders to express whether they experienced any differences in the mental health challenges experienced by young people who acquired HIV sexually and those that acquired it through mother to child transmission. Thirty-one responses were collected, and Figure 7 displays the results.

Figure 7 The number of stakeholder participants whose perception of differences in mental health challenges among young people who acquired HIV vertically (through mother to child transmission) and horizontally (sexually) fell into the identified themes.



Sexual transmission is associated with shame, guilt, a sense of failure but better acceptance of HIV status

Nine of the 24 responses touched on the assumption that young people who acquired HIV sexually were likely to feel guilt and shame over having contracted HIV. Participants felt that these feelings could predispose young people to mental health disorders such as depression and anxiety.

> *"I imagine that in the case of sexual acquisition, ideas of guilt, failure, rage could develop with oneself, which could mean predisposing factors for the development of problems of depression, anxiety, etc."* **YPLHIV, Americas**

However, those that contracted HIV sexually were believed to be more accepting of the diagnosis

> *"From the point of view of a paediatrician, young people with sexually acquired HIV vertically seem to have more anger - I assume it is because they have no part in contracting their HIV, whereas those with horizontal transmission are ultimately more accepting because the infection was as a result of their own actions. They also are older/more mature and more able to cope with their diagnosis and have more say in their treatment/care, which I think is more empowering/makes the overall experience more positive.*" **Stakeholder, Southeast Asia**

One participant noted that some would have gone through traumatising events such as rape, which could lead to mental health issues.

> *"The most traumatised are to those who had been raped."* **Stakeholder, Africa**

Mixed perceptions of vulnerability for young people who contracted HIV via mother to child transmission.

Those who contracted HIV vertically were perceived by stakeholders and YPLHIV to be less afflicted by feelings of judgement from society and self-blame. They were also believed to experience less stigma.

> *"Those who contracted HIV from mothers always accuse parents of irresponsibility."* **Stakeholder, Africa**

> *"Those who contracted HIV through mother to child transmission might be in a position where it's not their fault and family is usually supportive, so mental health issues might be minimal. Those that get it sexually are trying to hide the fact, or if it's known, they feel stigmatised."* **Stakeholder, Africa**

> *"Within Chilean society, HIV- people demean and are violent towards people living with HIV. This since the main, and the most associated, form of infection is through sex, making being HIV + more taboo. People tend to think that they contract because they are very promiscuous or careless. The victim is blamed much more than sympathized."* **YPLHIV, Americas**

> *"All this leads to social pressure felt by the person living with HIV. An example of this reality is the discomfort that we feel when having to reveal our diagnosis, or when listening to comments where HIV-positive people are blamed for their diagnosis. This discrimination reaffirms the stigma (…) and goes through our heads when we receive our diagnosis, and that continues*

> *to weigh us down when we constantly question our behaviours that imperatively are supposed to be healthier and more responsible."* **YPLHIV, Americas**

However, the young people who contracted HIV vertically were said to be as vulnerable to poor mental health if not more. Participants highlighted that some would be orphaned by HIV and likely to experience abuse by carers or guardians. It was also reported that non- or late disclosure of HIV status by parents or guardians was a mental health challenge.

> *"Those affected through mother to child are more vulnerable because they sometimes don't understand why they take medication. They suffer psychosis much than those affected sexually."* **Stakeholder, Africa**

> *"I myself had issues of refusing medical care because I did not accept my status since I didn't know that it was mother to child transmission and also both my parents passed away without knowing their status, so it was really hard for me to accept, so it took a number of sessions with health personnel for them to get me back to care. As of now am in good health."* **YPLHIV, Africa**

It was also noted that those who contracted HIV vertically were more vulnerable to poor mental health due to the length of dealing with HIV from birth through adolescence. Stakeholders mentioned that these young people experienced treatment fatigue due to difficulties understanding and accepting the diagnosis. Their burden of disclosure was different as disclosure implicated others.

> *"Those that contract vertically (are born with HIV) have had to have lifelong treatment and lifelong hospital appointments since birth and will need these for life. They may have treatment fatigue early on in life going through the challenges of adolescence with HIV/ absent family members who died / lack of support/structure? Personal feeling about how acquired diagnosis? Why me? Stigma fear of exposing mothers or other family members' status disclosure problems at school/college/uni relationships with other family member's possible resentment towards negative siblings."* **Stakeholder, Africa**

Differences in stigma experiences between young people who acquired HIV horizontally and those who acquired HIV vertically.

A comparison of the participants who reported experiencing different forms of stigma and discrimination on the basis of their HIV status showed that young people who acquired HIV vertically appeared more likely to report that they had experienced more forms of stigma and discrimination compared to those who acquired HIV horizontally. Only verbal '*abuse and ridicule*' and *'denial of services'* were experienced by equal proportions of young people from both groups. Those who acquired HIV horizontally were more likely to report experiencing losing their job, being expelled or evicted from their home, or being denied employment and social services. See **Figure 8** for an overview and details in

Table 11.

Figure 8 Percentage of young respondent who acquired HIV vertically (N=23) and horizontally (N=131) who experienced different forms of stigma and discrimination

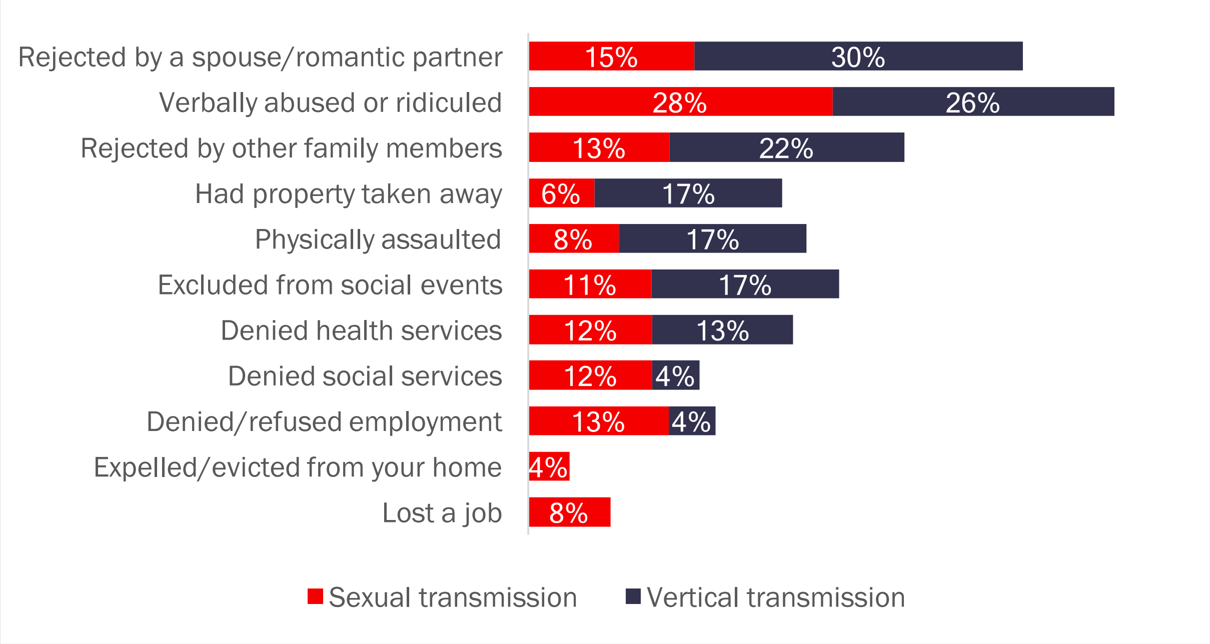


Table 11 Percentage of young respondent who acquired HIV vertically (N=23) and horizontally (N=131) who experienced different forms of stigma and discrimination

	Horizontal transmission			Vertical transmission		
Have you experienced any of the following?	Yes, I have personally experienced this	Not me but someone close to me	No, I have never experienced this	Yes, I have personally experienced this	Not me but someone close to me	No, I have never experienced this
	% of young people (N=131 per row)			% of young people (N=131 per row)		
Excluded from social events	11.4	11.5	77.1	17.4	26.1	56.5
Rejected by a spouse/romantic partner	15.4	17.7	66.4	30.4	30.4	30.4
Rejected by other family members	13.1	16.9	69.5	21.7	21.7	56.5
Verbally abused or ridiculed	28.2	13.7	58.0	26.1	17.4	56.5
Physically assaulted	8.4	14.5	77.1	17.4	8.7	73.9
Denied/refused employment	13	16.0	71.0	4.3	8.7	87.0
Lost a job	7.6	16.0	76.3	0.0	13.0	87.0
Expelled/evicted from your home?	3.8	11.5	84.0	0.0	0.0	95.7
Had property taken away	6.15	9.2	84.0	17.4	0.0	82.6
Denied health services	11.5	11.5	84.0	13.0	4.3	82.6
Denied social services	11.5	10.7	77.9	4.3	8.7	87.0

Confidence in the evidence behind advances in the HIV response

The HIV response has seen tremendous advances and living with HIV in 2020 looks very different from how it looked during the peak of the epidemic. Many of the advances are liberating and empowering for PLHIV. One of the significant advances pertains to the availability of effective treatment regimens which, when adhered to, also eliminate the risk of onward transmission of HIV.

We assessed participants' confidence in the evidence behind some of the major advances by asking them to rate their level of agreement with the following statements:

- I avoid sexual relations because I fear to transmit HIV sexually
- I know that a person on ART treatment who reaches and maintains an undetectable viral load cannot transmit HIV sexually (Undetectable=Untransmittable or U=U)
- I feel less anxious about passing on HIV sexually because I have enough confidence in the science behind U=U

Table 12 presents desegregated results, and **Figure 9** shows comparisons of the percentage of participants who agreed, i.e. strongly agree, agree or somewhat agree and those who disagreed (strongly disagreed, disagreed and somewhat disagreed) with the statements. The results show that only nine per cent were not aware of U=U, while one fifth did not have enough confidence in the evidence to feel liberated from the fear of transmitting HIV sexually. Not considering the proportion who were not aware of U=U means that at least twelve per cent were aware of the evidence but still anxious about transmitting HIV sexually. Forty-eight per cent feared transmitting HIV sexually to the extent that they avoided sexual relations.

Figure 9 The percentage of young participants (N=162) who agreed or disagreed with statements about their confidence in empowering advances in the HIV response

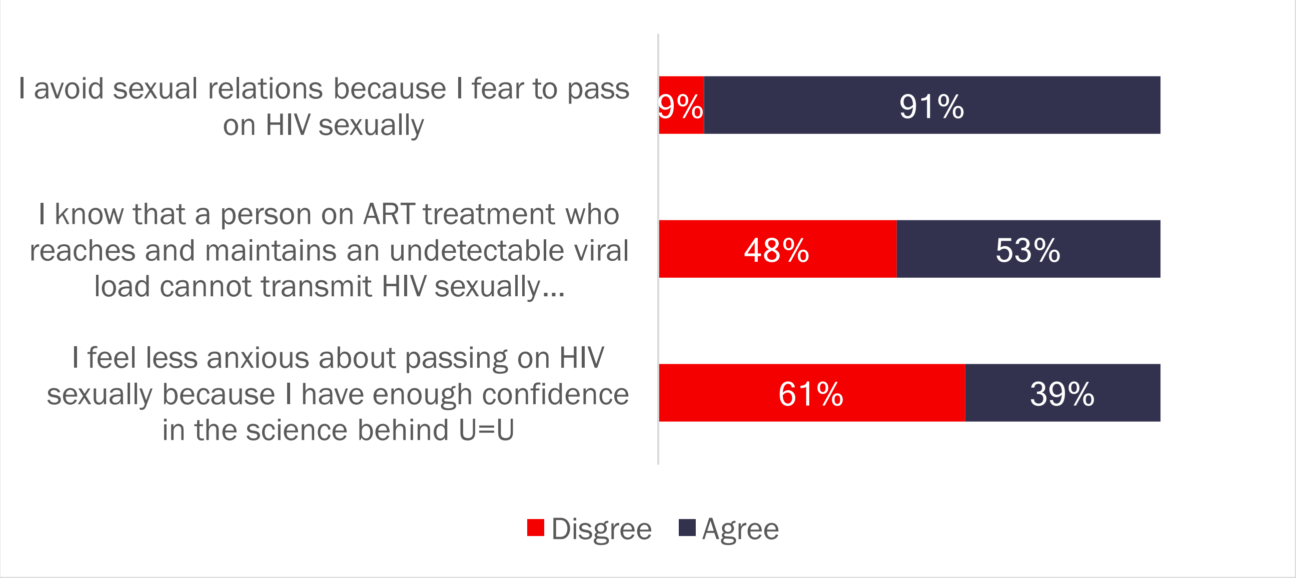


Table 12 The percentage of young participants (N=162) who expressed different levels of agreement and disagreement with statements assessing confidence in the evidence underlying critical innovations

Statements	Strongly disagree	Disagree	Somewhat disagree	Strongly agree	Agree	Somewhat agree	Total number of responses
I avoid sexual relations because I fear to pass on HIV sexually	24.1	14.8	8.6	20.4	15.4	16.7	162
I know that a person on ART treatment who reaches and maintains an undetectable viral load cannot transmit HIV sexually (Undetectable=Untransmittable or U=U)	4.9	0.6	3.7	59.9	19.8	11.1	162
I feel less anxious about passing on HIV sexually because I have enough confidence in the science behind U=U	4.2	4.9	11.7	40.1	25.3	13.6	162

Summary and implications

Stakeholders reported some slight differences in the nature of the traumatic experiences that young people who acquired HIV sexually and through mother to child transmission face. For example, the experience of stigma was believed to be different in that young people who contracted HIV vertically dealt with a milder form of stigma. Despite this, some stakeholders believed that vertical transmission was associated with a higher likelihood of mental health problems due to the length of time that these young people had to cope with an HIV diagnosis. Their childhood was also likely to be associated with trauma, including the likelihood of being orphaned by HIV. Although young people who contracted HIV sexually were believed to suffer from the worst form of stigma, they were also believed to be better at processing and coping with it.

The quantitative analysis suggested that all YPLHIV experience stigma regardless of the mode of transmission. The results suggest that the forms of stigma that each group was most likely to experience differed, although the underrepresentation of young people who acquired HIV vertically challenged the accuracy with which the two groups could be compared.

Disclosure of HIV status

Confidence to disclose one's HIV diagnosis

> *"Disclosure is a mental health problem. The way a young person living with HIV can manage his/her social life is different from how a person without HIV can socialise."* **Y+ Africa**

Participants assessed to what extent they were confident in their ability to disclose their HIV status and the adequacy of their knowledge about HIV for the purpose of challenging stigma. Three out of five participants believed that they had enough knowledge to challenge stigma, but only three out of ten were confident to disclose their HIV diagnosis I public, see **Figure 10**. Find detailed results in **Table 13**.

Figure 10 The percentage of young participants (N=162) who agree or disagreed with statements about their knowledge and skills to challenge stigma and confidence to disclose their HIV status publicly

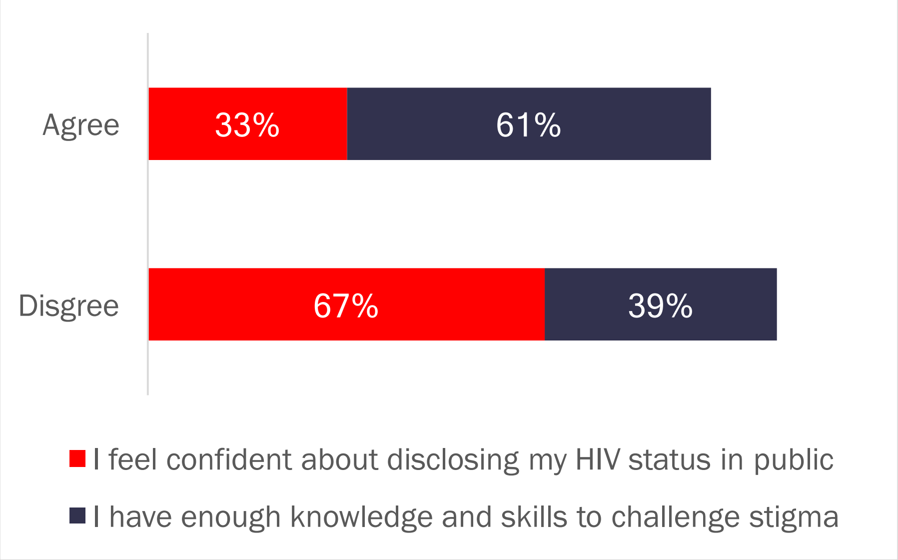


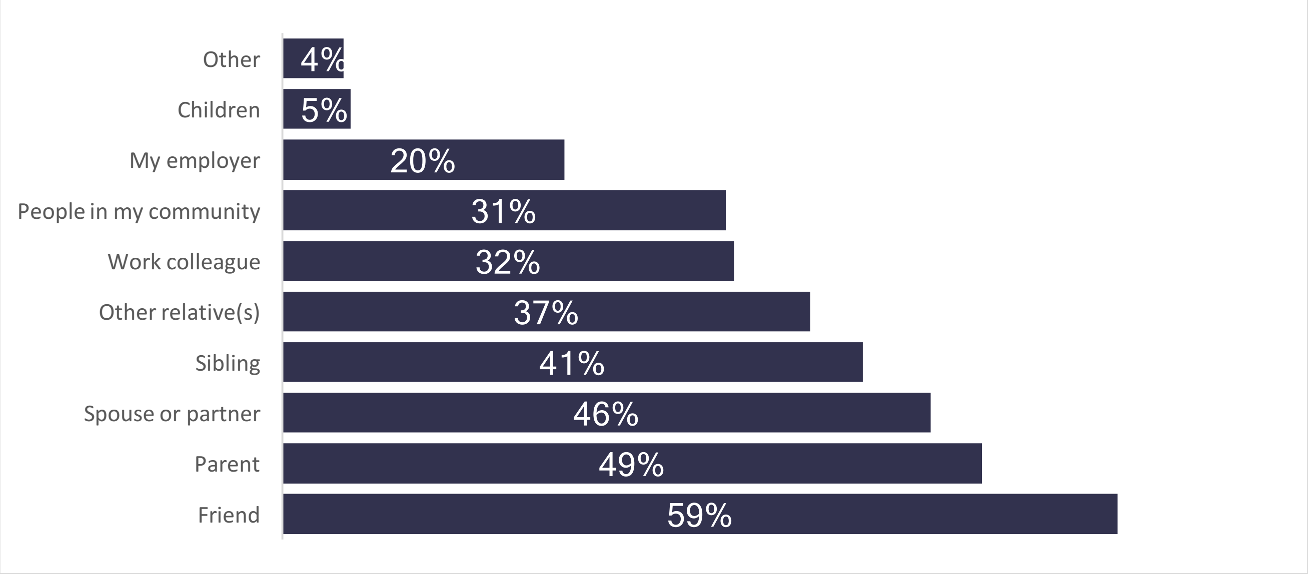
Table 13 The extent to which young participants (N162) were confident in their ability to disclose their HIV status and whether they had enough knowledge about HIV to challenge stigma.

Statements	Strongly disagree	Disagree	Somewhat disagree	Strongly agree	Agree	Somewhat agree	Total number of responses
I feel confident about disclosing my HIV status in public	37	14.8	14.8	14.8	9.3	9.3	162
I have enough knowledge and skills to challenge stigma	9.9	13.6	15.4	29.6	18.5	13	162

Young respondents provided their disclosure status, see **Figure 11**. Seven out of ten of the young participants had disclosed their HIV status to some degree. Around three out of five had disclosed to friends while half had disclosed to a parent. Only twenty per cent had disclosed to an employer.

Thirty-four per cent answered that their HIV-status was known by people that they did not confide in personally, meaning that they had experienced a breach in confidentiality whereby someone they confided had shared the information with others.

Figure 11 Percentage of young respondents (N=166) who had disclosed their HIV status to different categories of relations



*The total exceeds hundred per cent because some participants had disclosed to people within several categories of relations.

Benefits of serostatus disclosure

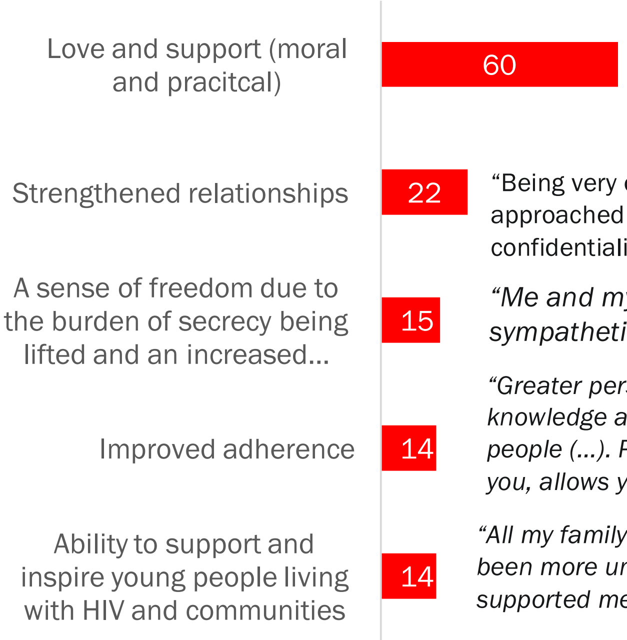
Disclosure did not only lead to negative outcomes, as demonstrated by the responses of 84 YPLHIV who shared positive disclosure experiences.

Most young people found the main benefits of disclosing their HIV status to be the support received from friends and family members, ex-and current partners and a greater feeling of freedom and self-acceptance, see **Figure 12**.

> *"HIV stigma can be defeated only when HIV-positive people are open. Stop snoozing. Make a claim about yourselves! Make a point; you are the People! And ordinary parts of society. No need to consider yourself an outcast. Love yourself and improve!* " YPLHIV, Europe

Not all participants had disclosed voluntarily; some did so out of necessity. For example, some participants from Africa mentioned being denied passes to leave school for their clinical appointments. This prompted them to disclose their seropositive status to school authorities, and the positive reaction they were met with gave them the confidence to continue a trajectory of disclosing. Sixty participants shared that disclosing their HIV status was a life-changing experience that turned fear into joy due to the support and understanding they received. Twenty-two participants reported that they experienced more loving and authentic relationships with their friends and families.

Figure 12 Themes emerging from 84 in-text responses regarding positive experiences of disclosure with supporting quotes



"When I shared with a friend they reacted very normally and guided me on what should be done next." **Y+ Southeast Asia.** *"I remember sometime in 2012 when I had defaulted. I then gathered courage to tell my cousin now she is my treatment buddy she helps to adhere well to my treatment"* **Y+ Africa**

"Being very open about my state, people "in the closet" of HIV have approached me with questions and always create very positive confidentiality" **Y+ Africa**

"Me and my partner got even closer than before. He was very sympathetic and understanding. ***Y+ Europe***

"Greater personal acceptance. Possibility of being able to expand knowledge about HIV by opening conversations in the lives of other people (...). Personally, revealing, when you feel it is necessary, frees you, allows you to really be yourself." ***Y+ Americas***

"All my family supported me since we learned the diagnosis and we have been more united since then, everything went smoothly, and everyone has supported me a lot." ***Y+ Americas***

Disclosing one's HIV status released one from the burden of keeping it a secret, especially because of an experience of being listened to and understood. It left one free to talk about HIV from a perspective of personal experience. Participant's accounts revealed that being able to educate peers and their communities had an empowering effect. Fifteen participants reported to a sense of freedom and increased confidence and self-acceptance as a result of disclosing their HIV status and sharing the burden. Fourteen responses addressed the ability to help and inspire others.

> *"I have had a lot of support from my friends. One experience that stands out was when I shared about my status online and my friend messaged me to say that she was so grateful that I had been open about it because it meant she finally convinced one of her friends to get tested for HIV which she had been trying to do for a long time. Part of being more open about it was encouraging and normalising getting tested for HIV, so I was so happy to hear."* **YPLHIV, Africa**

Disclosure was very critical for adherence because young people no longer needed to hide their medication or avoid being seen taking medication. Participants also enjoyed emotional and practical support in coping with and managing HIV, which they were deprived of while closeted.

Many participants explained that it was easier to disclose to people who were well informed about HIV.

> *"The only people who know my status are my current partner and my two previous sexual relationships. With my current partner, there was never a problem; he was very informed on the subject and has encouraged me to continue with the idea of maintaining a normal life."* **YPLHIV, Americas**

Likewise, those who felt they were well informed and had confidence in their communication skills found it easier to disclose, and they got positive reactions.

> *"All experiences are positive, probably because I can convey information correctly and constructively."* **YPLHIV, Eastern Europe**

Summary and implications

The burden of disclosure is demonstrated by the finding that more young participants felt knowledgeable and skilled enough to challenge stigma than were confident to disclose their HIV status. This finding also suggests that confidence in one's HIV knowledge is not an adequate determinant of young people's ability to disclose their HIV status, and that YPLHIV also need to have confidence in their communication skills. Despite the difficulty of disclosure, many young respondents had disclosed their HIV status to some degree. Participants were more likely to disclose to close relations than distant ones, and they found it easier to disclose to people who were knowledgeable about HIV because of the higher likelihood of a sympathetic response.

Disclosure of HIV status was not always voluntary, as some participants had been forced to disclose their HIV status to school authorities in order to attain permission to leave school for their medical appointments.

A majority of respondents had received positive reactions from the people that they disclosed to, and for some, being met with understanding the first time they disclosed lead them to disclose to more and more people. Consequently, addressing stigma and creating environments that are conducive for disclosure, should be one of the top agendas of the global HIV response. The benefits of disclosure were both physical and psychological as disclosure gave access to support and authentic human connections while also enabling optimal adherence to ART.

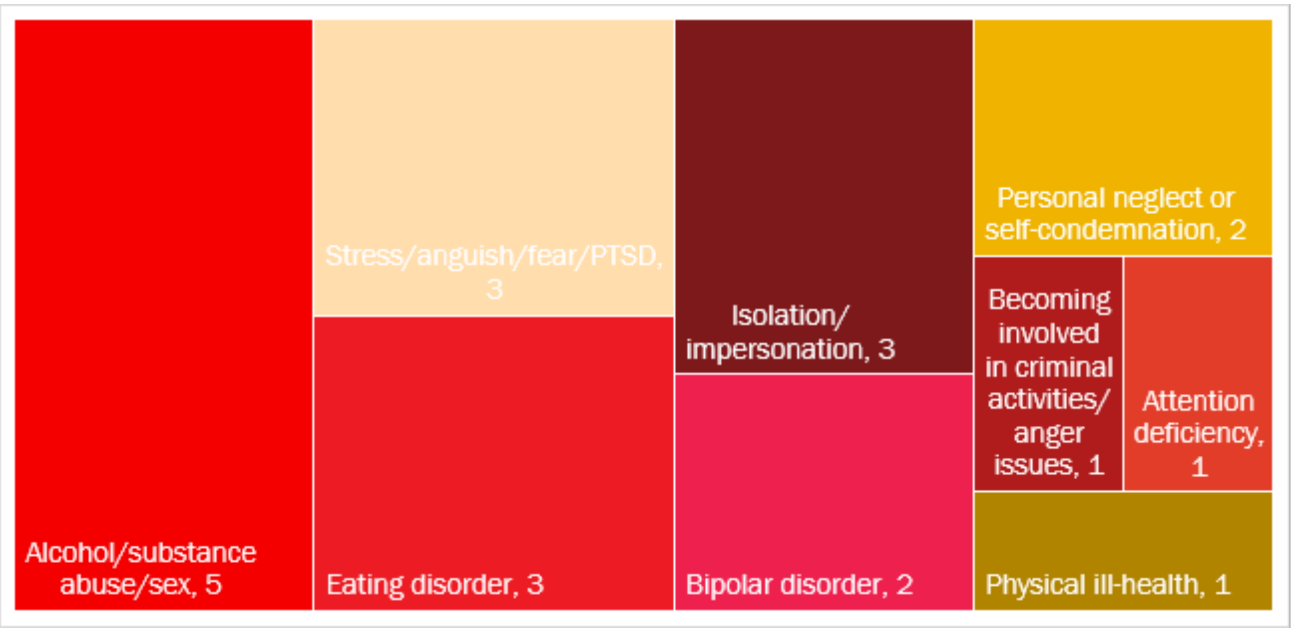
Manifestations of poor mental health

Stakeholders s' perceived manifestations of poor mental health among YPLHIV

Stakeholders were asked to share other ways in which mental health manifested in YPLHIV. Only 23 responses were collected, and the themes that emerged from their responses are depicted in

Figure 13. The following manifestations of poor mental health were mentioned: alcohol or substance abuse and sex, eating disorder, bipolar disorder, personal neglect or self-condemnation, involvement in criminal activities and poor physical health.

Figure 13 The number of stakeholders whose responses regarding the manifestation of mental health challenges fell into different themes



Self-reported mental health status during the last three months

> *"YPLHIV are more susceptible to depression and mental state fluctuations resulting from the need to constantly combat their health issues and stigma that makes most YPLHIV keeping their status discreet."* **Y+ Europe**

We asked the young respondents to rate the state of their mental health during the three months preceding their participation in the survey. **Table 14** shows the results. Around fifteen per cent of respondents felt that their mental health had been poor most of the time in the three months prior to taking part in the survey. One fifth had experienced good mental health most of the time in the three months before the survey. A majority (64%) had experienced good mental health some of the time and poor mental health some of the time which aligns with participant accounts regarding the fluctuating nature of their mental health status.

Table 14 Self-reported mental health status in the past three months

Rate	% of 162 young people
Good most of the time	20.4
Good some of the time and poor some of the time	64.2
Poor most of the time	14.8
Don't know	0.6
Total number of responses	162

Participants’ mood two weeks prior to the survey

Participants were presented with a set of questions to assess their mood in the two weeks leading up to the survey using a set of statements typically used to screen for depression and anxiety. **Table 15** contains desegregated the results, and **Figure 14** depicts aggregate results.

Although suicidal ideation or thoughts of hurting oneself were experienced ‘rarely or none of the time’ by forty-six per cent of the young respondents, ten per cent had experienced them most of the time. Close to thirty per cent had experienced poor sleep, and seventeen per cent had experienced sadness, hopelessness, or worthlessness ‘most of the time’. Thirty-eight per cent had experienced the first five negative moods ‘some of the time’ or ‘most of the time’. Seventeen per cent rarely felt hopeful about the future or that they were just as good as other people.

Figure 14 Participants’ rating of their mood for two weeks before taking part in the survey

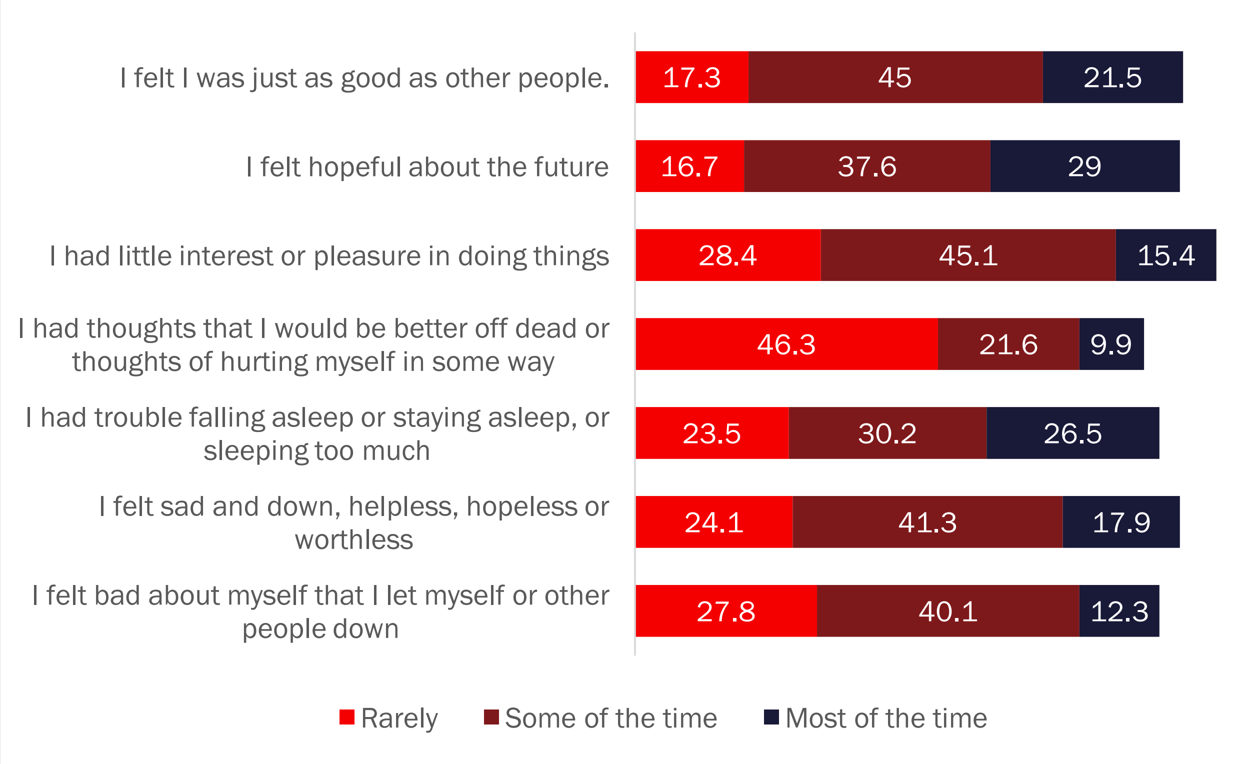


Table 15 Participants rating of their mood for two weeks before taking part in the survey.

	Rarely or none of the time (not more than 3 days)	Some or a little of the time (4-6 days)	Occasionally or a moderate amount of time (7-9 days)	Most or all of the time (10-14 days)	I have experienced this feeling for a period of two weeks or more within the past year but more than two weeks ago	I have experienced this feeling for a period of two weeks or more, but it was over a year ago
	(N per statement = 162)					
I felt bad about myself that I let myself or other people down	27.8	24.1	16	12.3	9.3	10.5
I felt sad and down, helpless, hopeless or worthless	24.1	22.2	19.1	17.9	6.2	10.5
I had trouble falling asleep or staying asleep, or sleeping too much	23.5	16	14.2	26.5	12.3	7.4
I had thoughts that I would be better off dead or thoughts of hurting myself in some way	46.3	9.9	11.7	9.9	9.3	13
I had little interest or pleasure in doing things	28.4	24.1	21	15.4	6.2	4.9
I felt hopeful about the future	16.7	18.5	19.1	29	9.9	6.8
I felt I was just as good as other people.	17.3	22.8	22.2	21.5	8.6	2.4

Alcohol use

Twenty-four per cent of the young participants were non-drinkers, but three-fifths drank alcohol *'monthly'* and *'two to four times or less in a month'*. Thirteen per cent drank alcohol two times a week or more. Participants who drank alcohol were asked a series of questions to gauge whether they had drinking problems. The results are displayed in **Table 16** and **Figure 15** below. A majority of the participants had never experienced the situations described in the statements, and a majority of those who experienced them did so less than monthly. Only one participant had experienced all of the situations described in the statements.

Figure 15 The percentage of participants (N130) reporting on statements assessing whether they had a drinking problem

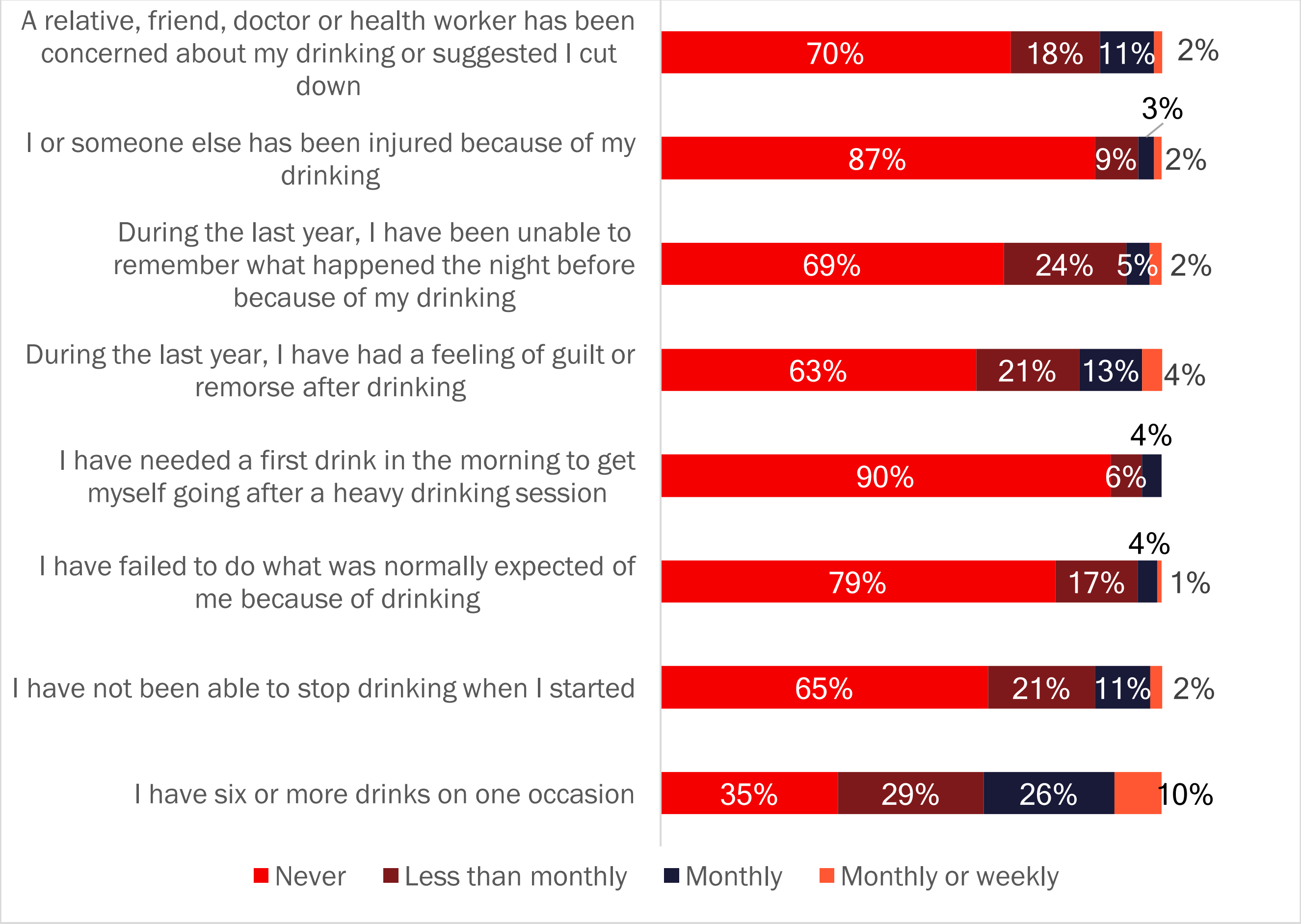
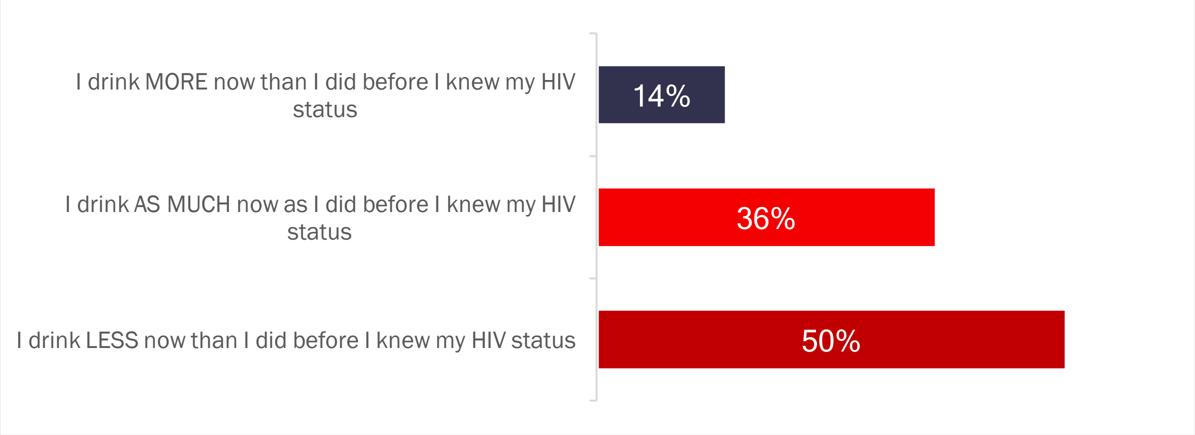


Table 16 The percentage of young participants (N130) reporting on statements to assess whether they had a drinking problem

Statement	Never	Less than monthly	Monthly	Weekly	Daily or almost daily
I have six or more drinks on one occasion	35.4	29.1	26	7.9	1.6
I have not been able to stop drinking when I started	65.4	21.3	11	0.8	1.6
I have failed to do what was normally expected of me because of drinking	78.7	16.5	3.9	0	0.8
I have needed a first drink in the morning to get myself going after a heavy drinking session	89.8	6.3	3.9	0	0
During the last year, I have had a feeling of guilt or remorse after drinking	63	20.5	12.6	1.6	2.4
During the last year, I have been unable to remember what happened the night before because of my drinking	68.5	24.4	4.7	1.6	0.8
I or someone else has been injured because of my drinking	86.6	8.7	3.1	0	1.6
A relative, friend, doctor or health worker has been concerned about my drinking or suggested I cut down	69.8	17.8	10.9	0.8	0.8

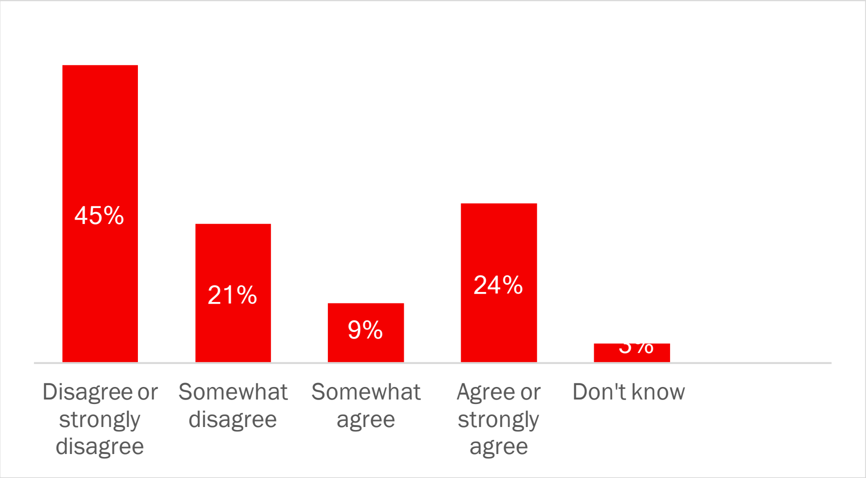
Half of the participants reported that they cut down their drinking after they found out that they were HIV-positive, the opposite was the case for fourteen per cent of the participants, who increased their drinking. The rest drank as much before their diagnosis as after. See **Figure 16.**

Figure 16 Percentage of young respondents (N=166) reporting differences in drinking behaviour before and after finding their HIV diagnosis



Although alcohol and drug abuse were the commonly reported manifestations of mental health issues by stakeholders, a majority disagreed with the statement: *'screening of alcohol and drug use is widely practiced.'*

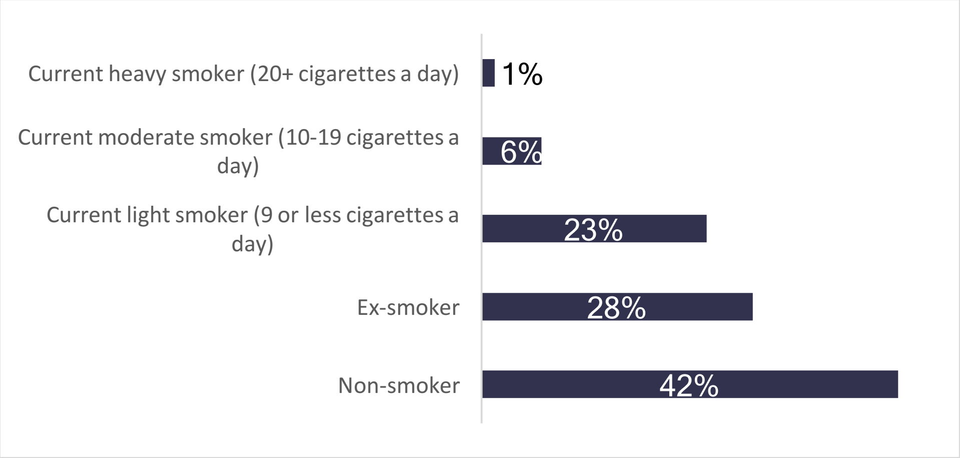
Figure 17 Perceptions of 33 stakeholders regarding the extent to which screening of alcohol and drug use is widely practised



Smoking

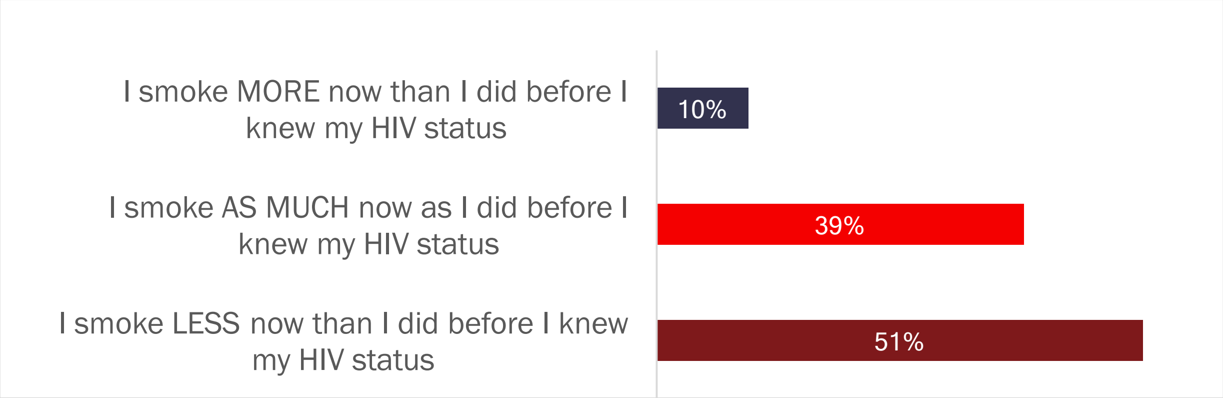
Two-fifths of the young respondents had never smoked and only one per cent of the sample of YPLHIV were current smokers. Twenty-eight per cent were ex-smokers.

Figure 18 Percentage of young respondents (N-166) reporting on their smoking behaviour



Similar to alcohol, around half of the young people had cut down on their smoking after their HIV diagnosis, while one in ten had increased their smoking habits. See **Figure 19.**

Figure 19 Percentage of young respondents reporting differences in smoking behaviour before and after their HIV diagnosis



Summary and implications

Alcohol, substance abuse, sex and stress/anguish/fear/PTSD were some of the common manifestations of poor mental health that stakeholders experienced, but the study suggests that screening for alcohol and drug abuse was not widely practiced. However, most young people in the survey indicated that they had reduced their consumption of alcohol and tobacco after their HIV diagnosis. The discrepancy might be explained by the fact that our study is not representative of all YPLHIV. It is particularly not representative of young people from less educated backgrounds.

Young participants' rating of their mental health within three months prior to their participation in the survey suggested that the mental health of YPLHIV fluctuates, which aligns well with the understanding that stigma experiences and other traumatic events are occasional and not constant occurrences. An exception being in the beginning, right after diagnosis. Similarly, the survey suggests that most YPLHIV's mood was good '*rarely'* or '*some of the time*' rather than '*most of the time'*. One could argue that the same applies to their-HIV negative counterparts, and comparative studies are required to better understand the difference, and how to better support YPLHIV.

Availability and access to mental health services

Availability of different forms of mental health services

Thirty-five per cent of the young respondents had accessed mental health services within a year before participating in the survey. **Table 17** displays the percentage of participants who affirmed the availability of different types of mental health services. Nearly the same proportion reported availability of peer-supported services as those reporting the availability of specialist-led services. Peer-led support groups and peer-to-peer counselling were also familiar sources of mental health support in all regions. However, more stakeholders reported availability of peer-based services than young people - see **Figure 20**.

Figure 20 Percentage of young respondents and stakeholders reporting on the availability of different forms of mental health support services

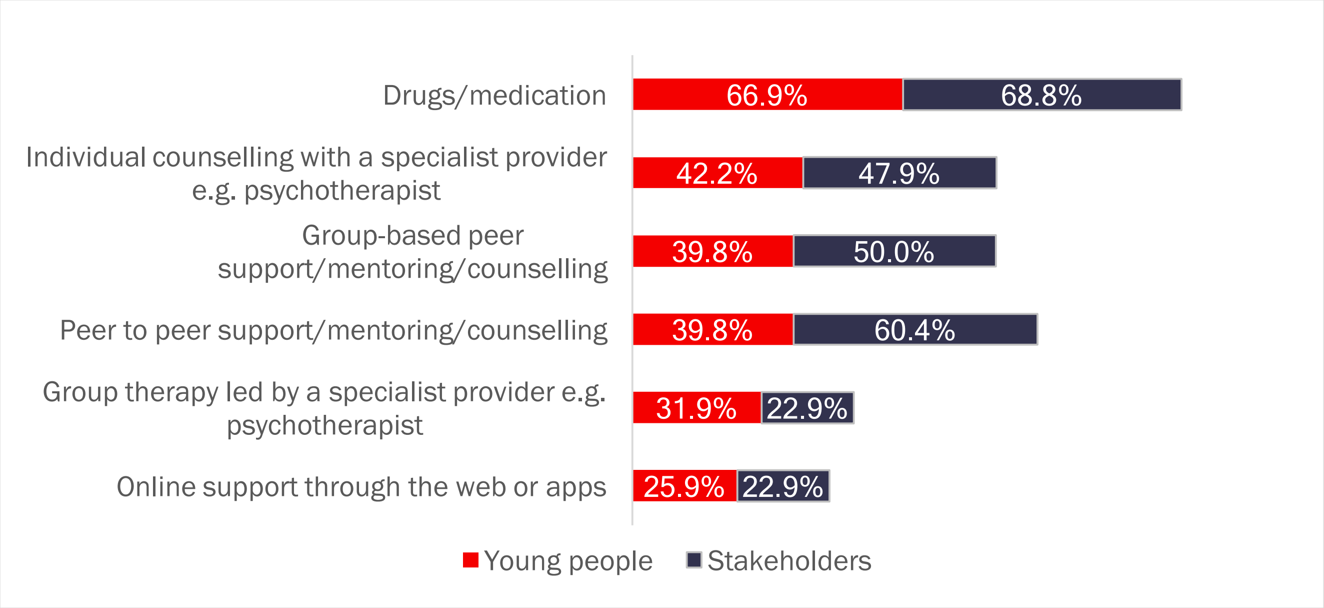


Table 17 Percentage of participants reporting on the extent to which different forms of mental health support services were available to young people living with HIV

	% of young people (Total N=166)	% of stakeholder (Total N=48)	% of all (Total N=214)
Drugs/medication	66.9	68.8	67.3
Individual counselling with a specialist provider, e.g., psychotherapist	42.2	47.9	43.5
Group-based peer support/mentoring/counselling	39.8	50.0	42.1
Peer to peer support/mentoring/counselling	39.8	60.4	44.4
Group therapy led by a specialist provider, e.g., psychotherapist	31.9	22.9	29.9
Online support through the web or apps	25.9	22.9	25.2
Don't know	17.5	2.1	14.0
None	5.4	6.3	5.6
Other	1.8	2.1	1.9

*Totals do add up to a one hundred per cent as participants could select more than one category.

Participants also suggested other support services that could help cope with stressors and other challenges, including youth camps and the use of alternative medicines such as Reiki healing.

A few participants found it beneficial to their mental health to engage in campaign activities such as condoms distributions, campaigns and/or other activities related to the HIV response. Such activities were also given as examples of available mental health support services, which would suggest that some participants found them therapeutic and beneficial for their mental health.

Awareness of where to access mental health support services or interventions

Nearly three quarters (72%) of young people were not aware of any research or support interventions addressing mental health among YPLHIV compared to forty-two per cent of stakeholders, see **Table 18** and **Figure 21** below. **Appendix 3** lists the organisations that participants mentioned in in-text responses.

Figure 21 Percentage of respondents who were not aware of an organisation implementing research or service delivery intervention addressing mental health among YPLHIV

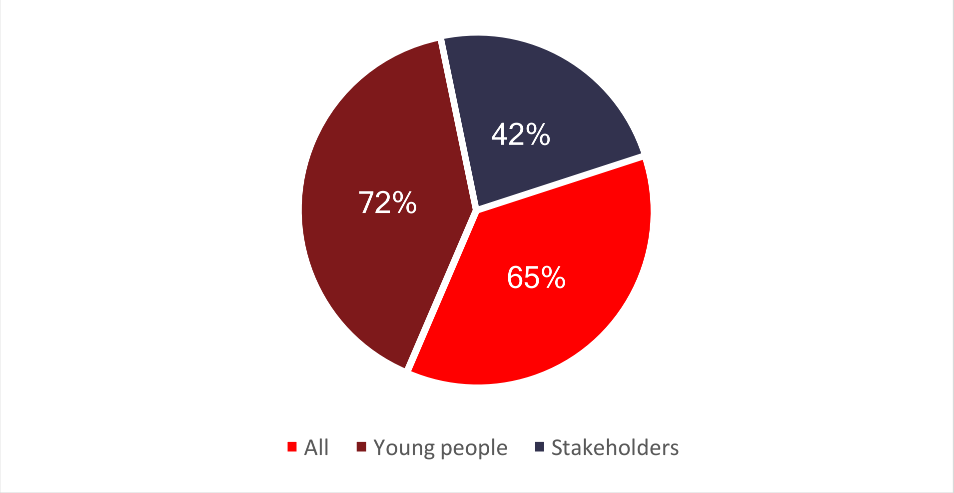


Table 18 Percentage of young respondents who knew of an organisation providing mental health support services to YPLHIV

	% of all (N=214)	% of young people (N=166)	% of stakeholders s (N=48)
Aware of an organisation doing research or implementing interventions on mental health	34.6	27.7	58.3
Not aware of an organisation doing research or implementing interventions on mental health	65.4	72.3	41.7

Consideration of mental health in different aspects of HIV services

We asked stakeholders to indicate their level of agreement or disagreement with mental health considerations in different aspect of HIV services. **Table 19** presents desegregated results. **Figure 22** below presents aggregate results where categories were dichotomised.

Combining the categories '*strongly disagree'*, '*disagree*' and '*somewhat disagree*' revealed that two-fifths of the sample population disagree with the statement mental health support needs of YPLHIV were identified at the time of HIV diagnosis through screening or other means'. It was the least proportion that disagreed with a statement. In contrast, the highest proportion of participants to disagree with the statement was sixty-four per cent, and they disagreed with the following statements, which indicates a general lack of consideration of mental health in HIV treatment consultations:

- HIV and mental health services are integrated; they are provided in the same facility or within the same consultation.
- Comprehensive/full mental health support is provided to adolescents during and after they transition from paediatric to adult services.
- Comprehensive mental health support is provided in paediatric services

Figure 22 The percentage of stakeholder respondents (N=33) who disagreed (strongly disagree, disagree and somewhat disagree combined) regarding the extent to which mental health was considered in different aspects of HIV services

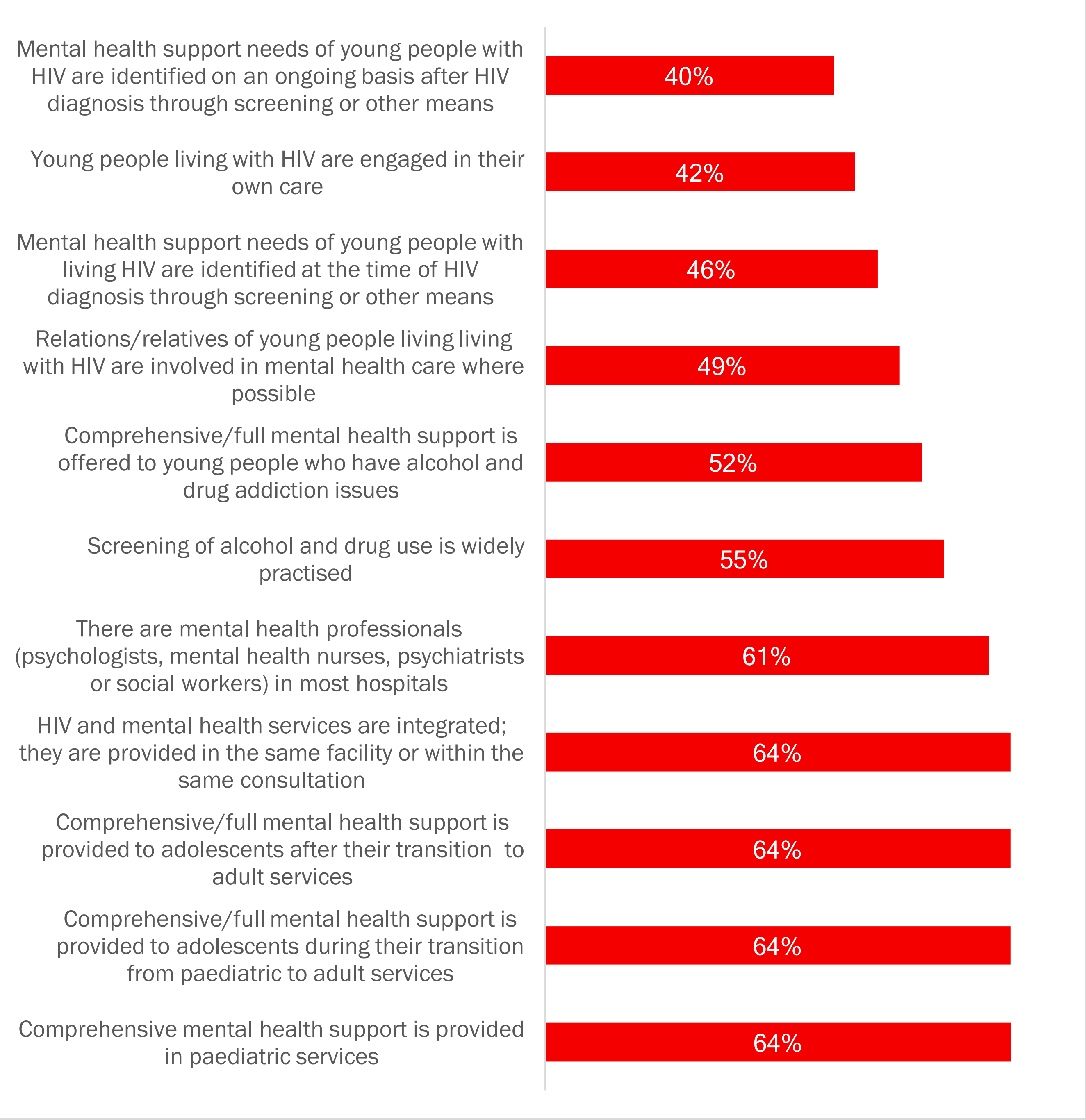


Table 19 The percentage of stakeholder respondents (N=33) regarding the extent to which mental health was considered in different aspects of HIV services

	Strongly disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Strongly agree	Don't know
Comprehensive/full mental health support is provided to adolescents after they transition from paediatric to adult services	24.2	18.2	21.2	18.2	15.2	3	0
Screening of alcohol and drug use is widely practised	24.2	21.2	9.1	18.2	15.2	9.1	3
HIV and mental health services are integrated; they are provided in the same facility or within the same consultation	24.2	21.2	18.2	15.2	15.2	6.1	0
Comprehensive/full mental health support is offered to young people who have alcohol and drug addiction issues	18.2	24.2	9.1	15.2	18.2	12.1	3
An effort is made to prevent poor mental health among young people with HIV	15.2	30.3	12.1	6.1	24.2	12.1	0
There are mental health professionals (psychologists, mental health nurses, psychiatrists or social workers) in most hospitals	15.2	27.3	18.2	27.3	0	12.1	0
Comprehensive/full mental health support is provided to adolescents during the transition of adolescents from paediatric to adult services	12.1	30.3	21.2	21.2	9.1	6.1	0
Relations/relatives of young people living with HIV are involved in mental health care where possible	12.1	21.2	15.2	21.2	18.2	12.1	0
Mental health support needs of young people living with HIV are identified on an ongoing basis after HIV diagnosis through screening or other means	9.1	15.2	15.2	27.3	18.2	12.1	2.9
Comprehensive mental health support is provided in paediatric services	9.1	36.4	18.2	18.2	15.2	3	0
Mental health support needs of young people living with HIV are identified at the time of HIV diagnosis through screening or other means	6.1	15.2	24.2	21,2	18.2	15.2	21.1
Young people living with HIV are engaged in their own care	3	9.1	30.3	18.2	27.3	12.1	0

Health provider’s knowledge and efforts

Participants were presented with four statements regarding health providers’ understanding of mental health, as well as their efforts in addressing mental health challenges faced by YPLHIV and asked to what extent they agreed with the statements. **Table 20** displays the desegregated results.

It is noteworthy, see **Figure 23,** that not more than one-fifth of young respondents believed that health providers fulfilled the actions described in the statements to a great or very great extent. Precisely twenty per cent believed that health workers had knowledge and understanding of mental health to ‘a great’ or ‘very great’ extent. Only eighteen per cent believed that providers recognise the value of addressing mental health challenges faced by YPLHIV.

Figure 23 The percentage of young participants (N=166) and stakeholders (N=214) reporting to what extent health service providers live up to statements regarding mental health service delivery to a great or very great extent.

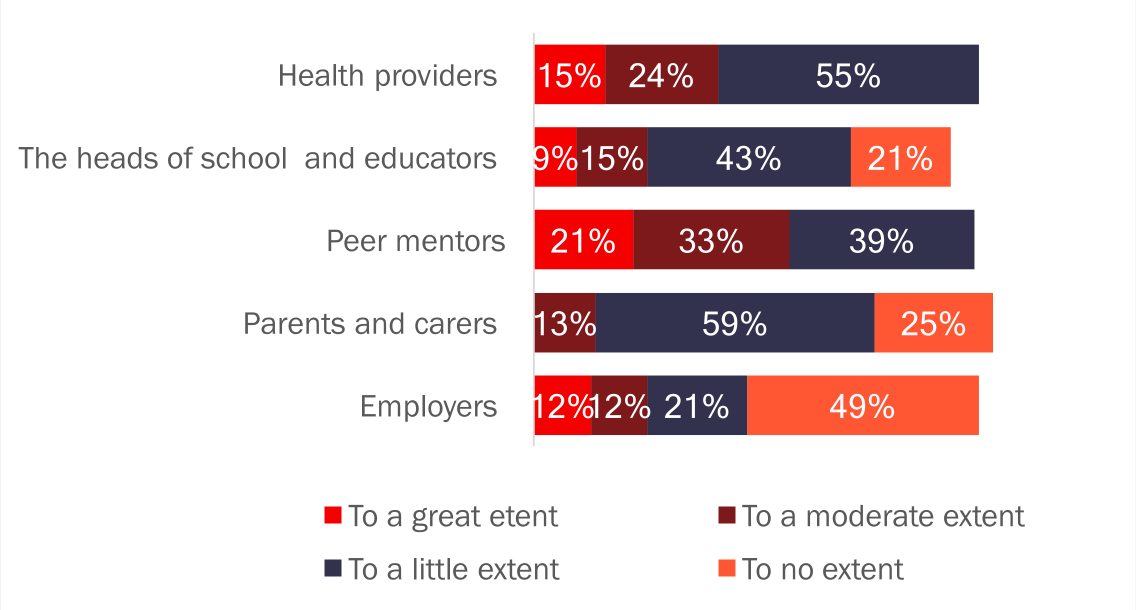
Table 20 Percentage of respondents reporting on the extent to which health service providers understand and put effort into addressing mental health challenges faced by YPLHIV

	% of young people (N=166)				% of stakeholders (N=48)				% of all (N=214)			
	To a small or very small extent	To a moderate extent	to a great or very great extent	Don't know	To a small or very small extent	To a moderate extent	to a great or very great extent	Don't know	To a small or very small extent	To a moderate extent	to a great or very great extent	Don't know
Have sufficient knowledge and understanding of mental health	37.3	39.8	19.9	3	29.2	47.9	22.9	0	35.5	41.6	20.6	2.3
Recognise the value of addressing mental health challenges faced by YPLHIV	37.3	39.8	18.1	4.8	35.4	39.6	22.9	2.1	36.9	39.7	19.2	4.2
Spend time or effort seeking to improve the mental health of YPLHIV	51.2	27.7	16.3	4.8	39.6	41.7	16.7	2.1	48.6	30.8	16.4	4.2
Implement strategies and approaches to addressing mental health challenges that are informed by research evidence	48.8	29.5	15.7	6	41.7	33.3	16.7	8.3	47.2	30.4	15.9	6.5

The extent to which different stakeholders are trained in mental health awareness as pertains to YPLHIV

We asked stakeholders to rate to what extent different stakeholders received awareness training on HIV and mental health with specific reference to their interaction with YPLHIV. The results are depicted in **Figure 24** and **Table 21.**

Figure 24 Percentage of respondents (N33) reporting on the extents to which different stakeholders received mental health awareness training.



* The percentages per stakeholder do not add up to a hundred per cent because the percentage responding ‘don’t know’ is omitted in the figure but can be found in Table 21.

Table 21 Percentage responses (N-214) on the extent to which different stakeholders received mental health awareness training.

	To a very great extent (there is ongoing and evolving quality training for all providers)	To a great extent	To a moderate extent	To some extent	To a small extent	To no extent (no training is provided)	Don't know
	(N=214 per row)						
To health providers	12.1	3	24.2	30.3	24.3	0	6.1
The heads of school and educators	0	9.1	15.2	18.3	24.2	21.2	12.1
peer mentors	6.1	15.2	33.3	18.2	21.2	0	6.1
Parents and carers	0		12.5	25	34.4	25	3.1
Employers	0	12.1	12.1	6.1	15.2	48.5	6.1

Nearly half of the stakeholders believed that employers of YPLHIV did not receive any mental health awareness training. A quarter perceived that parents and carers did not receive any mental health awareness training while one-fifth thought the same about heads of schools and educators. It is noteworthy that health providers who interact with young people in a clinical context were only believed to receive mental health awareness training to a great extent by fifteen per cent of the stakeholders. It was nearly the same proportion as for employers at one-fifth.

The extent to which mental health is discussed during HIV treatment consultations

More stakeholders than young people reported that mental health was discussed; always and often. Conversely, one in ten of the stakeholders, reported that mental health was never discussed during treatment consultations compared to one-fifth of the young people, see Table 22.

Figure 25 and Table 22. Similarly, slightly more young people than stakeholders felt that mental health was not discussed often. Detailed information can be found in Table 22.

Figure 25 The percentage of respondents reporting that mental health is always discussed, often, not often and never

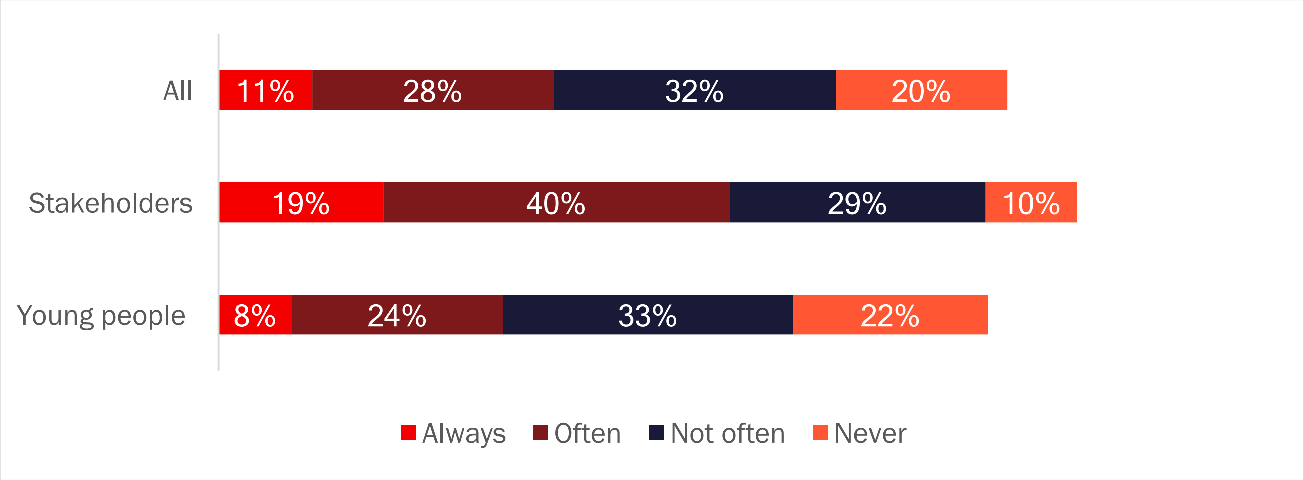


Table 22 Perceptions regarding the frequency of mental health-related discussions during HIV treatment consultations

	% of young people (N=166)	% of stakeholders (N=48)	% of all (N=214)
Always	8.4	18.8	10.7
Often	24.1	39.6	27.6
Not often	33.1	29.2	32.2
Never	22.3	10.4	19.6
Don’t know	12.0	2.1	9.8

Responsibility for initiating a conversation about mental health during HIV treatment consultations: providers or YPLHIV?

Young people and stakeholders agreed that it was health providers who, *'to a great extent'*, initiated conversations around mental health during HIV treatment consultations. The proportion of stakeholders who found this to be true was slightly higher than that of young people - see **Figure 29**. However, a higher proportion of young people than stakeholders felt that '*it was always'* young people, who initiated conversations around mental health during HIV treatment consultations. Refer to **Table 23** for more detailed results.

Figure 26 The percentage of stakeholders (N=48) and young (N=166) perceptions regarding the extent to which it was YPLHIV or health providers who took the initiative to discuss mental health conversation during HIV treatment consultations.

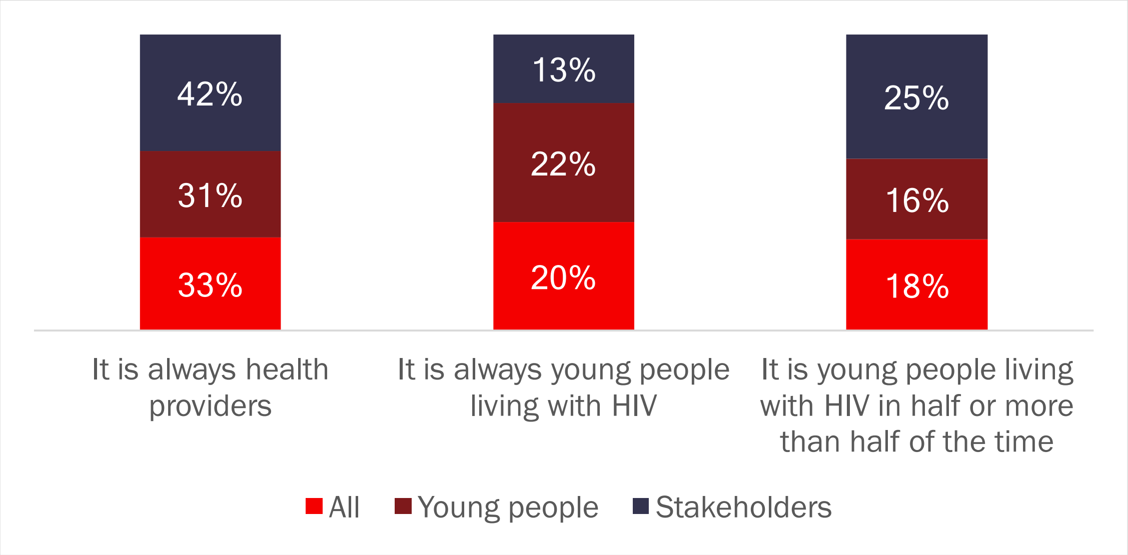


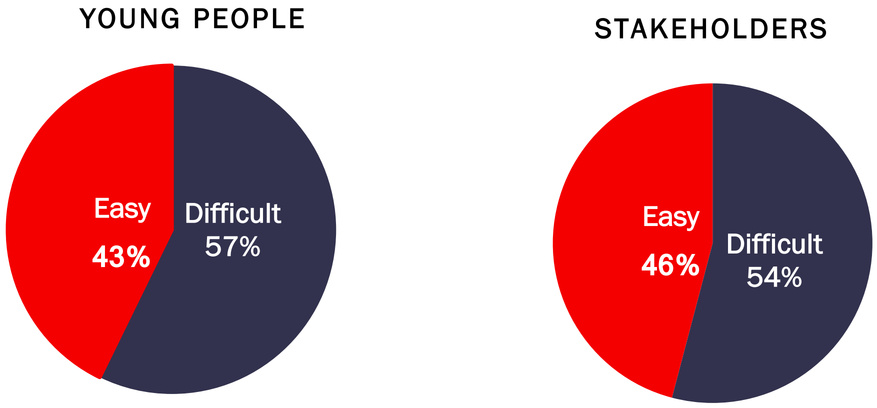
Table 23 Percentage of respondents who reported that young people or professional initiated mental health discussions during HIV treatment consultations.

	% of all (N=214)	% of young people (N=166)	% of stakeholders (N=48)
It is always health providers	33.2	30.7	41.7
It is always young people living with HIV	19.6	21.7	12.5
It is young people living with HIV in less than half the times	7.0	4.8	14.6
It is young people living with HIV half of the times	6.5	7.2	4.2
It is young people living with HIV in more than half of the times	11.7	9	20.8
Don't know/don't remember	22.0	25.5	6.3

The extent to which respondents found it easy or difficult to discuss mental health during consultations

Thirty-four per cent of the young respondents found it very difficult or difficult to discuss mental health during HIV treatment consultations, and the same was the case for sixteen percent of the stakeholders. **Figure 27** shows dichotomised percentages combining the categories ‘Very difficult’, ‘difficult’ and ‘somewhat difficult’ into one category and likewise for ‘very easy’, ‘easy’ and ‘somewhat easy’. The pie charts show that overall, the same proportion of young people and stakeholders found it difficult to discuss mental health. In both cases, a little more than half found it difficult.

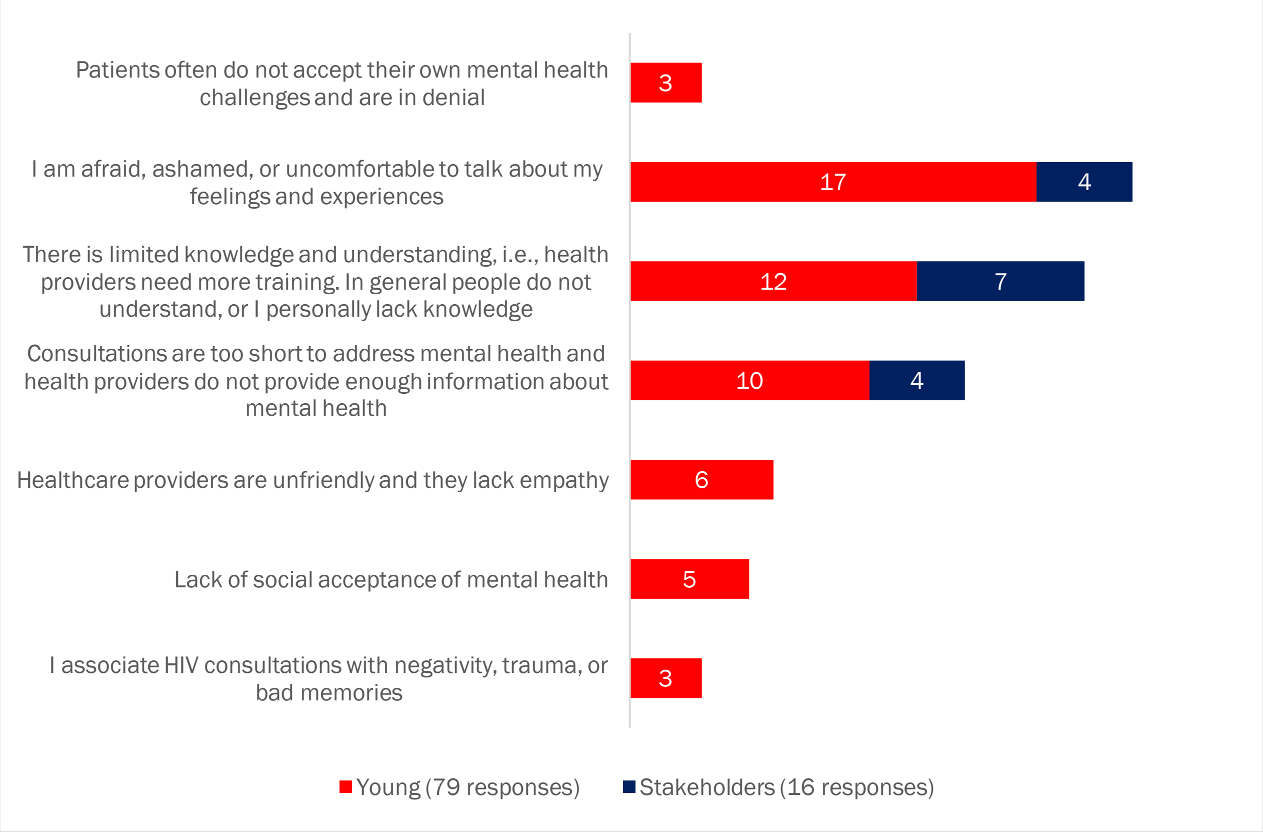
Figure 27 The proportion of young (N-166) and Stakeholders (N=48) who found it easy or difficult to discuss mental health.



Factors contributing to young people’s and stakeholders s’ difficulties with discussing mental health during HIV treatment consultations.

Different themes emerged from accounts by stakeholders and young respondents regarding the underlying reasons for difficulties in discussing mental health. **Figure 28** presents the themes using quotes taken directly from the data with minimal editing. Only young people from Europe (Eastern Europe) and Africa shared their views, but stakeholders from all regions contributed.

Figure 28 The number of young people and stakeholders who reported reasons why they found it hard to discuss mental during HIV consultations that fell into different themes



The central theme reported in 17 responses was that discussing mental health during HIV consultations was associated with fear, shame and discomfort. The shame appeared to be related to a perceived lack of social acceptance around mental health. There was no culture of discussing mental health in these regions (5 responses).

> *"Because I was raised in Russia, where mental health is not usually discussed unless you have some outward appearances of illness."* **YPLHIV, Europe**

A few stakeholders were of the opinion the experiences of fear and shame were attributable to the intergenerational gaps between young people and service providers, who were typically older adults.

The second most common reason reported in 12 accounts was poor knowledge and understanding regarding mental health services in society overall, including among respondents and healthcare providers. Not understanding what mental health means was mostly reported by young participants from the African regions.

> *"This happens if you don't have a professional to just describe what is mental health."* **YPLHIV, Africa.**

> *"Some health workers do not understand mental i.e. how it is manifested or how to diagnose it."* **Stakeholder, Africa**

One consequence of this knowledge deficit seemed to be that mental health was not given the kind of serious attention it deserved. For example, while some young people felt that they did not have enough knowledge about mental health to discuss it, others feared that providers would not take them seriously.

> *"Because I think the health provider may not take it seriously as I do."*
> **YPLHIV, Africa**

> *"Because I don't want to seem like a person who constantly complains."*
> **YPLHIV, Europe**

Another major service-related theme is the perception that HIV consultations were not the right place to discuss mental health; their focus was on HIV, and no time was allocated to discuss mental health. This issue was exacerbated by high caseloads in healthcare services.

> *"The health care provider is always having not enough time to discuss mental health because of a big number of clients at the health facility."* **Stakeholder, Africa**

Besides, young people did not like spending time in the HIV service environment, which they associated with trauma and bad memories (3 responses). Unfriendly and un-empathetic service providers (6 responses) perpetuated these negative emotions. For these participants, the HIV health care environment promoted poor mental health rather than contributing to its alleviation.

> *"Because doctors do not focus on it. And it is very sad: you are frightened, you feel rejected, useless. Doctors have no empathy for patients at all. They are like machines. In my opinion, doctors working with PLHIV should attend psychotherapy courses!"* **YPLHIV, Europe**

> *"I don't really want to spend long there. I associate it with negative vibes."*
> **YPLHIV, Africa**

The attitude of HIV care providers made it hard to trust them with detailed private information. Trust appeared to be an issue, even in interactions with qualified professionals.

> *"When it is a visit to my psychologist, I do not always tell right away about problems because of some cases after which I prefer to keep everything back and don't disclose the problems."* **YPLHIV, Europe**

Factors that make discussing mental health easy or difficult.

Similar themes emerged from young people's and stakeholders' accounts on why they found it easy to discuss mental health. See **Figure 29.**

Figure 29 The difference in responses between young people and stakeholders when asked why they found it easy to discuss mental health surrounding HIV

Three of the themes were present in both young people's and stakeholders' accounts; safe and friendly service environment, a service provider that could be trusted, and knowing the importance of being open about one's mental health. These factors were opposite factors contributing to difficulties in discussing mental health during HIV treatment consultations.

However, some factors which facilitated the ease of discussing mental health were unique to young and stakeholder respondents. For example, six young respondents shared that they found it easy to discuss mental health because they were open about their physical and mental health problems, or because they encountered competent health workers. Four stakeholders found it easy because they were also living with HIV and could personally relate to the experiences of young people, or because they worked in an organisation with necessary resources such as referral systems.

> *"Experience of dealing with adolescents / all PLHIV / knowledge of mental health problems and referral process/integration of this topic in a holistic consultation / built up a good rapport with young people over time."*
> **Stakeholder, Europe**

Summary and implications

This study suggests that drugs or medicine are the most common forms of mental health support services available for YPLHIV. However, some participants referred to pharmacological treatments for mental ill health such as antidepressants and ART interchangeably in textual responses. Therefore, it is likely that the percentage reporting availability of drugs/medicines was overestimated due to the possibility that some participants conflated the availability of ART treatment with the availability of pharmacological treatments for mental ill health. The results also suggest that YPLHIV were vital players in the provision of mental health services through their provision of peer-lead support services. The difference in the proportion of stakeholders reporting availability of peer-based services compared to young people suggests an overestimation on the part of stakeholders, but it might also reflect young people's lack of acknowledgement of these services as mental health support services.

The study demonstrates that young people's active involvement in the HIV response was likely to have a therapeutic effect on mental health. This understanding aligns well with young people's need for a purpose, which was one of the attributes that defined mental health for young participants –see **Table 7**. The least proportions reported the availability of online services. In addition, most young participants were not aware of mental health support services or interventions, which implies that young people are not aware of where to access mental health services.

The survey demonstrated that mental health was not adequately considered in HIV treatment services with high proportions of participants reporting poor integration of mental health services in HIV treatment services and lack of comprehensive mental health services. Moreover, less than a quarter of respondents believed that health providers had sufficient knowledge about mental health, recognised the importance of addressing mental health challenges faced by YPLHIV or put effort into it.

The results suggest that, of all the important stakeholders in safeguarding the mental health of YPLHIV, employers were least likely to get mental health training, as well as heads of schools and educators and parents and carers. However, health workers were less like to receive mental health training than YPLHIV. Therefore, it was not surprising that mental health was not discussed in half of the HIV treatment consultations, and that half of the stakeholders reported that they found it difficult to discuss mental health. Half of the young people also found it difficult to discuss mental health, and it was concerning that two-fifth of the participants reported that young people were expected to initiate mental health discussions. The most common barriers to discussing mental health during HIV treatment consultations were young people's association of discussing their emotions with fear, shame and discomfort, limited knowledge and understanding of mental health among health workers and time constraints. The barriers above were reported by both young people and stakeholders, and in addition, young people reported that unfriendliness and lack of empathy among health workers was a hindrance. Conversely, factors that facilitated discussion of mental health included a friendly and safe environment, the trustworthiness of the service provider and understanding of the importance of discussing mental health by both young people and health providers. In addition, health workers found it easy when there was a system in place, such as an effective referral pathway. Openness about physical and mental health, including openness about ones' HIV status made it easy to discuss mental health for YPLHIV.

Accessibility of mental health services

Close to three-fifths of the young participants had experienced situations where they failed to access mental health services. Twenty-eight per cent reported that they were hindered in accessing mental health services by high pricing. Fourteen per cent were hindered by long distances, and one-fifth reported being hindered by mental health-related stigma. Close to half of the young respondents reported that they feared accessing HIV-services, while two-fifths feared accessing mental health services.

Experiences of successes and failures to respond to mental health challenges faced by YPLHIV

Participants were asked whether they had experienced or heard of any situations where health services were successful in addressing mental health challenges faced by a young person living with HIV, and situations where services had failed to respond successfully. Success was operationalised as a timely response leading to positive outcomes. Close to half of the respondents had experienced unsuccessful situations, while close to two-fifths had experienced successful situations. More stakeholders reported having experienced successful responses than young people, see graph in **Figure 30**. More detailed results are in **Table 24**.

Figure 30 Percentage of participants N=214) who had experienced situations where health services were successufl or unsuccessful in

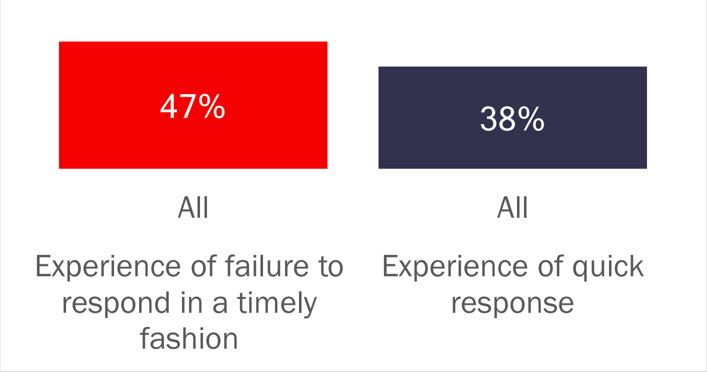


Table 24 Percentage of all participants who reported having experienced situations where services responded successfully or unsuccessfully to mental health challenges faced by a young person living with HIV

	Experience of experience of failure to respond in a timely fashion'			Experience of a successful response		
	% of all (N=214)	% of young people (N=166)	% of stakeholders (N=48)	% of all (N=214)	% of young people (N=166)	% of stakeholders (N=48)
Experience	47.2	45.8	52.1	37.9	35.5	45.8
No experience	52.8	54.2	47.9	62.1	64.5	54.2

The conduciveness of mental health services to young people

We presented the participants with four statements on different aspects of mental health service access, refer to **Table 25** for detailed results.

Around seven out of ten of the young people disagreed (disagreed, disagreed and somewhat disagreed) with all four statements, see **Figure 31**. The most considerable difference between the proportion of young people and stakeholders was observed in the extent of their disagreement with the statement: *"YPLHIV have free access to mental health services"*

Figure 31 The percentage of participants who disagreed with statements regarding the accessibility of mental health services for YPLHIV

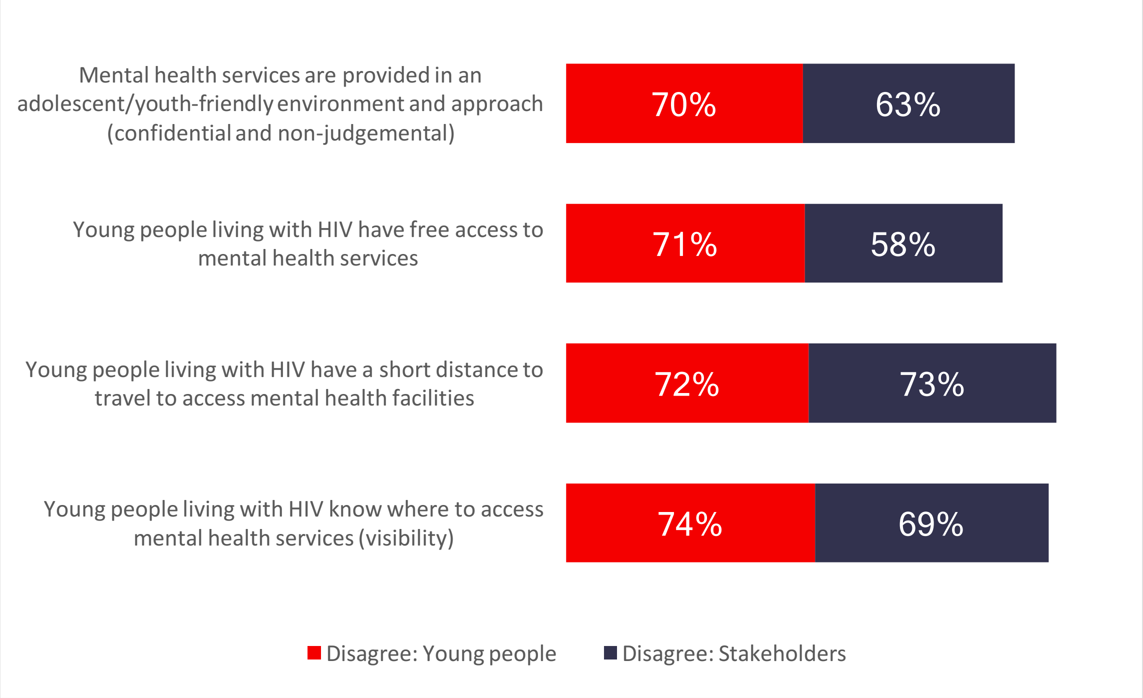


Table 25 The extent to which respondents agreed with statements regarding the accessibility of mental health services for young people living with HIV

	% of young people (N=166)					% of stakeholders (N=48)					% of all (N=214)				
	Disagree or strongly disagree	Some what disagree	Agree or strongly agree	Some what agree	Don't know	Disagree or strongly disagree	Somewhat disagree	Agree or strongly agree	Some what agree	Don't know	Disagree or strongly disagree	Somewhat disagree	Agree or strongly agree	Some what agree	Don't know
Young people living with HIV know where to access mental health services (visibility)	52.4	21.1	10.8	7.8	7.8	50	18.8	18.8	10.4	2.1	51.9	20.6	12.6	8.4	6.5
Young people living with HIV have a short distance to travel to access mental health facilities	44.6	19.3	18.7	7.2	10.3	47.9	22.9	20.8	4.2	4.2	45.3	20.1	19.2	6.5	8.9
Young people living with HIV have free access to mental health services	34.9	18.1	24.7	11.4	10.8	45.8	8.3	29.2	14.6	2.1	37.4	15.9	25.7	12.1	8.9
Mental health services are provided in an adolescent/youth-friendly environment and approach (confidential and non-judgemental)	32.5	17.5	22.9	10.2	16.9	41.7	12.5	25	18.8	2.1	34.6	16.4	23.4	12.1	13.6

Barriers to mental health service access associated with different mental health service providers

Participants mentioned three main types of mental health support service providers, and these were associated with different barriers and facilitators.

Non-governmental and community-based organisations (NGOs & CBOs)

The predominant and most trusted providers of mental health support services were non-governmental organisations specialising in HIV. Non-governmental organisations were reported to provide free services by most participants except a few in Latin America who gave the impression that they paid for the services. A challenge experienced with NGO services was that they were project-based, which meant that they were time-limited. This was depicted in several responses where participants bemoaned the cessation of a project or programme.

> *"Previously it was done by the world fund project in Ecuador, now everything is finished, and nothing is done."* **Stakeholder, Americas**

Community-based organisations (CBOs) were also highlighted as key players in the delivery of different forms of mental health services in Latin America and Africa. CBOs worked voluntarily, which affected the quality of the services.

> *"Community-based organisations offer peer services and virtual support; this work, in most cases, is voluntary and unpaid."*
> **Stakeholder, Americas**

Public institutions

Other providers included public institutions such as the NHS in the UK or the public service in Ecuador. A few participants, like in the quote below, referred to mental disorders which indicated that they associated the term mental health with mental disorders and mental health services with psychiatric services.

> *"The Ministry of Health provides free psychological and psychiatric service in Ecuador, in addition to there being aid groups for PLHIV."* **YPLHIV, Americas**

Many participants in Africa, Latin America and Eastern Europe reported a shortage of specialist providers leading to long waiting time for appointments and long distances to specialist clinics which tended to be in bigger cities. The few specialists were also overworked; thus, services were of poor quality.

> *"Mental health care, in general, is very patchy, unreliable, disorganised and overburdened."* **Stakeholder, Americas**

Both provider and young people's accounts revealed that by the time referrals to specialist services were made, the case was often severe and often too late, and the care provided insufficient.

> *"Yes* [there are some success stories of access of young people being helped in time and with a positive outcome]*, but most of the time it is too late, and the case is always desperate."* **Stakeholder, Africa**

There were long waiting times, and delays in service provision and long distances had to be travelled to access care.

> *"This wasn't extremely quick, but I told my clinic I was suffering mentally a few years ago. I was referred to the specialised HIV counsellor at the clinic a couple of months later."* **YPLHIV, Africa**

> *"I was on the waiting list for two months."* **YPLHIV, Americas**

> *Unless the youth should have a short distance of travel to access mental health services (…), youth are doomed to suffer from mental health problems.* **Stakeholder, Africa**

> *"In big cities, we have well-developed peer-support groups. There are some institutions where you can get free prescribed antidepressants. However, it is infrequent. I accidentally heard from friends."* **YPLHIV, Europe**

Service opening hours were also not conducive for young people in employment

> *"I cannot reach the hours they give. Whenever I go, they are already taken."* **YPLHIV, Americas**

Complaints were made of unqualified providers in Africa and Latin America. At the same time, a couple of participants in Eastern Europe complained of a lack of HIV competence among specialist mental health providers in polyclinics.

> *"A psychological counsellor in my clinic is not a good professional. It is not only a matter of having staff but also having qualified staff."* **YPLHIV, Americas**

> *"[Mental health support is provided] in polyclinics, but they are not always competent and sometimes do not know how to talk about HIV. You should be lucky to find or "match" with your perfect specialist. We have psychologists in HIV/AIDS centres."* **YPLHIV, Europe**

A participant suggested that the root cause of the poor mental health provision in public institutions was that mental health was not an integral component of the 'essential' service package.

> *"These services are usually not included among 'essential' services."*
> **Stakeholder, Africa**

Private mental health providers

Because the supply of specialist services in the NGO and public sector were scarce, young people were forced to seek services in the private and semi-private sectors. However, these services came at a cost, and not all young people could afford them. Even if they could afford the services, some did not value mental health enough to consider therapy a necessary expense. Participants suggested that mental health services should be free like ARV treatments or that they should be subsidised.

> *"Mental health drugs are sold in my country; some of the youth cannot afford to purchase, hence derails the whole purpose of healing; these drugs should be provided for free like those ARVs."*
> **Stakeholder, Africa**

> *"Lack of professionals in the public area, since accessing it privately is very expensive."* **YPLHIV, Americas**

> *"Access to mental health should be guaranteed as a human right, enshrined in a political constitution. Meanwhile, at least, access to mental health could be "subsidised."* **YPLHIV, Americas**

In Chile, those with health insurance through their employers were privileged because they could access both HIV and mental health services at no cost or a subsidised rate. The privilege of being able to pay was also that one could find a psychotherapist of choice—a specialist who was a good 'match' as some participants put it. Services were also able to get services closer to home.

> *"I was lucky to find a psychologist online, we liked each other right away, and she's brilliant. It is a private consultation, and I have the privilege of being able to pay for it. However, I know that there are people who attend public health and do not have the opportunity to access mental health, as it is scarce and inaccessible."* **YPLHIV, Americas**

> *"My ISAPRE (prepaid/private health) promptly managed the possibility of taking examinations in the same commune in which I resided, after exposing my problem of moving to a great distance."*
> **YPLHIV, Americas**

Other barriers

Some barriers were general and not associated with any specific provider, or it was not clear whether they were associated with either of the types of providers. These are presented below.

Poor mental health literacy in the community

It was noted that those affected by HIV, including YPLHIV, and their families and communities, lacked understanding of mental health and were unable to recognise the need for mental health services.

> *"Failure by the affected and their communities, including their families, to recognise that their children have or may be exposed to mental health issues."* **Stakeholder, Africa**

> *"The fact that most don't know if they have mental issues."* **Stakeholder, all regions**

Participants felt that knowledge about mental health could lead to improvements in health-seeking behaviours. Many suggested solutions such as information campaigns, workshops and community activities aimed at breaking mental health-related taboos.

> *"I would really like if you could directly civic educate most youths who are HIV positive about their mental health with the use of affordable media sources like WhatsApp or Facebook. Such initiatives would enhance the knowledge of mental health upon YPLHIV."* **YPLHIV, Africa**

Communities and families were also thought to require communication skills and opportunities to talk with young people. Participants indicated that addressing poverty would avail parents and caregivers with opportunities to talk with adolescents and young people. The quote below suggests that young people in Mozambique could not get answers from their families or communities due to limited time as searching for subsistence took up most of the people's time.

> *"Mental health and public health problems in Mozambique; since most of the population lives various adversities, especially those who live in a disadvantaged family. Their parents or caregivers do not have much time to talk to their children, and when teenagers and young people have a problem they hardly find an answer in the family, and that is why they start having these problems in their day-to-day."* **Stakeholder, Africa**

The neglect of empowerment in HIV treatment

Generally, there was dissatisfaction with HIV treatment services for their predominant focus on treating HIV and the neglect of aspects related to how to live with HIV.

> *"Psychiatrists focus heavily on medication and too little on empowerment, cognitive processes, and social care, in general, is also poor."* **Stakeholder, Americas**

For example, many participants complained that fears and anxieties related to treatment were rarely addressed in newly diagnosed young people.

> *"I think it is a very important issue to tackle with young people or any person who lives with HIV since, at the beginning when one only discovers that they have the disease, it is very complicated, everything falls apart, and you do not see an exit at the end of the tunnel, but not for having the disease but because of the social stigma that comes with having the disease and the fear that your family discriminates or judges you. The fact that you do not have support or the fear of dying for not knowing if you will receive treatment or if it is working."* **Stakeholder, Americas**

Lack of information about where to access mental health services

Participants in all regions painted a picture of complex pathways for accessing mental health services. The example below is from a participant from Eastern Europe who discussed different available options from different actors and their strengths and weaknesses.

> *"In AIDS centres, the services are better, but it may depend on the regions and regional mentality: somewhere doctors do their work not very conscientiously, they are not very friendly. It also depends on the situation. Not all HIV+ know where to go for help. In special institutions, services are of high quality and provided in a good atmosphere, but in-state clinics, the environment may be not very comfortable."* **YPLHIV, Europe**

However, some did not even know where to access mental health services.

> "[**I** failed to access services because] *I didn't know where to go with the problem." **YPLHIV, Eastern Europe***

And a few participants in Africa and Europe did not think there were any mental health services in their country, while some did not expect mental health to be a concern for HIV treatment services.

> "I don't know if we even have this service is available in my country."
> **YPLHIV, Africa**

Fear of non-confidentiality, and experiences of stigma and discrimination in clinical settings

Some participants did not trust that health workers would keep their information confidential. Some had experienced non-confidentiality during clinical encounters which demotivated them.

> *"I agree that the health provider makes the conversation between us confidential."* **YPLHIV, Africa**

> *"The offices of all the programs are full since they serve sex workers, PLHIV, MSM GB and the general population. By the way, they call your name and confidentiality is broken, there are looks and sometimes that causes anxiety and you end up avoiding going."* **YPLHIV, Americas**

The neglect of peer-educators/counsellors

Responses from stakeholders indicated that peer-educators were trained in mental health management and counselling, but a few peer-to-peer trainers reported that while they were trained to support others, they were not offered any support. They felt that providers mistook them for having everything under control when they too needed mental health support.

> *"I am a peer supporter, and all counsellors thought I was playing games but didn't actually need the service, since I am presumed to know it all."* **YPLHIV, Africa**

Facilitators of mental health access

A lot of the facilitators that young people mentioned were the direct opposite of the barriers presented above. For instance, a lot of participants mentioned that bringing specialist services closer to the communities could facilitate access. Two unique facilitators were identified as follows:

The role of peer-referrals in facilitating access to mental health services.

Participants were asked whether they experienced situations where a young person was able to access mental health services successfully. Success was operationalised as timely access and a positive outcome. Most responses from young people in Africa involved situations in which the respondents facilitated their peer's access to mental health services. Most of the cases involved newly diagnosed peers who were struggling to accept their diagnosis. It was apparent that the respondents were able to recognise that their peers were struggling because the mental health of their peers had deteriorated to a point where it was evident to an untrained eye. Fortunately, most of the accounts had positive endings, such as in the three examples below.

> *"A number of my friends were struggling with denial and giving up on life. One actually attempted suicide about three times. When I reported to the centre, the counsellor engaged her, and now she graduated this year as a teacher."* **YPLHIV, Africa**

> *"After seeing that one of my neighbours was having a mental health problem, and yet he was a YPLHIV, I quickly contacted my facility,*

> *which immediately sent an ambulance and took him in isolation. They provided him with a psychological supporter who kept on interviewing him until conditions started getting better."* **YPLHIV, Africa**

> *"I was able to help a peer get linked to one of the support groups to help him to adapt to his status and include in our community."* **YPLHIV, Africa**

Online services

Online services represented a solution for bringing services closer to young people, although this was restricted to those with access to the internet, which our sample was so privileged to have. Hospitals and clinics were often traumatising to young people due to confidentiality and trust issues.

> *"There are practically no trusted health services for YPLHIV to access on mental health."* **YPLHIV, Europe**

Participants from Eastern Europe desired more online support options with specialist providers. The same was the case in Latin America where the case was made that online services constitute low-cost solutions suitable for sensitising young people about HIV and supporting those living with HIV in urban settlements with appropriate levels of internet access.

> *"Sensitise online due to the fact that it is the route that is most used nowadays and that young people occupy much more to eliminate the stigma that comes from going to therapy and, of course, about HIV."* **YPLHIV, Americas.**

A few participants from the Africa region solicited online peer-chatting platforms for more relatable service.

> *"We need something like peer-to-peer online chatting. Feels safer and like someone relates. My 50-year-old health work is really nice but just so unrelatable. And again, I associate the clinic with negative vibes. I feel sad to be there, and I just don't want to be seen there."* **YPLHIV, Africa**

Summary and implications

Participants had experienced more situations where services had failed to respond in a timely fashion to the mental health needs of YPLHIV than situations where services had responded appropriately. In addition, many young people had experienced situations where they failed to access mental health services, and results suggest that accessing these services was stress-inducing for young participants, many of whom feared accessing HIV and mental health services.

Different types of mental health service provider were associated with different challenges. Although non-governmental organisations provided free services, they were not sustainable. Public services in Latin America, Africa and Eastern Europe lacked specialist providers, meaning that referrals were only made for severe cases, and long distances had to be travelled to access them. Private providers were charged fees and required long travel, except in case of online service providers. Other barriers to accessing mental health services included poor mental health literacy in the community, the neglect of empowerment in HIV treatment services, a lack of information about where to access services, and fear of non-confidentiality. Two facilitators of access to mental health services were peer-referrals and online services, although the latter has a limited reach due to poor rates of internet access in some countries.

Prioritisation of mental health in policy and practice

This chapter explores mental health prioritisation at different levels of the HIV-response in relation to both policy and practice.

Prioritisation of mental health by different actors in the HIV response

Participants were asked to rate the extent to which they believed that different actors prioritised the mental health of YPLHIV. The results are depicted in Table 26.

A high proportion of the YPLHIV who answered the survey felt that international, national, and community-based HIV organisations gave high priority to the mental health of YPLHIV and that they as YPLHIV, also prioritised mental health. A low proportion of YPHIV felt that health care providers, families, policymakers, and communities prioritised YPLHIV's mental health. Schools were believed to have the lowest prioritisation of YPLHIV's mental health.

The pattern of responses from stakeholders was broadly similar. However, more stakeholders than young participants felt that organisations prioritised the mental health of YPHIV, and fewer felt that families of YPHIV, policymakers and communities prioritised mental health in this group. Stakeholders also felt that schools gave a low priority to mental health in YPHIV.

Figure 32 Percentage of 48 stakeholders and 166 young people who believed that different actors highly prioritised the mental health of YPLHIV.

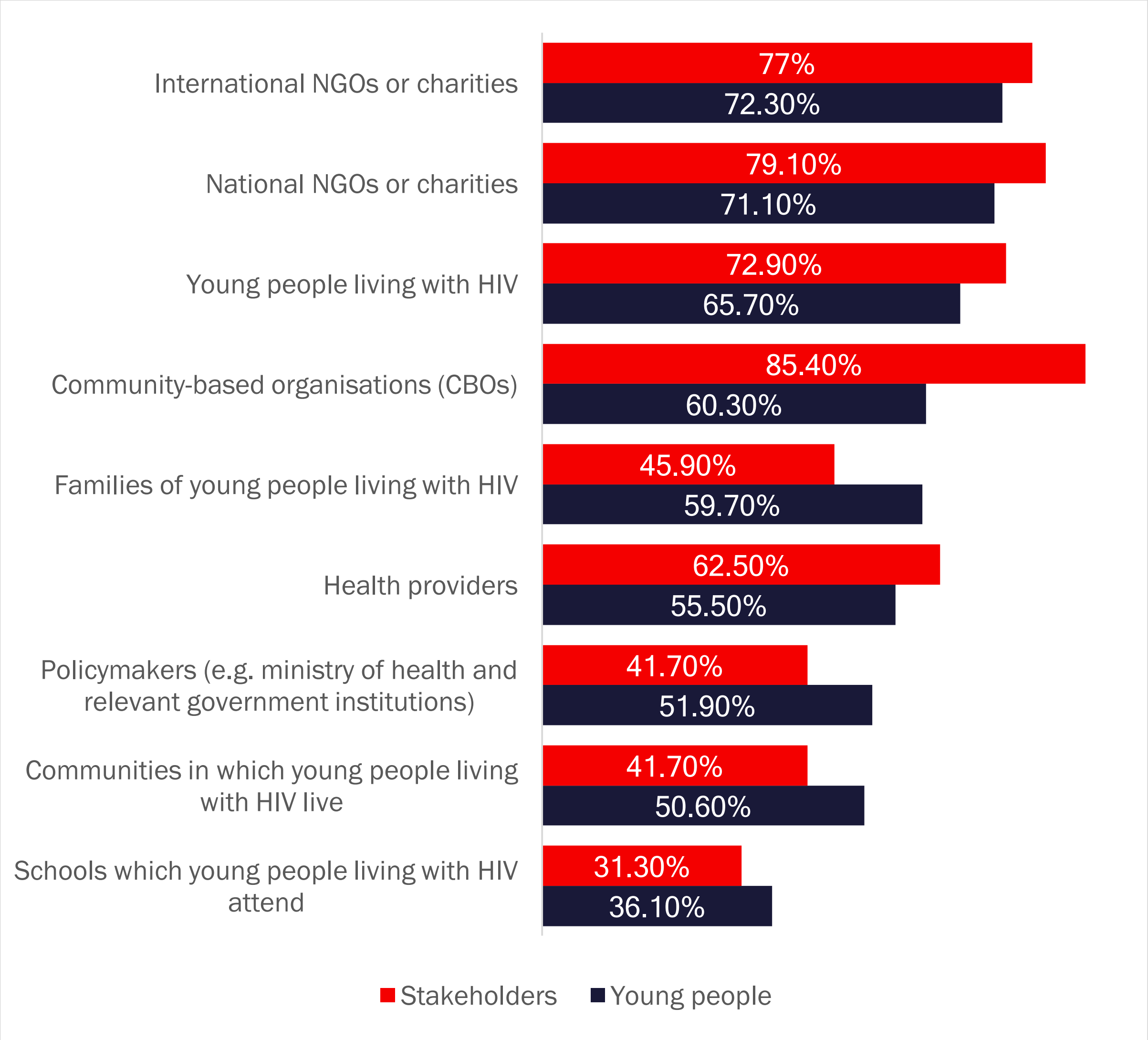


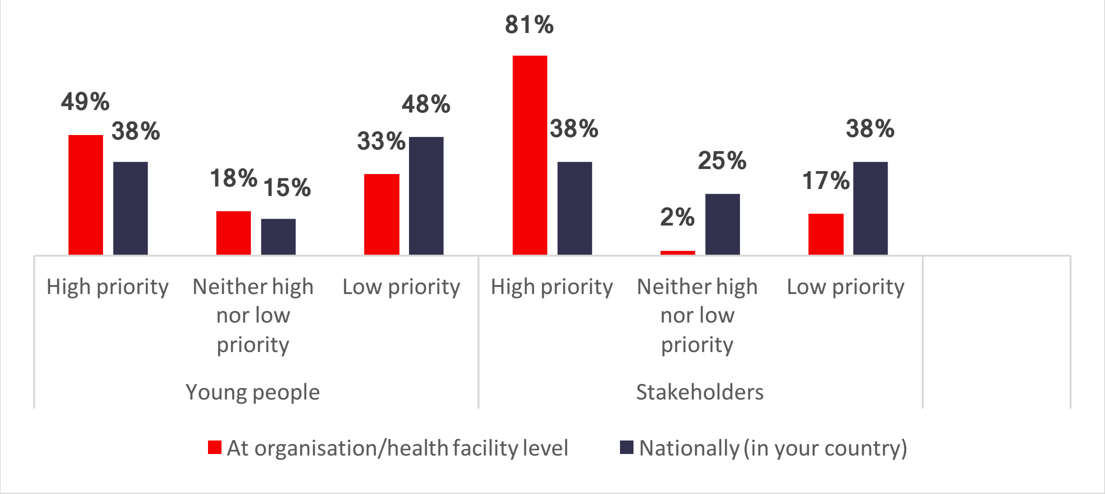
Table 26 Young people and professionals' perceptions of the extent to which different actors prioritise mental health

	% of young people (N = 166)			%of professionals (N=48)		
Themes	High priority	Neutral	Low priority	High priority	Neutral	Low priority
Young people living with HIV	65.7	12.7	20.4	72.9	14.6	12.6
Families of young people living with HIV	59.7	14.5	25.8	45.9	33.3	20.8
Communities in which young people living with HIV live	50.6	15.7	33.7	41.7	18.8	39.7
Schools which young people living with HIV attend	36.1	20.5	42.8	31.3	14.6	54.1
Health providers	55.5	18.7	24.6	62.5	20.8	16.7
Policymakers (e.g. ministry of health and relevant government institutions)	51.9	11.4	36.7	41.7	25	33.4
Community-based organisations (CBOs)	60.3	16.3	23.4	85.4	4.2	10.4
National NGOs or charities	71.1	13.9	15	79.1	6.3	12.5
International NGOs or charities	72.3	12.7	15	77	8.3	14.6

Prioritisation of mental health at the organisational and national levels

Half of the YPLHIV thought that the organisation or facility which they worked for or from which they received treatment prioritised mental health compared to eight out of ten stakeholders. On the contrary, close to two-fifths of both stakeholders and young people felt that mental health was highly prioritised at the national level.

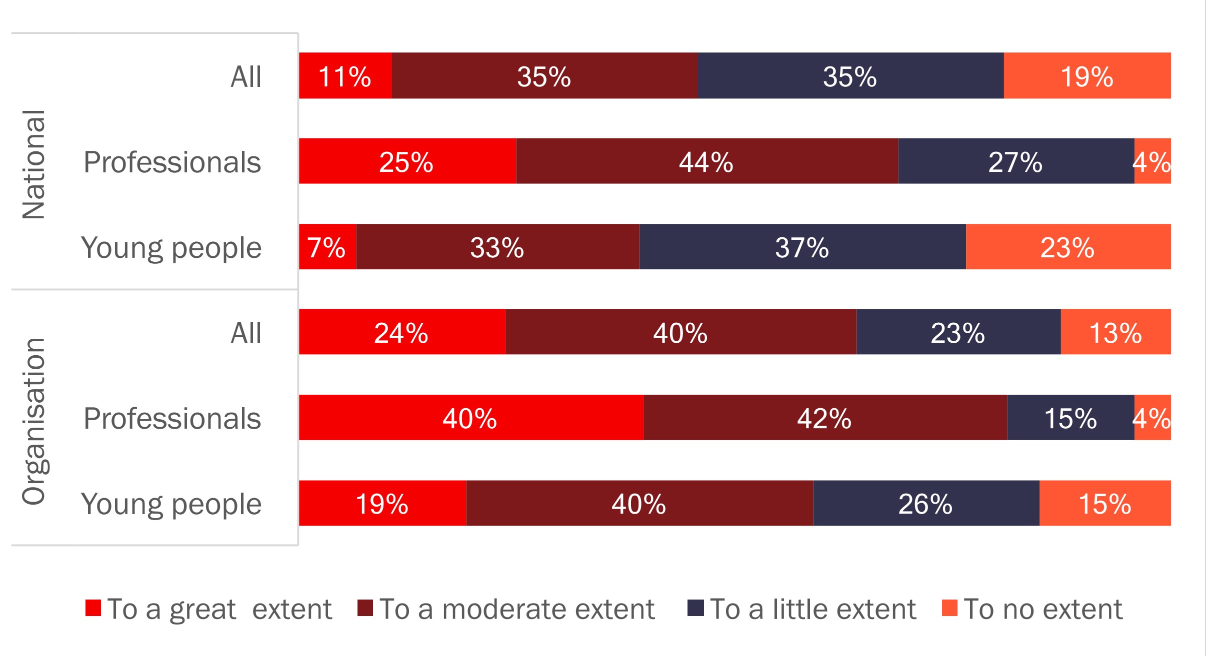
Figure 33 Perceptions of prioritisation of the mental health of YPLHIV at the National or organisational level



Prioritisation of mental health in national and organisational policies, strategies, guidelines, standards

Overall, participants felt that national-level policies, strategies, guidelines and/or standards prioritised mental health less compared to organisational-level policies. Over half (35% + 19%) of all participants felt that mental health was prioritised to '*a little or no extent'* in policies at the national level compared to thirty-six per cent (23% + 13%) at the organisational level. Two times more stakeholders than young people believed that mental health was addressed in national and organisation policies.

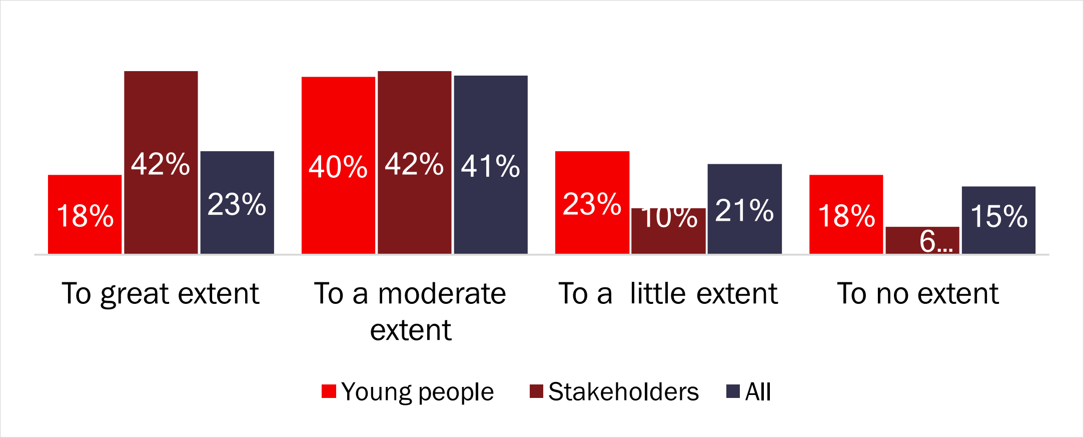
Figure 34 Perceptions regarding the extent to which policies, strategies and standards at national and organisational levels mention/address mental health



Prioritisation of mental health by organisations/health facilities through programmes and interventions - be it service delivery, research, and advocacy organisations.

A higher proportion of stakeholders than young people (42% vs 18%) believed that their organisations or health service facility addressed mental health in their programming to a '*great extent*', while equal majority proportions of young people and stakeholders, around 40%, felt that their organisations addressed mental health to a *'moderate extent'*. Thirty-six per cent (21% plus 15%) held that mental health was prioritised to a '*little or no extent*' by their organisation through interventions and programmes, see **Figure 35**.

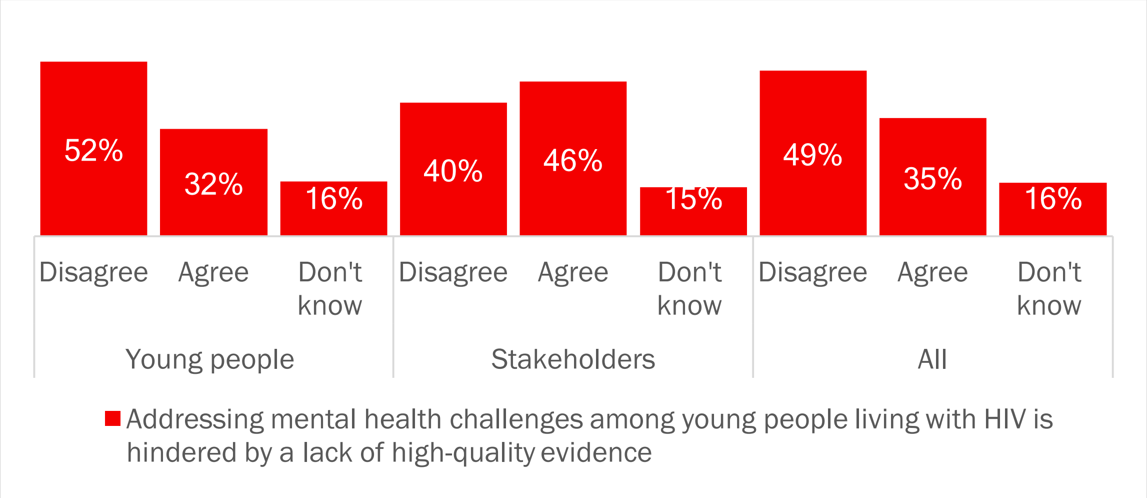
Figure 35 Perceptions regarding the extent to which mental health is addressed by organisations through interventions and programmes



Availability of quality research on mental health among YPLHIV

Figure 36 presents participants' perceptions of the statement: in my country, lack of good quality research evidence hinders the promotion of mental health for YPLHIV. The categories aggregated such that *'disagree'* is a combination of categories: Strongly disagree, disagree and somewhat disagree and likewise, '*agree'* is a combination of '*strongly agree*', '*agree'* and *'somewhat agree'*. There were mixed perceptions about the availability of quality evidence. Nearly half of all participants disagreed, while thirty-five per cent agreed with the statement. More young people agreed with the statement compared to stakeholders.

Figure 36 Perceptions on the extent to which lack of good quality research evidence hinder the promotion of mental health among YPLHIV



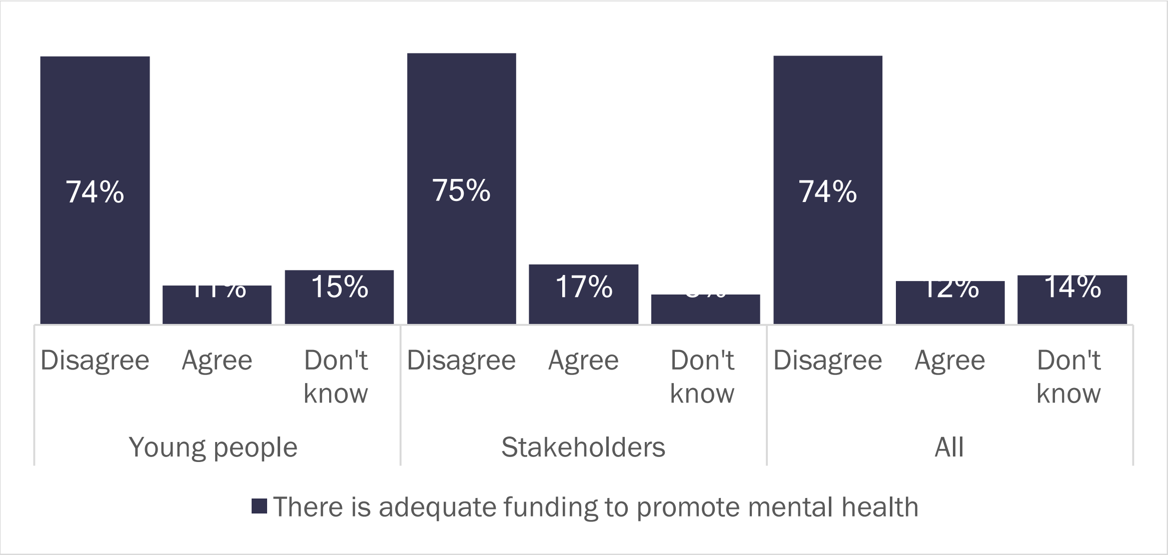
* Disagree is a combination of categories: Strongly disagree, disagree and somewhat disagree and likewise, agree is a combination of strongly agree, agree and somewhat agree.

Availability of funding to promote mental health among YPLHIV

Figure 37 presents participants perceptions of the statement: '*In my country, enough funding is allocated to promoting mental health among YPLHIV*'.

Around three-quarters of all respondents disagreed with the statement, and twelve per cent agreed–a higher proportion of stakeholders with the statement than young people.

Figure 37 Perceptions on the extent to which countries allocate adequate funding for the promotion of mental health among YPLHIV



Summary and implications

Mental health was not believed to be sufficiently prioritised in policies and guidelines at national and organisational levels, although prioritisation at organisational level was believed to be better. A higher proportion of stakeholders than young people believed that mental health was addressed to a great extent in policies. A similar pattern of perceptions was observed regarding the prioritisation of mental health in programmes and interventions at the organisational level whereby a higher proportion of stakeholders than young people reported that interventions and programmes addressed mental health to a great or very great extent.

Half of the participants believed that good quality research was available to support, but still, a high percentage believed that lack of good quality research was a hindrance for mental health promotion among YPLHIV. Participants agreed that a lack of funding to address mental health among YPLHIV was a challenge.

Making a change

This chapter focuses on ideas and suggestions for a way forward with regards to making a positive change towards the promotion of mental health among YPLHIV. It explores survey participants' perception of their own influence as well as the influence of other actors.

Perceived influence on policy

Participants were asked to what extent YPLHIV have an influence on the HIV response. **Figure 39 and Figure 38** below display the aggregate results where two categories have been combined into one. Find disaggregated results in **Table 27**.

Overall, young people reported having less influence on HIV-related policies, strategies, and guidelines as well as interventions and programmes at both country and facility or organisational levels compared to stakeholders. Both young people and stakeholders had more perceived influence on policies and interventions at the organisations and facilities where they worked or received treatment than at the country level.

Around seven out of ten young participants believed that YPLHIV had little or no influence on HIV interventions and programmes or strategies and guidelines at the organisational level. Eight of ten thought that they had little or no influence on the national level programmes and policies. A lower proportion of stakeholders who took part in the survey believed that YPLHIV had little or no influence on interventions programmes and policies at the organisational level; compare **Figure 39 and Figure 38.**

Figure 38 stakeholders participants' perceptions regarding the extent to which young people have an influence on policies and interventions at national and organisational levels

Figure 39 Young participants' perceptions regarding the extent to which young people have an influence on policies and interventions at national and organisational levels

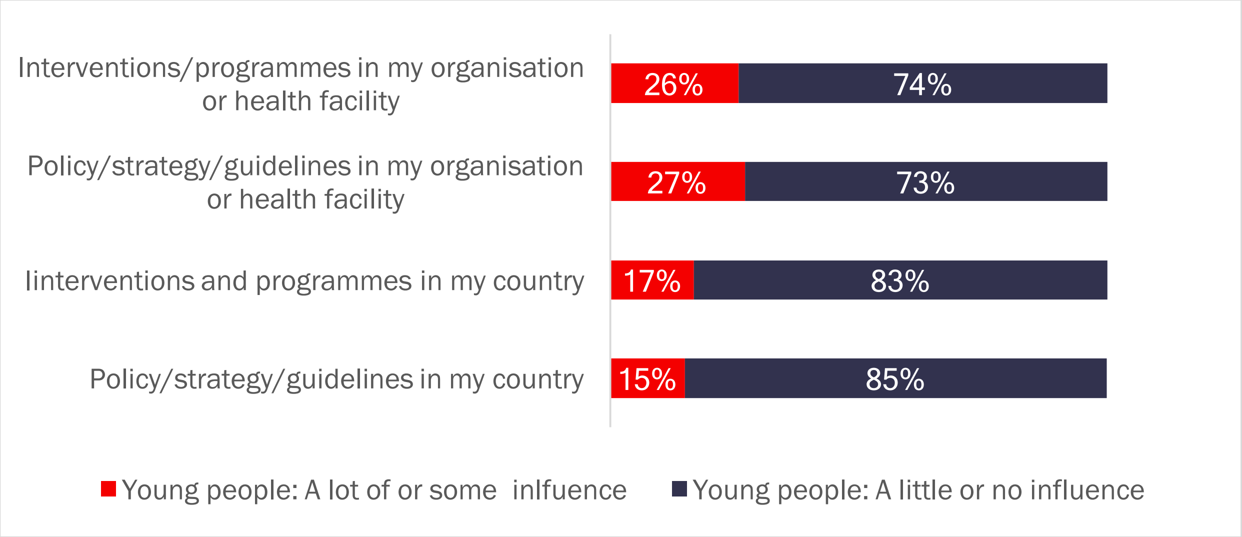


Table 27. The percentage of young people and professionals reporting different levels of perceived influence on policy/strategies/guidelines and interventions/programmes at country and organisational/facility levels

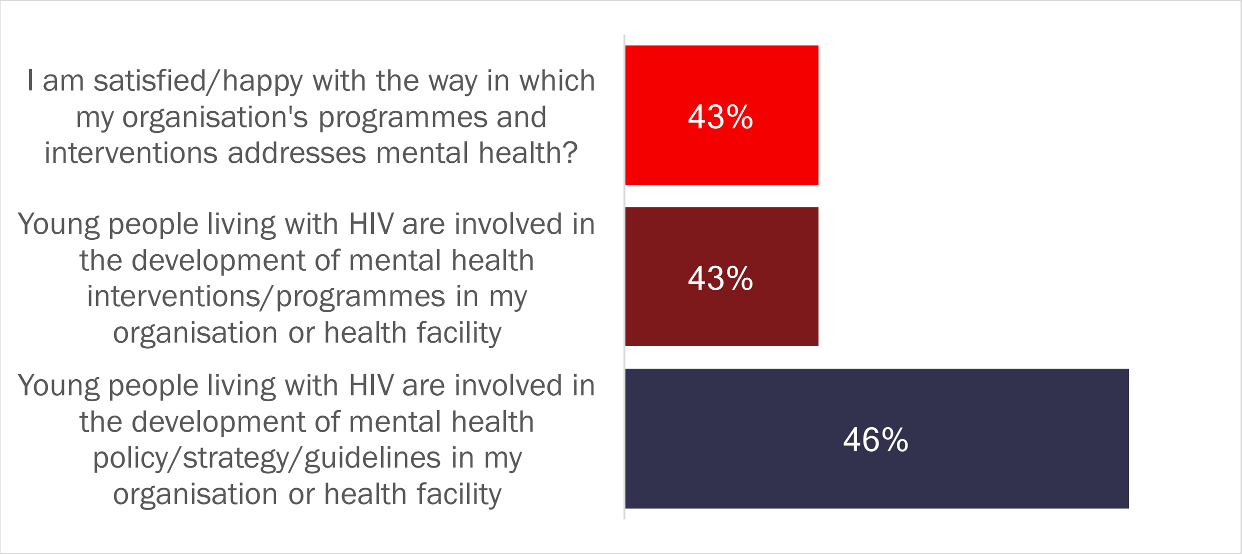
	% of (young people (N=166)			% stakeholders (N = 48)		
	A lot of influence	Some influence	A little or no influence	A lot of influence	Some influence	A little or no influence
[a] Policy in my country	3.6	11.4	84.9	10.4	20.8	68.7
[b]Programmes in my country	3.6	13.3	83.1	6.3	25	68.8
[a]Policy in my organisation or health facility	7.2	19.9	72.9	20.8	39.6	39.6
[b]Programmes in my organisation or health facility	7.2	18.7	74.1	22.9	41.7	35.4

[a] Policy covers policy/strategies and guidelines
[b] Programmes covers both programmes and interventions

Young people's perceptions of the extent of their involvement in policy and programme/intervention development at the organisational level.

Figure 40 shows that forty-six per cent of young participants believed that YPLHIV were not involved in the development of interventions and programmes in the organisation they worked or the facility where they received treatment. A similar proportion indicated that they were satisfied with the delivery of mental health services. Slightly more young people disagreed with the statement that YPLHIV were involved in the development of HIV-related policies at the national level. **Table 28** features more detailed data on this question.

Figure 40 Proportion of young respondents who ***disagreed*** *with statements regarding the involvement of young people in the development of policy and interventions at the organisational level*



*Based on data from 166 young respondents. Stakeholder respondents were too few to provide meaningful insight.

Table 28 Proportion of young respondents who disagreed or agreed with affirmative statements regarding the involvement of young people in the development of policy and interventions at the organisational level as well as satisfaction with organisational level management of mental health among YPLHIV.

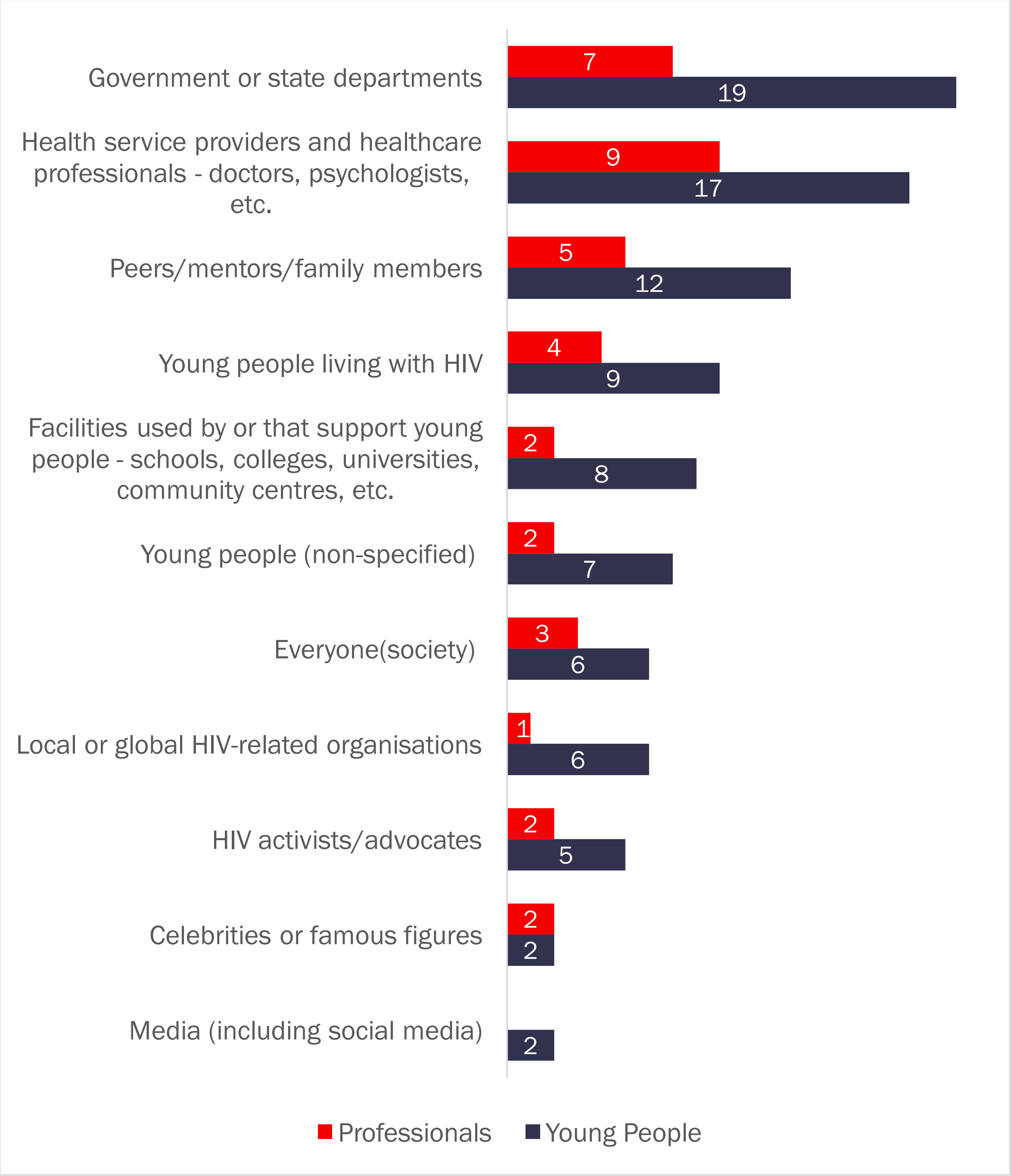
	Young people (N per row =166)		
	Disagree	Agree	Don’t know
YPLHIV are involved in the development of mental health policy/strategy/guidelines	46.2	32.7	21.1
YPLHIV are involved in the development of mental health interventions/programmes	43	42.3	14.7
I am satisfied/happy with the way in which my organisation’s programmes and interventions addresses mental health	43	46.7	10.4

*Disagree is a combination of categories: Strongly disagree, disagree and somewhat disagree and similarly for agree.

Influential actors in the HIV response according to study participants

Participants were asked to share their thoughts about actors they felt had the power [influence] to promote mental health among YPLHIV. **Figure 41** displays the resulting range of themes.

Figure 41 Percentage of young people and stakeholders who agreed with the themes regarding entities with the power to promote mental health among YPLHIV



*Based on 22 responses from stakeholders and 68 responses from young people.

Perceived influential actors were similar among young people and stakeholders except for the theme 'Media' (including social media), which was only suggested by young people. Governments, health workers and peers and mentors were believed to be influential by most participants. The influence that governments and state departments possessed was attributed to their law-making and financing capacities, while providers were thought to have power among others by virtue of their knowledge and expertise but also their capacity to exert influence on their employers, be it public or private. However, there was an emphasis on the need for action rather than lip service from these actors.

> *"I believe that there must be an important position of the doctors, of the professionals, that demand the owners of the entities that provide health. That must also come from the same ministry of health, but in an effective way, not as a speech, on the other hand, I consider that the organisations and people who live with HIV should make our voices heard about our needs but knowing that they will take us seriously."* **YPLHIV, Americas.**

Actors also associated with the power to positively influence mental health were YPLHIV themselves due to their first-hand experience. One participant elaborated that young people living openly with HIV have significant influence because of their potential to break down stigma by addressing misconceptions.

> *"People living openly with HIV in the community have the power to promote positive mental health among YPLHIV through challenging stigma simply by talking about living with the condition and challenging misconceptions. Reducing such stigma can have a powerful impact on improving the wellbeing of YPLHIV by making sure the stigma of the condition does not have a negative impact on their mental health."* **YPLHIV, Americas**

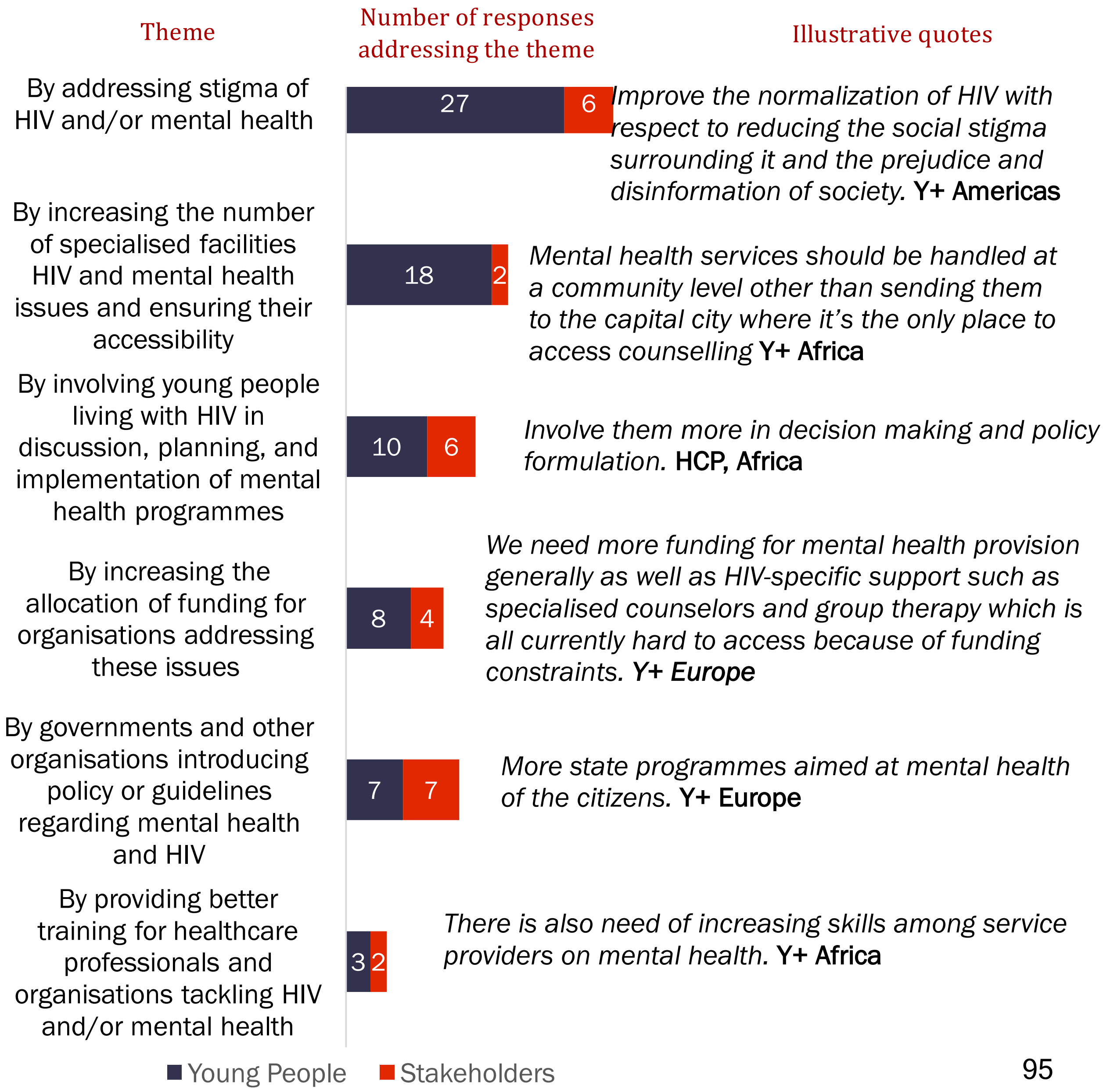
Suggestions for ways to improve the mental health of young people living

Twenty stakeholders and 92 young people shared their thoughts on what can be done to improve the mental health of YPLHIV, and six themes were identified from these responses.

Six stakeholders and 27 young people agreed that addressing stigma is key to improving the mental health of YPLHIV. Participants proposed two ways of addressing stigma: 'campaigning for greater awareness of HIV and/or mental health' and 'encouraging and providing better education on mental health and/or HIV for peers, families, and communities'. The suggestion of campaigning was only found among young people, who envisioned a peer-to-peer approach to campaigning on HIV-related stigma led by the community of YPLHIV. A suggestion was given by a young respondent from Southeast Asia to create mental health awareness through street drama. Participants asserted that awareness creation could help to eliminate misconceptions and taboos around both mental health and HIV, which could lead to the normalisation of HIV and mental health.

Although most responses addressed awareness raising in communities and society in general, two responses highlighted the need to make newly diagnosed YPLHIV aware of the mental health challenges associated with living with HIV and supporting them to deal with them. The suggestion to educate communities and families about mental health was also closely tied to HIV in that participants felt that mental health problems experienced by YPLHIV could be addressed more directly by educating families and carers so that young people can have people to confide in about their HIV-positive status and related challenges.

Figure 42 The percentage of young people and Stakeholders who agreed with individual themes addressing the question: How can we improve the mental health of YPLHIV?



Theme	Number of responses addressing the theme (Young People)	Number of responses addressing the theme (Stakeholders)	Illustrative quotes
By addressing stigma of HIV and/or mental health	27	6	*Improve the normalization of HIV with respect to reducing the social stigma surrounding it and the prejudice and disinformation of society.* **Y+ Americas**
By increasing the number of specialised facilities HIV and mental health issues and ensuring their accessibility	18	2	*Mental health services should be handled at a community level other than sending them to the capital city where it's the only place to access counselling* **Y+ Africa**
By involving young people living with HIV in discussion, planning, and implementation of mental health programmes	10	6	*Involve them more in decision making and policy formulation.* **HCP, Africa**
By increasing the allocation of funding for organisations addressing these issues	8	4	*We need more funding for mental health provision generally as well as HIV-specific support such as specialised counselors and group therapy which is all currently hard to access because of funding constraints.* ***Y+ Europe***
By governments and other organisations introducing policy or guidelines regarding mental health and HIV	7	7	*More state programmes aimed at mental health of the citizens.* **Y+ Europe**
By providing better training for healthcare professionals and organisations tackling HIV and/or mental health	3	2	*There is also need of increasing skills among service providers on mental health.* **Y+ Africa**

Eight young people and four stakeholder's responses addressed the need for an increase in funding allocation for addressing mental health. They acknowledged that funding is required to improve the accessibility of specialised mental health services and support at the community level and to address stigma. Increasing the number of specialised facilities was suggested by 18 young people and two stakeholders.

Ten young people and six stakeholders thought that involving YPLHIV in decision making including by inviting them to the table when planning and implementing programmes, is key to improving mental health among YPLHIV.

An equal number of stakeholders and young people (7) recommended increased donor aid and state-level prioritisation and leadership through mental health interventions and programmes including the adoption of laws, policies and campaigns. A specific policy that was mentioned was making mental health a compulsory element of HIV treatment or a requirement that mental health care is included in monitoring and accreditation standards.

Summary of findings and implications

The results imply that young people are not adequately involved in designing policies and programmes at the national and organisational levels. Comparing the perceptions of stakeholders and young people reveals that stakeholders overestimate young people's influence on policies and programmes at different levels, which might indicate lower forms of involvement such as tokenism, rather than active and meaningful involvement. The results also indicate that a high proportion of YPLHIV are not satisfied with the mental health services available to them, which is not surprising given the indication that they are not adequately involved in efforts to identify and address their mental health needs.

Involvement of young people in discussions, planning and implementation was one of the suggested actions that can promote mental health among YPLHIV. However, addressing HIV and mental health stigmas and increasing the number of specialist providers were believed to be key actions for promoting mental health among YPLHIV.

Discussion and recommendations.

The following discussion will draw on key insights from this study to generate recommendations on the way forward for improving mental health among YPLHIV. Apart from recommendations, strengths, limitations of the study are discussed.

Before you proceed, we encourage you to keep in mind that the sample of YPLHIV who responded to the survey was not representative of the global population of YPLHIV. Notably, the sample primarily represents educated Latin American men (including transgender men). However, the issues raised in the study appeared to resonate with all participants, irrespective of demographic characteristics.

Towards a bespoke definition of mental health for YPLHIV

We set out to understand what mental health means for YPLHIV and discovered that mental health is a complex phenomenon that means different things to different people. We generated a bespoke definition of mental health, applicable to YPLHIV globally, although the definition represents a work in progress given the study limitations discussed later.

Mental health/wellbeing entails a state of harmony between one's inner and external self that is based on a sense of physical, social, emotional, and spiritual adaptation. It is the capacity to feel, think, and act in ways that enhance wellbeing while respecting the importance of culture, equity, social justice, interpersonal connections, and personal dignity. Mental health is variable; it exists on a continuum between extreme wellbeing and severe mental ill health, and an individual's mental health can vary and fluctuate along the continuum. Maintaining mental health across the lifespan relies on one's ability to cope with challenges and life's stressors, adapt to new situations, and self-manage. Mental health empowers us to thrive and flourish.

This definition is akin to the existing definitions in that it is abstract and not easily translatable to actions for improving mental health. Thus, this study demonstrates that a bespoke definition of mental health can be attained by asking YPLHIV to define mental health based on their personal experiences. Such an approach recognises recognise the lay perspective which is fundamental to health promotion practice (34).

Many of the definitions suggested by young people in the study (see **Table 7**), circled around individual strengths and abilities. The suggested mental states and dispositions were things that could be addressed. For instance, one of the attributes that young people associated with mental health and wellbeing was *'living in the moment'*. The practice of mindfulness enables one to focus one's awareness on the present moment, thus, the practice of mindfulness might be a useful tool for YPLHIV to achieve mental wellbeing. Mindfulness also helps to achieve inner '*peace and mental clarity'* as well as*self-'knowledge/awareness' and an 'ability to accept the way things are,'* which were other attributes of mental health mentioned by young people in this study. Mindfulness has shown a positive effect on both psychological and HIV-disease outcomes among YPLHIV (35). In addition, a study in Hong Kong found that self-compassion and mindfulness can act as buffers against self-stigma among young people (36).

> **Recommendation:** This study has taken initial steps of identifying personal dispositions, mental states, and general outlook that characterise mental health for YPLHIV. Further research is needed to complete and validate a list of components that could serve as a point of reference for intervention development for YPLHIV. Such a list would support services to promote mental health through activities aimed at strengthening individual resilience.

> However, the generated abstract definition suggests that these efforts would yield the best results in combination with efforts to tackle social and environmental elements that contribute to poor mental health.

COVID-19 and mental health

This study supports claims that human-made and natural disasters such as armed conflict, earthquakes, and epidemics increase the incidence of mental and emotional health problems in affected communities (3). The study shows that COVID-19 and the associated lock-down has intensified already existing problems of access to treatment and worries related to health management for YPLHIV. In addition, young people were fearful of having a compromised immune system and a high vulnerability to contracting COVID-19, experiencing severe symptoms, and potentially dying from it. There were fears that the supply of HIV treatment, which was already poor before COVID, would be further compromised. Another concern was that health systems would opt not to provide Covid treatment to people living with HIV in the worst-case scenario where treatment for COVID-19 needed to be rationed.

> **Recommendation:** the current COVID-19 pandemic should be a point for learning on how to tackle similar health crisis in the future in ways that minimise adverse mental health impact on PLHIV. One thing that is clear from the results of this research is that there is a need for more sustainable and robust treatment procurement and supply chains as well as affordable and flexible care for PLHIV during crises. It is also crucial that bespoke information is disseminated at the earliest possible time and through trusted and varied channels, online and offline, to alleviate fear due to uncertainties.

Mental health challenges and manifestations of poor mental health

In addition to other everyday stressors and traumatising events, that may also be experienced by people not living with HIV, the mental health of YPLHIV is highly influenced by traumatic experiences related to HIV stigma and discrimination and managing HIV. Normal life stressors can exacerbate HIV-related stressors and traumas and vice-versa, leading to mental health disorders such as depression and anxiety. Trauma here refers to experiences that cause intense physical and psychological stress reactions. It can refer to

> *"a single event, multiple events, or a set of circumstances that is experienced by an individual as physically and emotionally harmful or threatening and that has lasting adverse effects on the individual's physical, social, emotional, or spiritual wellbeing".* **(37)**

These findings are supported by findings by a review of literature on HIV and trauma (38), that found high but variable rates of trauma in PLHIV, ranging from 10%-90%.

Recommendation: the picture painted by our analysis supports the case for the introduction of trauma-informed care as a basic standard for HIV treatment and support. The trauma-informed approach in this context involves:

> *"an understanding of trauma and an awareness of the pervasive impact it can have across settings, services, and populations. It involves viewing trauma through an ecological and cultural lens and recognising that context plays a significant role in how individuals perceive and process traumatic events, whether acute or chronic."* – **adapted from (39).**

Trauma-informed care refers to a strengths-based service delivery approach:

> *"that is grounded in an understanding of and responsiveness to the impact of trauma, that emphasises physical, psychological, and emotional safety for both providers and survivors, and that creates opportunities for survivors to rebuild a sense of control and empowerment"* **(40).**

In other words, HIV services should take into consideration the intersection of HIV and trauma, including the bidirectional link between the traumatic consequences of living with HIV and other everyday stressors and traumas. HIV services should avoid being a traumatic experience for YPLHIV and they should support YPLHIV to cope with past traumas and prevent future ones.

Substance abuse and mental health

Many studies have reported a high prevalence of abuse of tobacco, alcohol, and illicit drugs among both young people and adults living with HIV globally (41). A majority of young participants reported cutting down on their drinking and smoking behaviours after their diagnosis. This could be expected of a highly educated sample population. Educational attainment has been associated with high levels of health literacy, which in turn is associated with health promoting behaviours among young people (42-44). However, it is widely acknowledged that substance abuse and mental health disorders are interlinked. This study supports others that suggests that substance abuse is an indicator of poor mental health such that poor mental health should be suspected as the underlying problem for YPLHIV presenting with substance abuse problems. Unfortunately, this study also suggests that screening for substance abuse is not widely practised in clinical contexts, which means lost opportunities for detecting and addressing mental health challenges.

Recommendation: routine screening for substance abuse should be an integrated component of HIV treatment services, alongside screening for mental health disorders, primarily depression and anxiety. In addition, it is imperative for services to have an ongoing open dialogue with YPLHIV on these matters and ensure high literacy levels regarding health risks associated with alcohol, tobacco and other illicit substance use. Services should support young people to distinguish between recreational substance use and addiction and help prevent the later.

Prioritisation of mental health

This study demonstrates a suboptimal prioritisation of mental health at both organisational and policy levels and suggests that most of the available services and support systems have little to no national policy basis. One of the consequences of this was the agreement among participants that there was inadequate funding to address the mental health challenges faced by YPLHIV. The lack of funding for the global mental health crisis has previously been highlighted (3, 45).

Most participants in this study believed that governments and state departments were the most influential actors to bring about change through their legislative and financing capacities. Many also felt that health service providers could be influential, but they too were not believed to adequately prioritise mental health. Furthermore, the study suggested that health workers did not receive mental health awareness training, which fits well with reported lack of mental health literacy among health professionals, including skills to discuss mental health with YPLHIV. Institutions that support young people, such as educational institutions and community centres, were also considered influential, but they too lacked mental health awareness training.

This study suggests that while there exists high-quality research evidence to justify and guide mental health support services, more is needed. Evidence of cost-effective mental health interventions are available, but there is a need to explore their adaptability and scalability within routine primary care contexts in low-and middle-income countries (46).

> **Recommendation:** There is a need for investment in research into the treatment and promotion of mental health among YPLHIV globally but most especially in low-and middle-income countries. Research is needed on the effectiveness of existing approaches for addressing mental health issues faced by YPLHIV as well as effective approaches to adaptation and scaling. Efforts should also be put into eliminating the stigma associated with mental disorders through sensitisation and awareness raising campaigns and programmes.
>
> Training should be provided to key stakeholders in the HIV response, and as a minimum standard, health providers and educators should be trained. Other stakeholders might also be considered critical to the response depending on the context.

Affordability and access

The major barriers to mental health access reported in this study were lack of specialised providers, cost, distance, long waiting time, lack of knowledge of where to access mental health services and unwelcoming service environments, including fear of poor provider attitudes and non-confidentiality. Some barriers were associated with specific types of mental health providers. For instance, while NGOs were regarded to be the best provider of mental health services, the services were criticised for lacking sustainability. Public services were criticised for having few specialists meaning that long distances were involved. The grievance related to private providers was the high cost, although this was not an issue for some participants in countries like Chile, who had insurance through their employer. These issues were only reported in low-income countries. Most of these issues have been highlighted in previous research around access to mental health services by young people (45) or PLHIV (15).

Recommendation: Governments and donors need to provide longer term funding for programme sustainability and channel funding directly to local or youth led CSOs delivering services at grassroots level. Furthermore, government and donors should invest in increased training of mental health professionals and increased provision of specialist mental health services in rural areas through outreach services and mobile clinics. Generally, donors and governments should also invest in improving mental health literacy, (47), particularly among stakeholders in the response to the HIV pandemic and most importantly, among YPLHIV, their carers and health providers. Increased public/private partnerships in the provision of mental health services can help reduce the cost of private services for YPLHIV. It is also critical to invest in expanding online mental health provisions as appropriate to country contexts. Further research is needed to tailor services to the needs and preferences of YPHIV in different regional and national contexts. Overall, there is a need in invest in youth-friendly services (48, 49). It is unacceptable that in 2020, YPLHIV are still experiencing HIV-stigma in healthcare settings when healthcare institutions should be the ones to set an example. Institutions that are serious about ending HIV-stigma should implement the Positive Allies Charter Mark :

> *A free and unique charter mark available for all organisations, whether they are large or small and whether they have paid employees or volunteers. This is designed to show that your organisation is friendly toward and inclusive of, PLHIV and that you actively challenge HIV stigma. No matter the size, type or shape of your organisation, you are eligible to apply. This charter mark is open to organisations based in the United Kingdom and internationally.* **(50)**

Mental health in HIV treatment services

Many studies have highlighted the need for mental health to be integrated into HIV treatment services (23), and this cannot be emphasised enough when it comes to the challenges faced by YPLHIV. Adolescence and youth cover a transitioning phase where adolescents and young people may need to move from one service to another. For instance, young people might be required to move from paediatric to adolescent services or from adolescent services to adult services (51). Mental health support should be integrated into all services to promote mental health throughout the transition, and effective communication between services should facilitate continuous care. This is particularly important for young people who contracted HIV through mother to child transmission because HIV disclosure to children can be a traumatising experience. Children's mental health should be safeguarded in this period as failure to do may lead to mental health challenges in adolescence, young adulthood, and adulthood. The study also suggested poor integration of mental health into different stages of the transition process and in HIV treatment services generally.

> **Recommendation:** mental health should be an integrated component of HIV treatment services; from paediatric through adolescent to adult services. Mental health should be treated, but also the mental health impact of treatment approaches should be considered. Ideally, microlevel clinical integration should be aimed for, where coordinated person-centred care is provided in a single process across time, place and discipline, and with a single care plan for both HIV and mental health. (52, 53).

Involvement of young people in the HIV response

This study found that young people's general outlook on life was also thought to influence mental health; however, this was connected to the availability of opportunities for self-realisation and achieving one's dreams. Young people acknowledged the need for interconnections with others and the environment. A key aspect of this was the need to find meaning and a purpose in life as well as the need to feel needed and part of society. This study proposes that some YPLHIV find meaning and a purpose from being meaningfully involved in the HIV response. Among other things, young people were involved in the delivery of mental health services both officially through roles as peer counsellors or peer-supporters, but they also played a critical informal role of 'referring' their peers to mental health services. Unfortunately, these referrals were often done late when peers being referred had reached a crisis point. The study also demonstrated that with the right support, YPLHIV are capable and willing to be instrumental in addressing HIV stigma.

Young people have advocated for their meaningful involvement in the HIV response for several years with little progress. It is encouraging that, recently, UNAIDS has made efforts to champion meaningful youth participation. Some steps have been taken in the right direction including the recent publication on a three-lens approach to mainstreaming youth in the HIV response (54) as well as the fact that meaningful engagement of YPLHIV in the global response was a key message for World Youth Day on 12th August 2020 (UNAIDS, 2020). However, this study demonstrates a need for real action rather than lip service or tokenism from governments and institutions such as UNAIDS. This study joins others that support the case for increased meaningful involvement of young people in all stages and areas of the HIV response. Meaningful also implies that young people should be involved in determining the terms for their involvement.

> **Recommendation:** YPLHIV have an important role to play in the HIV response, and, as outlined above, it benefits their mental health to do so; thus, it is our recommendation that donors, governments, and organisations should

involve YPLHIV in all process of the response and that their involvement should be on their own terms. In particular, the potential of young people openly living with HIV to contribute to the eradication of stigma should be capitalised on.

Study strengths

This study provides a comprehensive exploration of mental health among YPLHIV and covers a wide variety of topics relating to this. It draws on the perspectives of YPLHIV as well as professionals, including activists, researchers, and health workers, among others. In particular, the voice of YPLHIV is underrepresented in mental health research, which makes this report relevant, especially in this era of COVID-19 which has intensified the need for appropriate mental health services for young people generally, but even more so for YPLHIV, as demonstrated by this study.

Study limitations

Our samples of young people and professionals did not live up to the intended sizes for all regions. We had a good representation of young people from Latin America, with the exception that Chile was over-represented. Generally, the sample sizes were not adequate for comparisons across different demographic locations. Our samples from Southeast Asia and Western-pacific were particularly small. That we did not report regionally stratified results as originally intended does not mean that we are negligent of the regional differences, some of which emerged in the qualitative content analysis. However, the most interesting insight from the study was the commonality of mental health challenges experienced by YPLHIV across the surveyed regions. The differences that emerged in the qualitative work mainly highlighted that some issues were more salient in some regions than others. Thus, a limitation of the study is that it does not provide insights into the differences in the salience of the issues in the different regions.

Recruiting adequate sample sizes in all regions of the world proved more challenging than originally anticipated. The challenges of recruiting were partly influenced by differences in mental health literacy levels and the perceived need for mental health services. The study results are thus biased towards people with good mental health literacy and a high perceived need of improvement in the mental health provisions available to YPLHIV in their countries. The notion that mental health literacy influenced eligible candidates to engage with the survey was evidenced in correspondence between the lead researcher and potential participants, who wanted to ask what the survey involved to decide if it was for them. Most of these young people decided to respond to the survey after the lead researcher explained what mental health means and why it is important. Most of the correspondence in this case was with young people from the African region.

Apart from mental health literacy, the high response rate from Chile appeared to be attributable to the fact that a Chilean organisation, Fundación Chile Positivo, assisted with the dissemination of the survey in Latin America. Although some responses were collected from other Latin American countries, most came from Chile, where respondents were familiar with the organisation that was sharing the survey. Similarly, although Y+ Global is a global organisation, it is more active in sub-Saharan Africa, which could explain why more responses were collected from the region. For the francophone countries in Africa and the Eastern Mediterranean region, language barriers limited participation, which was expected. Overall, we did not recruit many participants from places we expected to get a lot of interest, such as South Africa, the UK and the USA.

The sample of young people was not representative of YPLHIV in that more than half of the group of YPLHIV who took part were highly educated, with a majority having an undergraduate degree or above. This means that our study does not capture the voices of less privileged young people who have no formal education or who have not been to high school, and their experiences are expected to be significantly different. The sample also has a poor representation of women (including transgender women), despite there being a similar prevalence of HIV in both gender groups globally (55). That the sample was highly educated is not surprising given that the survey was disseminated online which means that respondents were expected to know how to read and write, and to have access to electronic devices and the internet. This barrier was compounded by the length of the survey, which was motivated by a need to explore issues pertaining to both mental health and diverse social determinants of mental health. The gender representation was not surprising due to gender inequalities in access to and control of resources (56). In person data collection was originally planned but this was not possible due to physical the COVID-19 pandemic.

Future iterations of the survey should strive to incorporate face-to-face survey administration with the help of field interviewers. A shorter survey exploring key issues would gain a higher response rate and sampling a few representative countries per region would facilitate collaboration with local organisations that could add credibility to the research.

Conclusion

YPLHIV should be counted among populations that are particularly vulnerable to poor mental health, and that need special attention. Attending to the mental health needs of YPLHIV requires a renewed and galvanised commitment to delivering 'youth-friendly' health services within the HIV sector. In addition, attention should be paid to increasing HIV and mental health literacy in society generally, and particularly among key stakeholders in response to HIV among YPLHIV. Integrating mental health into HIV services is necessary to prevent the onset of severe mental ill health among YPLHIV and to promote their mental health. Involving young people in planning and delivering HIV and mental health services is critical to achieving the desired health outcomes. Lastly, there is a need for continued research on the impact of HIV on the mental health of YPLHIV and how this can be prevented and/or mitigated. All these activities require an increase in financial investment towards addressing the impact of HIV on YPLHIV.

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Appendices

Appendix 1.

Regional sampling quotas -sample

Eastern Mediterranean		Year	AIDS-related Mortality rates	above or below the median	Target sample
Djibouti	DJI	2017	67.00917	above	
Sudan	SDN	2017	16.24058		
United Arab Emirates	ARE	2017	7.411787		
Oman	OMN	2017	3.078762		
Pakistan	PAK	2017	2.794231		
Morocco	MAR	2017	1.703507		
Tunisia	TUN	2017	1.590854		
Libya	LBY	2017	1.454907		
Yemen	YEM	2017	1.40217		75 young people75 stakeholders
Saudi Arabia	SAU	2017	1.349111		
Lebanon	LBN	2017	1.34663	below	
Afghanistan	AFG	2017	1.087497		
Iran	IRN	2017	0.897638		
Bahrain	BHR	2017	0.716294		
Iraq	IRQ	2017	0.253943		
Qatar	QAT	2017	0.231818		
Jordan	JOR	2017	0.230537		
Kuwait	KWT	2017	0.1237		
Egypt	EGY	2017	0.068272		75 young people; 75 stakeholders
Syria	SYR	2017	0.067839		

Western Pacific		Year	AIDS-related Mortality rates	above or below the median	target sample
Micronesia (country)	FSM	2017	33.09083	above	75 young people; 75 stakeholders
Somalia	SOM	2017	17.63649		
Papua New Guinea	PNG	2017	15.4814		
Cambodia	KHM	2017	9.018716		
Laos	LAO	2017	8.130944		
Vanuatu	VUT	2017	6.045707		
Malaysia	MYS	2017	5.313659		
Solomon Islands	SLB	2017	5.181522		
Marshall Islands	MHL	2017	5.174687		
Philippines	PHL	2017	3.995494		

China	CHN	2017	1.951689	below	
Tonga	TON	2017	1.295725		
Fiji	FJI	2017	1.11464		
Brunei	BRN	2017	1.037396		
Mongolia	MNG	2017	0.638707		
Kiribati	KIR	2017	0.420064		
Australia	AUS	2017	0.268313		
South Korea	KOR	2017	0.207845		
New Zealand	NZL	2017	0.205785		75 young people; 75 stakeholders s
Japan	JPN	2015	0.133954		

Appendix 2

Country	**Number of participants**
Americas (Latin America)	
Chile	56
Mexico	16
Colombia	8
Argentina	8
Bolivia	8
Guatemala	5
Brazil	2
Equator	2
Costa Rica	1
Honduras	1
Peru	1
Africa	
Uganda	7
Malawi	3
Zimbabwe	3
Rwanda	2

Zambia	2
Burundi	1
South Africa	1
Tanzania	1
Europe	
Russia	16
Ukraine	3
UK	2
Spain	1
The Netherlands	2
Moldavia	1
South-East Asia	
India	7
Myanmar	1
Nepal	1
Western pacific	
Philippines	1

Appendix 3

Table 29 Organisations implementing mental health interventions or research projects

Region	Name of organisation	Research or intervention
Latin America		
Guatemala	CAS	Works to prevent the transmission of HIV and other STIs in gay and bisexual men in a social environment without stigma or discrimination. https://casgt.org/
Chile	ONG savia	Foundation Savia A not-for-profit organisation with volunteers working to 'break the barriers of misunderstanding, social exclusion, intolerance and discrimination' for those living with HIV. http://www.fundacionsavia.cl/
Chile	AccionGay.	Chilean AIDS Prevention Corporation (ACCIONGAY) Work with three aims: to reduce the risk of HIV transmission, support PLHIV, mitigate negative social and cultural impacts of HIV. Work on the basis that all people have a right to health and bodily autonomy, so work to increase people's knowledge and ability to make decisions for themselves. http://www.acciongay.cl/
Chile	Movimiento por la Diversidad Sexual (MUMS)	A gay rights movement.
Chile	Círculo de estudiantes viviendo con VIH (Circle of students living with HIV)	A group of activists sharing information and events on social media to educate people on testing, condom use, stigma and more. For instance, one event advertised is for YPLWHIV and includes training and workshops. They also say 'We have no excuses for not starting to organise ourselves: young people are a fundamental part of the national response that the HIV emergency needs in our country' https://www.facebook.com/cevvih/
Mexico	SENCIDA	National Center for the Prevention and Control of HIV and AIDS - https://www.gob.mx/censida
Mexico	Yaaj and positive youth. But they demand activism in exchange for aid	'a civil association dedicated to promoting the protection and respect of the human rights of LGBT+ people and the creation of a more equal society'. http://yaajmexico.org/yaaj-in-english/

Mexico	CONASIDA	Conasida - National Council for the Prevention and Control of HIV and AIDS An organisation attached to the Ministry of Health that says it is 'a permanent coordinating body for the public, social and private sectors to promote and support prevention and control of HIV'
Brazil	Universidade Estadual do Rio de Janeiro (UERJ) Grupo pela vidda RJ	Rio de Janeiro State University. Not-for-profit, work to deconstruct stigma and reintegrate PLWHIV into social life and defend the human rights and dignity of PLWHIV. Hosts various groups and activities for PLWHIV, offers free legal assistance. seeks to be involved in creating public health policies, and participates in conferences, events, and meetings with the state and other HIV organisations, including UNAIDS. http://www.pelavidda.org.br/site/
Brazil	Universidade do Estado do Rio Grande do Norte - UERN.	Some students are dedicating themselves to the theme of HIV. UERN students are even developing research on Auriculotherapy and Reike to help improve the immunity of PLHIV
Colombia	Fundación Jóvenes Positivos (Young positives Foundation).	They accompany young people when they have problems receiving their medications, to have a medical appointment, to access a psychotherapist or support from a couple.
Argentina	Rosas Foundation in Córdoba	Therapy companions who address the issue of HIV.
	Guest Foundation in Buenos Aires.	
Chile	Fundación Chile positive Cevvih (centro de estudiantes viviendo con VIH).	https://www.chilepositivo.org/ A project focusing on education for the prevention of HIV and STIs - carries out research about the social variables of HIV, carried out training, public interventions. Aim to be 'nationally and internationally recognised social leaders for our work on HIV, promoting respect and dignity of people'
Bolivia	The Network of PLHIV in Bolivia (REDBOL)	With the support of Save, the Children generated two meetings of children and adolescents living or affected by HIV where support for this population began.

	La asociación un nuevo camino (ASUNCAMI)	ASUNCAMI lead a team of PLHIV Peer Educators who are generating general follow-up to the newly detected cases of HIV including young people and some adolescents
Africa		
Uganda	Rainbow Mirrors Uganda	Offers online counselling services for Transwomen, with a drop-in centre with a full-time counsellor to address issues of mental health—a peer to peer community model to reach out to more victims of violence and stigma cases.
Uganda	Awesome Mind Speaks	An NGO in Uganda leading change in mental health with an emphasis on integrating mental health and sexual reproductive health and HIV/AIDs awareness campaigns
Uganda	PMJ Foundation Uganda	A community-based organisation that creates awareness about HIV, guides and counsels and even extends medical services to the affected families.
Uganda	Action for Fundamental Change and Development (AFFCAD)	The not-for-profit organisation started to transform living conditions in Kampala's slums by 'empowering the children, youth, and young women through education, health, and economic empowerment programs' https://www.affcad.org/
Zambia	Strong minds organisation in Zambia	A social enterprise that provides mental health services to impoverished African women - in particular, depression. https://strongminds.org/
Zambia	Renaisense organisation	A private counselling and therapy service. https://www.renaisense.net/ -
	Tendai open minds project by	A research project at Kings College London that addresses depressions among PLHIV.
Uganda	Uganda Network of YPLHIV/AIDS	https://unypa.org/ An organisation started to 'provide leadership and coordinate the greater and meaningful involvement and participation of YPLWHIV in Uganda in the national, regional, and global HIV and AIDS response'. They advocate for young people's involvement in addition to promoting access to care and treatment for YPLWHIV and fighting stigma and discrimination.
Uganda	Makerere University Joint AIDS program	https://mjap.mak.ac.ug/ Provide HIV/AIDS services including testing, post-exposure prophylaxis, basic HIV/AIDS

		care, support for victims of gender-based or sexual violence.
Uganda	Uganda Harm Reduction Network	http://ugandaharmreduction.org/ A youth-led drug user initiative responding to the drugs crisis in Uganda - provide information and practical interventions to people who use drugs. One strand of this is combatting the correlation between drug use and HIV diagnosis.
Eastern and Southern Africa	The Harm Reduction Consortium, regional Africaid	Received funding from the Robert Carr Fund for Consortium partners to work on joint projects, advocacy, and events regarding drug harm reduction, as well as HIV advocacy work
Not disclosed	Winam Care for Adolescents,	https://africaid.org/ Work to improve the standing of women through mentoring initiatives Tanzania
Not disclosed	Compassion Ministries	https://www.compassion.com/child-development/christian-ministries/ Provide the option for someone to 'sponsor a child.'
Zimbabwe	Friendship Bench (Dr Dickson Chibanda, prof Simbarashe rusakaniko)	https://www.centreforglobalmentalhealth.org/dr-dixon-chibanda An initiative/research investigating the use of 'Friendship benches' to improve psychological wellbeing
Zimbabwe	University of Zimbabwe school of medicine under the psychiatry department.	Research on drug & alcohol use on PLHIV & AIDS.
Kenya	HIV AIDS People Alliance of Kenya (HAPA.	An LGBT led organisation with counsellors who help the newly tested and a buddy system that help the newly diagnosed with adherence
Mozambique	REPSSI	Regional Psychological Support Initiative A leading organisation in 'mainstreaming psychological support into programmes and services for girls, boys, and youth in East and Southern Africa' - work in 13 African countries. http://www.repssi.org/
	OASIS	'Doctors with Africa Organisation' The organisation is based in Italy and works in 8 African countries to provide medical aid and expertise, as well as carrying out capacity-building activities, conduct, and disseminate research https://www.oasisglobal.org/our-work/? https://doctorswithafrica.org/

	CUAMM- Medicos com Africa	National Association for the support of Seropositive and AIDS Patients (ANSS) The mission of the organisation is to 'promote the prevention of the transmission of HIV/AIDS and to improve the wellbeing of people infected and/or affected by HIV/AIDS'. http://www.anssburundi.bi/
Burundi	ANSS BURUNDI (RNJ+)	Their mission is to 'effectively and directly involve HIV-positive youth/adolescents in the fight against new infections and to promote their rights and overall burden' - the organisation run various programmes to support this mission. http://www.rnjplusburundi.org/
South-East Asia		
	Ya_all, Manipur	Works towards young people and their mental health including youths affected or infected with HIV
Thailand	TREAT Asia/amfAR - Asia Chiang Mai University-Thailand	TREAT = Therapeutics Research, Education, and AIDS Training in Asia A collaborative network of clinics, hospitals, research institutions and civil society working to ensure the effective delivery of HIV treatments. https://www.amfar.org/treatasia.html
Thailand	Chulalongkorn University - Thailand	Chiang Mai University - Completed research in collaboration with Thai Red Cross AIDS Research Centre https://www.rihes.cmu.ac.th/thaictu/?lang=en
Thailand	Thai Red Cross AIDS Research Center - Thailand	
India	BJ Medical College - India	BJ Medical College - produces/researches ARTs? https://timesofindia.indiatimes.com/city/pune/ART-centre-sees-shortage-of-2nd-line-HIV-drug/articleshow/9534380.cms
	CHIMERA - Dr A Sohn, Dr M Wainberg	Part of TREAT Asia, amfAR - https://www.amfar.org/nih-awards-research-training-grant-to-treat-asia%E2%80%93columbia-university-collaboration/
Europe		
Russia	AIDS.CENTER foundation	
	EVA Association	Indirectly touched on, about ARVT and stigma
	Перебои.ru, группы поддержки (Outages.ru, support groups)	

Ukraine	Teenergizer - about PLHIV drug users	Now they have a lot of live broadcasts and online activities about psychological comfort, self-esteem, how to quarantine, and more.
UK	Chiva	Children’s’ HIV Association The organisation’s mission is ‘to ensure that children, young people and families living with HIV become healthier, happier, and more in control of their own futures’ – to do this they engage YPLWHIV with camps, education of schools, regional support, and more.