# HEALTH-RELATED QUALITY OF LIFE AMONG PEOPLE LIVING WITH HIV IN THE CZECH REPUBLIC

## Research report

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# Health-related quality of life among people living with HIV in the Czech Republic
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# 1. Introduction: Health-related quality of life in the era of widely available ART and the significance of the "fourth 90" target

The development of effective antiretroviral therapy (ART) has enabled most people living with HIV (PLHIV) to achieve long-term viral suppression and has transformed HIV infection into a manageable chronic condition. As a result of this shift in the medical effectiveness of treatment, the topic of health-related quality of life (HRQoL) has come to the fore as a key indicator of further progress in the care of PLHIV (Andersson et al., 2020).

The original UNAIDS 90-90-90 targets for controlling the epidemic (by 2020: 90% of all people with HIV know their diagnosis, 90% of those diagnosed are on ART, and 90% of those treated have suppressed HIV replication) have been met or significantly advanced in many countries (Lazarus et al., 2016; UNAIDS, 2014a). However, these targets do not take into account the persistent challenges faced by aging people with HIV and do not reflect the fact that many PLHIV, despite successful and effective treatment, experience a reduced quality of life in terms of mental, social, or sexual well-being (Lazarus et al., 2016). For this reason, the original trio of 90s has been supplemented by a "fourth 90", which aims to ensure that 90% of people living with HIV live with a good quality of life (UNAIDS, 2019). However, achieving this "fourth 90" requires solutions that go beyond viral suppression through ART and include broader determinants of health and well-being (Andersson et al., 2020).

Attention is thus shifting to factors such as mental health, social support, and, in particular, HIV-related stigma, which can prevent people from fully benefiting from treatment. For example, research shows that poor mental health or experiences of stigma among PLHIV reduce treatment adherence (Katz et al., 2013; Miners et al., 2014) and that achieving viral suppression alone does not guarantee a good quality of life (Miners et al., 2014; Zeluf-Andersson et al., 2019). For example, a meta-analysis of dozens of studies confirmed that HIV stigmatization has a significant negative impact on various health indicators in PLHIV, including depression and lower self-rated quality of life (Rueda et al., 2016). A groundbreaking finding in recent years is also the fact that when viral load is suppressed, the risk of HIV transmission through sexual contact is essentially zero, which has given rise to the well-known destigmatization strategy symbolized by the acronym U=U ("Undetectable = Untransmittable"). This finding has fundamentally influenced public health strategies (UNAIDS, 2018b). Paradoxically, however, the persistent stigma and discrimination associated with HIV continue to adversely affect the lives of people with this diagnosis (Rueda et al., 2016).

Improving HRQoL in PLHIV therefore requires innovative integration of prevention programs focused on psychosocial aspects and removing barriers such as stigma and mental illness.

## Czech context

In the Czech Republic, modern ART is widely available and the vast majority of people treated for HIV achieve stable viral suppression. Considering global developments, the Czech professional community now focuses on the quality of life as another key parameter in the care of PLHIV. The National Program for Addressing HIV/AIDS for 2023–2027 has therefore included among its priorities the creation of a methodology for measuring HRQoL in people living with HIV and the establishment of a baseline assessment of this indicator (Ministry of Health of the Czech Republic, 2023). Specifically, activity No. 4.3.5 of the National Program set the task of developing a methodology for measuring HRQoL in PLHIV and implementing a pilot assessment of the baseline level of this indicator by the end of 2025 (Ministry of Health of the Czech Republic, 2023). The Ministry of Health has entrusted the National Institute of Public Health (SZÚ) in cooperation with the National Institute of Mental Health (NUDZ) with the fulfilment of this task. With the financial support of the Czech World Health Organization (WHO) office, a working group consisting of representatives of both institutions, clinical experts, and representatives of the Czech AIDS Society prepared and implemented a pilot study focused on the quality of life (HRQoL) in people living with HIV, contributing to the fulfilment of the goal of the so-called “fourth 90” in the Czech Republic. With regard to the Ukrainian community living in the country, the research materials were prepared in Ukrainian as well as Czech.

# 2. Stigmatization: definition, forms, mechanisms of action, and impact on HRQoL in PLHIV

The term stigmatization generally refers to a social process in which a person is assigned a "tainted" identity based on certain characteristics (whether real or perceived), which disqualifies them from full social acceptance (Goffman, 2009). Erving Goffman's now classic definition describes stigma as an attribute that deeply devalues its bearer in the eyes of society (Goffman, 2009). More recent conceptualizations emphasize that stigma arises from the interaction of multiple factors. According to Link and Phelan (2001), it is a combination of processes of labelling, stereotyping, separating "us" and "them," loss of social status, and discrimination that occurs in a context of unequal power relations in society. In the case of HIV, stigmatization stems from prejudices associated with this infection (e.g., the perception of HIV as a consequence of "irresponsible" or otherwise "improper" behaviour) and is reflected in legal and social structures (Kolářová, 2013). HIV stigma is closely linked to existing power relations in society and often overlaps with other prejudices against otherwise marginalized groups that are disproportionately affected by HIV (e.g., LGBTQ+ people, people who use drugs, sex workers, migrants, etc.) (Stangl et al., 2013). This accumulation of multiple disadvantaged identities is referred to as intersectional stigma and, as a result, causes some PLHIV to face multiple stigmas simultaneously (Turan et al., 2025). Turan et al. (2025) therefore recommend that research and interventions take into account this intersection of different stigmas and not limit themselves to isolated categories, as they believe that this is the only way to design effective strategies targeting complex forms of stigmatization.

## Mechanisms of stigma's impact on health and quality of life

Decades of research on minority stress have shown that stigma is a **chronic stressor** (Meyer, 2013; Pachankis et al., 2015; Pitoňák, 2017) that has psychological and practical impacts on the lives of people with HIV. At the individual level, fear of rejection leads to hiding one's diagnosis, avoiding social contact, and limiting the use of health services (Gesesew et al., 2017; Sayles et al., 2009). People who fear stigmatization often delay HIV and other STI testing and also enter care later because they avoid the widely stigmatized label of "HIV-positive person." A systematic review in low- and middle-income countries has shown that perceived stigma significantly increases the risk of late initiation of HIV treatment (Gesesew et al., 2017). Similarly, in American studies, stigma correlated with poorer adherence to ART and reduced willingness to seek health care (Rintamaki et al., 2006; Sayles et al., 2009). In addition to behavioural consequences, stigmatization has a demonstrable impact on mental well-being. Exposure to repeated discrimination and social rejection undermines self-esteem, evokes feelings of loneliness and hopelessness, and can lead to the development of depressive and anxiety symptoms (Rueda et al., 2016; Slater et al., 2015). Social support acts as a protective factor that can mitigate the effects of stigmatization (Rao et al., 2012). This finding highlights the importance of peer support and community networks in the care of PLHIV.

## The impact of HIV stigma on HRQoL

HIV stigma has been repeatedly identified as one of the most significant predictors of a poorer health-related quality of life among PLHIV. A number of studies from different countries and populations consistently find a strong inverse association between the level of perceived stigma and the overall self-rated quality of life or mental well-being of people living with HIV (Holzemer et al., 2009; Reinius et al., 2018; Rueda et al., 2016; Zeluf-Andersson et al., 2019). For example, Holzemer et al. (2009), in a study of 726 PLHIV in an international sample, found that perceived stigma measured on a multidimensional scale contributes independently to explaining the variance in the quality of life, and even after taking into account clinical factors and physical symptoms, stigma remains a significant factor reducing quality of life. Similarly, a study from Spain (Fuster-Ruizdeapodaca et al., 2014) involving 557 PLHIV analysed in detail the different impacts of two forms of stigma: experienced and internalized. Using structural modelling, the authors showed that experienced discrimination had a direct negative impact on the quality of life, which even identification with the group identity (i.e., identification with the PLHIV community) could not mitigate. In contrast, the impact of internalized stigma on the quality of life was indirect and fully mediated by certain aspects of identity (especially the emotional relationship to the group of people living with HIV), with stronger identification with the "HIV community" paradoxically having a negative impact in this case and reinforcing internalized stigma (Fuster-Ruizdeapodaca et al., 2014). This conclusion suggests that in highly stigmatized groups, the increased salience of belonging to a stigmatized group can lead to a deterioration in self-perception, which is an important finding for intervention planning, showing, for example, that simply strengthening the group identity may not be beneficial.

In an environment with highly accessible and effective treatment, the question arises as to what extent stigma continues to affect the quality of life of PLHIV. A study from Sweden —a country where approximately 95% of diagnosed PLHIV have suppressed viral loads —found that although most patients report a high quality of life, there remains a subgroup whose quality of life has been significantly reduced by HIV (Zeluf-Andersson et al., 2019). Factors associated with a poorer quality of life included psychological and psychosocial aspects in particular: e.g., feelings of hopelessness, negative self-perception related to HIV, persistent physical symptoms, the adverse effects of treatment, but also social determinants such as a recent experience of homelessness (Zeluf-Andersson et al., 2019). These results confirm that even in a developed healthcare system, the quality of life cannot be taken for granted and HIV continues to be a burden, particularly in terms of mental health and social functioning. Similarly, a Swiss study focusing on PLHIV over the age of 50 identified poor mental health, poorer physical health, a long duration of HIV infection, a lack of available support, and financial problems as key predictors of a reduced quality of life, while sufficient perceived social support significantly improved the quality of life (Nideröst & Imhof, 2016). Hence, in the context of high ART availability, the so-called *"soft"* factors related to the psychosocial conditions of PLHIV's lives become increasingly important. Last but not least, it appears that depression and anxiety (often as a result of internalized stigma or minority stress) are among the most common comorbidities in PLHIV, which significantly reduce their quality of life (Nobre et al., 2017; Rueda et al., 2016). Nobre et al. (2017) found in a study from Finland (n = 453) that the main factors associated with a high quality of life among PLHIV were good mental health (absence of depression), employment, a stable relationship, and a better financial situation. In contrast, viral and immunological indicators (e.g., CD4 count) had no significant effect (Nobre et al., 2017). This result again underscores that in the era of effective treatment, the quality of life of PLHIV is determined more by socioeconomic and psychological factors than by the medical parameters of HIV infection alone.

## Implications

HIV stigma is now seen not only as a medical problem, but also as a **human rights** issue and an obstacle to achieving the goal of ending the AIDS epidemic as a public health threat by 2030 (UNAIDS, 2019). Eliminating stigma and discrimination is therefore integrated into strategic documents. In December 2017, UNAIDS announced a global partnership to eliminate all forms of HIV stigma and discrimination (UNAIDS, 2018a). It stated that effective destigmatization interventions are necessary to improve the HRQoL of PLHIV ("the fourth 90"). Approaches to date have included, for example, public campaigns to raise awareness of HIV, training for healthcare professionals, programs to meet people living with HIV, and changes in legislation to reduce discrimination (Stangl et al., 2013; UNAIDS, 2014b).

The National AIDS Trust recommends that stigma be addressed simultaneously at the level of laws and policies, in institutions (health care, schools, workplaces), in communities, and among individuals. Each proposed intervention should also consider *where* stigma occurs (context), *what* specifically needs to be changed, and *how* to achieve this (National AIDS Trust, 2024). Another important principle is the involvement of people living with HIV themselves in the design and implementation of these activities (Bogart & Uyeda, 2009; UNAIDS, 2007)

Overall, reducing stigma and improving the quality of life of PLHIV are closely related and represent a necessary prerequisite for the success of global efforts to "end the AIDS pandemic" and fulfil the principle of health equity (Andersson et al., 2020; UNAIDS, 2019).

# 3. HRQoL in PLHIV in Czechia: National HIV/AIDS Program 2023–2027 and the role of the pilot study

Extending the concept of HRQoL into the care of PLHIV requires reliable tools and methodology for its measurement. In the Czech context, the impetus for the creation of such a methodology was the National HIV/AIDS Program 2023–2027, which set the strategic goal of developing a quality of life indicator for PLHIV and determining its baseline values in the population (Ministry of Health of the Czech Republic, 2023). To achieve this goal, a working group was formed, consisting of representatives from the National Institute of Public Health, the National Institute of Mental Health, the non-profit sector, and clinical experts. The first step was to conduct a review of available tools for measuring quality of life and select one that would be suitable for pilot use in the Czech Republic.

## Selection of a tool for measuring HRQoL

There are a number of general tools for measuring quality of life, but for the purposes of this project it was necessary to use an instrument specifically developed for PLHIV, which is **validated** and, at the same time, sufficiently short and practical for administration in the field among a population that has long been difficult to reach using quantitative methods in Czechia.

The working group therefore considered several possible tools. One of them was, for example, the **WHOQOL-HIV** questionnaire, created by the World Health Organization as a specialized version of the general WHOQOL-100 quality of life scale for people living with HIV. WHOQOL-HIV exists in a 120-item version and a shortened BREF version with 31 items. The tool provides comprehensive coverage of six domains of the quality of life (physical, psychological, level of independence, social relationships, environment, and spiritual/existential) (World Health Organization, 1998). However, the disadvantage was the absence of a Czech version and the still considerable length of even the shortened form. We were concerned that filling out approximately 30 questions specifically related to HIV would be time-consuming for many participants and could lead to a lower willingness to participate. Another option considered was the **HAT-QoL** (HIV/AIDS-Targeted Quality of Life Instrument) questionnaire developed by Holmes and Shea (1998). However, this tool was published in the 1990s and contains 42 items focusing on various domains of life with HIV (Holmes & Shea, 1998). We ruled out the HAT-QoL due to its length, relative obsolescence, and licensing uncertainties.

After weighing the pros and cons of other available options, the team ultimately decided on the **PozQoL** (Positive Quality of Life) questionnaire. This tool was developed in Australia in close collaboration with the community of people living with HIV and was published in 2018 (Brown et al., 2018). The main advantages of PozQoL include:

- Practicality: PozQoL contains only 13 items, so it is not too burdensome for participants to complete. The brevity of the questionnaire was also a key criterion in view of the planned method of distribution and the effort to maximize its return rate.
- Specificity and validity: The scale was specifically developed in collaboration with PLHIV and was rigorously validated on a sample of 465 PLHIV in Australia (Brown et al., 2018).

The result of the development is a questionnaire battery with four subscales that has good psychometric properties. The authors demonstrated high internal consistency of the domains (the entire scale (α=0.95) and their subscales: Health Concerns (α=0.91), Psychological (α=0.91), Social (α=0.82), and Functional (α=0.87)) and confirmed that PozQoL correlates with other health indicators in the expected manner (Brown et al., 2018).

- Content breadth: PozQoL covers four key domains of the quality of life relevant to HIV:
    - (1) *Psychological* (e.g., mood, life satisfaction, self-esteem),
    - (2) *Social* relationships and sense of belonging,
    - (3) *Health concerns* (subjective perception of health, concerns about physical health now and in the future); and
    - (4) *Functional* domain (ability to perform everyday activities, independence, sense of meaning in life despite HIV)
- The items are formulated both positively (e.g., "I enjoy life") and negatively (e.g., "I am concerned about the impact of HIV on my health"), which helps to reduce one-sidedness of the responses. Each item is rated on a scale of 1–5 according to the degree of agreement. After recoding the negatively worded items, an overall score and the subscores for individual domains are created. Scores can be summative or average (PozQoL, 2020). A higher score indicates a better quality of life.
- Availability and adaptability: PozQoL is a freely available, non-commercial (open-access) tool and has been translated into more than 30 languages since its inception, which also facilitated our work on the Czech version. There is a detailed implementation manual for the tool (PozQoL, 2020), and previous translations provided guidance on preserving the meaning of the items. Importantly, the authors of PozQoL and its sponsor (ViiV Healthcare) allow localized modifications free of charge, which removed legal barriers to its use in the Czech Republic.

## Czech and Ukrainian versions of PozQoL

When preparing the Czech adaptation, we followed the recommended methodologies for translating psychological scales (Wild et al., 2005). As a team, we developed three parallel translations of the original English items into Czech, which we then harmonized into the final version. This version was then subjected to back-translation, and we subsequently resolved any ambiguities to verify that the meaning of the items had been preserved. All discrepancies or unclear formulations were adjusted based on consensus within the team. At the same time, we obtained the consent of the authors of the tool to carry out the Czech adaptation. In addition to the Czech version, we also provided a Ukrainian language version of the questionnaire, taking into account the demographic composition of the PLHIV population in the Czech Republic (where Ukrainians constitute the second largest group). For this, we used the existing official Ukrainian version of PozQoL (available on the project website) and made some minor adjustments for terminological consistency; the check was performed by a native speaker (a member of the team). The final Czech and Ukrainian versions of the PozQoL were then pilot tested on a group of PLHIV during a summer camp to verify their comprehensibility. The pilot participants confirmed that the questions were understandable to them. Even before the actual data collection, the project obtained the **Ethics Committee approval** (protocol no. SZÚ/10422/2025 dated July 30, 2025), ensuring that the chosen procedure complied with ethical research standards. Informed consent of the study participant was part of the questionnaire.

## Pilot study and other questionnaire content

Given the aforementioned link between the quality of life of PLHIV and their mental health and social support, the working group decided to supplement the pilot questionnaire survey with several other validated tools. The aim was to capture the **key factors influencing HRQoL** in PLHIV without making the questionnaire too long or demanding. Specifically, the following scales were included:

- **PHQ-9** (Patient Health Questionnaire-9): a short nine-item questionnaire focused on depressive symptoms based on the DSM-IV diagnostic criteria (Kroenke et al., 2001). The PHQ-9 is used worldwide to screen for depressive symptoms and is also well established in the Czech clinical environment. It has been used, for example, in the **Opatruj.se** platform for online mental health monitoring; see Aliev et al. (2020). By including the PHQ-9 in the study, we will obtain quantified data on the degree of depressive symptoms among participants, which will allow us to analyse the relationship with the quality of life scores.
- **GAD-7** (Generalized Anxiety Disorder-7): a seven-item tool for detecting generalized anxiety (Spitzer et al., 2006). Like the PHQ-9, the GAD-7 is widely used in clinical practice for the rapid assessment of anxiety symptoms. Depression and anxiety are among the most common mental disorders in people with chronic diseases, including HIV (Rueda et al., 2016), and their presence can significantly reduce quality of life. By including the GAD-7, we can determine the prevalence of anxiety disorders among Czech PLHIV and, if necessary, control their influence when assessing HRQoL.
- **Social support item:** To assess subjectively perceived social support, we used the Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet et al., 1988), specifically its Czech adaptation (Pitoňák et al., 2024). This scale contains 12 items assessing support from family, friends, and significant others. Each item is rated on a seven-point Likert scale. Social support was included because, as the above-mentioned studies show, it plays a crucial role in adapting to life with HIV and can modify the impact of stigmatization on HRQoL (Nideröst & Imhof, 2016; Rao et al., 2012).
- **Demographic and clinical data:** The questionnaire naturally also included other basic sociodemographic information (age, sex and gender identity, education, marital status, employment status, region of residence) to enable the description of the sample and the assessment of the impact of socioeconomic factors on the quality of life. Clinical data related to HIV were also included: the length of time since diagnosis and since starting treatment, the presence of an AIDS diagnosis, presence of other chronic diseases, any recent HIV-related hospitalizations, and the name of the HIV centre where the patient is monitored (including whether treatment was started at the same centre or elsewhere/abroad). Information on the estimated travel time to the HIV centre was also included as an indicator of geographical accessibility to care. This information will allow

subsequent analysis to examine, for example, differences in HRQoL by length of life with HIV, comorbidity, or the place of care provision.

Overall, a comprehensive questionnaire was created that combines the standardized PozQoL scale for measuring the quality of life with several additional metrics of mental health and social situation. This comprehensive approach reflects the fact that HRQoL in PLHIV is a multidimensional construct, influenced by health status, mental health (Nobre et al., 2017), and social background (Nideröst & Imhof, 2016). All selected tools are short and validated, ensuring that the questionnaire minimizes respondent burden.

# 4. Methodological description of the pilot study: objectives, design, PozQoL tool, administration, and plan of statistical analyses

The HRQoL pilot study among PLHIV in Czechia was designed as a cross-sectional study aimed at determining the baseline quality of life of people living with HIV and testing the practical applicability of the questionnaire described above.

**The main objectives of the study were**

(1) to obtain pilot data on the health-related quality of life of PLHIV in Czechia,

(2) to identify the factors most significantly related to HRQoL (especially the presence of depression, anxiety, level of social support, stigmatization, etc.), and

(3) to create a methodological basis for long-term monitoring of these indicators within the National Program for HIV/AIDS in Czechia.

The study was designed as a pilot study, i.e., it also focused on the practical verification of data collection methods and possible adjustments prior to future follow-up research or routine monitoring. The pilot survey included adults (aged 18 years and older) living with HIV who are monitored at one of the HIV centres in the Czech Republic. We did not strive for a strictly random selection; the aim was to reach the widest possible range of PLHIV in a given time window so that the sample would best reflect the diversity of the PLHIV population (in terms of age, region, gender, treatment regimen, the length of time living with HIV, etc.). Hence, this study involved a non-probability sample based on self-selection across all regions of the Czech Republic, with the support of healthcare professionals at HIV centres.

## Questionnaire administration

Data collection was carried out in a combined form, i.e., **both online and in the form of a paper questionnaire** for maximum accessibility *(the Czech as well as the Ukrainian questionnaires are attached to this report)*. The SZÚ and NUDZ, in cooperation with HIV centres, prepared a distribution strategy: in all 10 HIV centres (Prague, University Hospital Bulovka; Prague, Central Military Hospital; University Hospital Plzeň; University Hospital Ostrava; University Hospital Brno; Masaryk Hospital in Ústí nad Labem; University Hospital Hradec Králové; Hospital České Budějovice; Regional Hospital Liberec; University Hospital Olomouc), with the prior consent of their founder, information posters in Czech and Ukrainian were displayed in waiting rooms with a QR code linking to the electronic questionnaire form (Survio platform). Patients could thus complete the questionnaire on their smartphone or later on their home computer.

Anyone wishing to do so could request a paper form from the nurse at the relevant HIV centre. After completion, the paper questionnaires were placed in sealed envelopes and deposited in secure collection boxes directly at the HIV centre to ensure the anonymity of the responses. These forms were then periodically sent by the medical staff to the SZÚ, where they were converted into a digital format (by manual data entry). No personal identifiers of participants were collected. The questionnaire did not contain any names, national identification numbers, or other unique information; each completed questionnaire was assigned a unique code. The anonymity and confidentiality of the data were thus guaranteed, which was key to obtaining honest answers, especially for the sensitive questions concerning mental health and experiences with stigmatization.

## Data collection

The questionnaire survey began at the end of September 2025 and lasted approximately six weeks, until the beginning of November 2025. During that period, participants coming for check-ups at the HIV centres were continuously informed about the possibility of participating in the study by the posters on notice boards or by the staff. This procedure made it possible to obtain a sufficiently large sample to assess the quality of life of people living with HIV in the Czech Republic. During data collection, the ratio of online vs. paper completions was monitored. Finally, roughly half of the respondents used the online option, which confirmed the practicality of QR codes and digital data collection.

## Data evaluation

After data collection was completed, data from the online system and digitized paper questionnaires were merged into a single database. This was followed by statistical analysis, which was conducted in several steps:

- Descriptive analysis: First, the basic characteristics of the sample were described – age structure, representation of men, women, trans and non-binary participants, average time since diagnosis, clinical indicators (e.g., percentage of people with a history of AIDS or other chronic diseases), etc. The results in individual scales were summarized separately: average HRQoL score (PozQoL overall and in domains), average PHQ-9 and GAD-7 scores, average social support score from the MSPSS questionnaire (overall and in domains). This provided the first-ever estimate of the quality of life of PLHIV throughout the Czech Republic, which can be used as a baseline for future comparisons.
- Analysis of the internal structure of the tool: As part of the pilot testing of the Czech version of PozQoL, the reliability of the scale was checked (Cronbach's alpha for the overall scale and subscales). Later, exploratory and confirmatory factor analysis will be performed to confirm that the items cluster into the expected domains (psychological, social, health concerns, functional).
- Correlation analyses and testing of group differences: The main focus of the analysis was to explore which factors are significantly related to quality of life. Using correlation analyses and subgroup comparisons, relationships such as the following were examined: higher depression/anxiety scores vs. lower QoL, low social support vs. lower QoL,

experience of AIDS or comorbidity vs. QoL, or differences in QoL by gender, age, or length of treatment.

Data processing and statistical evaluation were performed using Stata statistical software, release 17 (Stata Corp LLC, College Station, TX, USA.) and IBM SPSS Statistics (Version 24.0; IBM Corp., 2016). Group comparisons were based on Student’s t-test and Fisher’s exact test. P-values less than the significance level of 0.05 indicated a statistically significant difference.

# 5. Results

In this report, we present the main findings of the research, while more extensive analyses will be published in forthcoming scientific papers. In presenting the results, we take an advantage of the fact that, in addition to the Czech sample, we have also a sufficiently large sample of Ukrainian patients. Therefore, we compared these two groups where methodologically appropriate.

## Description of the Czech and Ukrainian samples

A total of 594 people living with HIV completed the questionnaire. Two additional questionnaires from respondents under the age of 18 were excluded from the analysis. The Czech sample consisted of 466 respondents, while the Ukrainian sample consisted of 128 people. More than half of the Czech sample (55.8%) completed the questionnaire online, while in the Ukrainian sample the ratio was reversed (75.0% completed the paper version of the questionnaire). The difference in the method of completion was statistically significant ($P < 0.001$) (see Table 1).

Table 1 Number of respondents in the Czech and Ukrainian samples according to how they completed the questionnaire.

| Way of completing the questionnaire | CZ Sample | UA Sample | Total |
|---|---|---|---|
| Online | | | |
| N | 260 | 32 | 292 |
| Percent | 55.8 | 25.0 | 49.2 |
| Paper | | | |
| N | 206 | 96 | 302 |
| Percent | 44.2 | 75.0 | 50.8 |
| Total | | | |
| N | 466 | 128 | 594 |
| Percent | 100.0 | 100.0 | 100.0 |

In the Czech sample, 90.7% of respondents identified as male, while in the Ukrainian sample, the gender composition was essentially balanced (50.4% identified as male). The gender composition of the two samples was statistically significantly different ($P < 0.001$) (see Table 2). The characteristics of the Ukrainian sample may be influenced by two factors. Firstly, historically different modes of transmission (more heterosexual) and secondly, the ongoing war in Ukraine, where women significantly outnumbered men among those seeking asylum in the Czech Republic.

Table 2 Composition of the Czech and Ukrainian samples by sex

| Sex | | CZ Sample | UA Sample | Total |
|---|---|---|---|---|
| Males | | | | |
| | N | 421 | 64 | 485 |
| | Percent | 90.7 | 50.4 | 82.1 |
| | Age – mean (SD) | 43.5 (10.4) | 42.4 (7.1) | 43.4 (10.1) |
| Females | | | | |
| | N | 43 | 63 | 106 |
| | Percent | 9.3 | 49.6 | 17.9 |
| | Age – mean (SD) | 41.4 (11.2) | 42.9 (8.1) | 42.3 (9.4) |
| Total | | | | |
| | N | 464 | 127 | 591 |
| | Percent | 100.0 | 100.0 | 100.0 |
| | Age – mean (SD) | 43.3 (10.5) | 42.7 (7.6) | 43.2 (10.0) |

There was no statistically significant difference in mean age between the two samples. Nor was there a statistically significant difference between the sexes (see Table 2).

In terms of the respondents' education (see Table 3), the two groups differed significantly ($P < 0.001$). Compared to the Ukrainian group, the Czech group had a higher proportion of people with completed secondary and tertiary education (68.2% vs. 38.6%).

Table 3 Czech and Ukrainian samples by level of education (values are given in percentages)

| Education | CZ Sample | UA Sample | Total |
|---|---|---|---|
| Elementary | 7.4 | 9.5 | 7.8 |
| Secondary vocational education | 24.5 | 52.0 | 30.4 |
| Complete secondary education with a leaving certificate | 37.9 | 14.2 | 32.8 |
| University level incl. B.A. | 30.3 | 24.4 | 29.0 |

The Czech sample was largely represented by patients living in the capital city of Prague (30.8%), followed by patients from the Moravian-Silesian Region (16.9%), South Moravian Region (12.4%), South Bohemian Region, Central Bohemian Region, and Ústí nad Labem Region. Ukrainian patients were mainly from the Moravian-Silesian Region (19.8%), followed by the South Bohemian Region, the Pilsen Region, and the Ústí nad Labem Region (each 13.8%) (see Table 4).

Table 4 Respondents’ region of residence (values are given in percentages)

| Region of residence | CZ Sample | UA Sample | Total |
|---|---|---|---|
| Prague, the Capital City | 30.8 | 8.6 | 26.3 |
| Central Bohemian Region | 8.0 | 3.5 | 7.1 |
| South Bohemian Region | 8.2 | 13.8 | 9.4 |
| Pilsen Region | 3.0 | 13.8 | 5.2 |
| Karlovy Vary Region | 1.3 | 3.5 | 1.7 |
| Ústí nad Labem Region | 7.2 | 13.8 | 8.5 |
| Liberec Region | 2.0 | 0.0 | 1.6 |
| Pardubice Region | 0.4 | 0.9 | 0.5 |
| Vysočina Region | 1.3 | 0.9 | 1.2 |
| South Moravian Region | 12.4 | 10.3 | 12.0 |
| Zlín Region | 3.3 | 2.6 | 3.1 |
| Olomouc Region | 5.2 | 8.6 | 5.9 |
| Moravian-Silesian Region | 16.9 | 19.8 | 17.5 |

Table 5 summarizes the centres where Czech and Ukrainian patients are currently being treated. In the Czech sample, patients are mainly treated at health care centres located in the capital city of Prague, as well as in Ostrava and Brno. In contrast, patients in the Ukrainian sample are predominantly treated in Brno, Ostrava, Plzeň, Ústí nad Labem, České Budějovice, and Prague, corresponding to the regional distribution of Ukrainian refugees in the Czech Republic.

Table 5 Health centre where the patient is currently being treated (values are given in percentages)

| Specialised HIV Health Centres | CZ Sample | UA Sample | Total |
|---|---|---|---|
| University Hospital Bulovka, Prague | 22.5 | 10.0 | 19.9 |
| Central Military Hospital – Military University Hospital Prague | 14.9 | 0.8 | 12.0 |
| University Hospital Plzeň | 6.3 | 18.3 | 8.8 |
| University Hospital Ostrava | 21.4 | 20.0 | 21.1 |
| University Hospital Brno | 16.7 | 23.3 | 18.0 |
| Masaryk Hospital in Ústí nad Labem | 8.0 | 13.3 | 9.1 |
| University Hospital Hradec Králové | 0.2 | 0.0 | 0.2 |

| | | | |
|---|---|---|---|
| Hospital České Budějovice | 6.9 | 12.5 | 8.1 |
| Regional Hospital Liberec | 0.7 | 0.0 | 0.5 |
| University Hospital Olomouc | 2.4 | 1.7 | 2.2 |

## PozQoL questionnaire: the main instrument for assessing the quality of life of people living with HIV

The PozQoL questionnaire represents the main source of knowledge about the quality of life of people living with HIV in the Czech Republic. We have preliminarily assessed the psychometric qualities of the instrument based on item analysis and reliability analysis (internal consistency). The results of the item analysis are summarized in Table 6.

Table 6 Item statistics of PozQoL questionnaire – mean and standard deviation (SD)[a]

| Items of PozQoL | Mean | SD |
|---|---|---|
| 1. I am enjoying life. | 3.59 | 0.96 |
| 2. I worry about my health.[b] | 3.35 | 1.08 |
| 3. I lack a sense of belonging with people around me.[b] | 4.07 | 1.07 |
| 4. I feel that HIV prevents me from doing as much as I would like.[b] | 3.99 | 1.15 |
| 5. I feel good about myself as a person. | 3.33 | 1.08 |
| 6. Having HIV limits my opportunities in life.[b] | 3.94 | 1.11 |
| 7. I worry about the impact of HIV on my health.[b] | 3.42 | 1.11 |
| 8. I feel in control of my life. | 3.47 | 1.00 |

| | | |
|---|---|---|
| 9. I am afraid that people may reject me when they learn I have HIV.[b] | 2.77 | 1.34 |
| 10. Managing HIV wears me out. [b] | 4.17 | 0.99 |
| 11. I feel that HIV limits my personal relationships.[b] | 3.67 | 1.23 |
| 12. I fear the health effects of HIV as I get older.[b] | 3.23 | 1.23 |
| 13. I am optimistic about my future. | 3.44 | 1.05 |

[a] N = 533 adult Czechs and Ukrainians patients living with HIV (cases with any missing values were not included into the table)

[b] Negatively worded items were recoded for further calculation of scale and subscale means so that higher scores for all items indicate a better quality of life

## Internal consistency of the Czech version of PozQoL

We measured the internal consistency of the PozQoL questionnaire using Cronbach's alpha. The results indicate excellent reliability of the instrument as a whole (alpha = 0.89) and of the individual subscales. The exception is the Social subscale, where a value of 0.71 can be interpreted as good reliability. The results of the internal consistency analysis confirm that the scale measures with high reliability and accuracy (see Table 7).

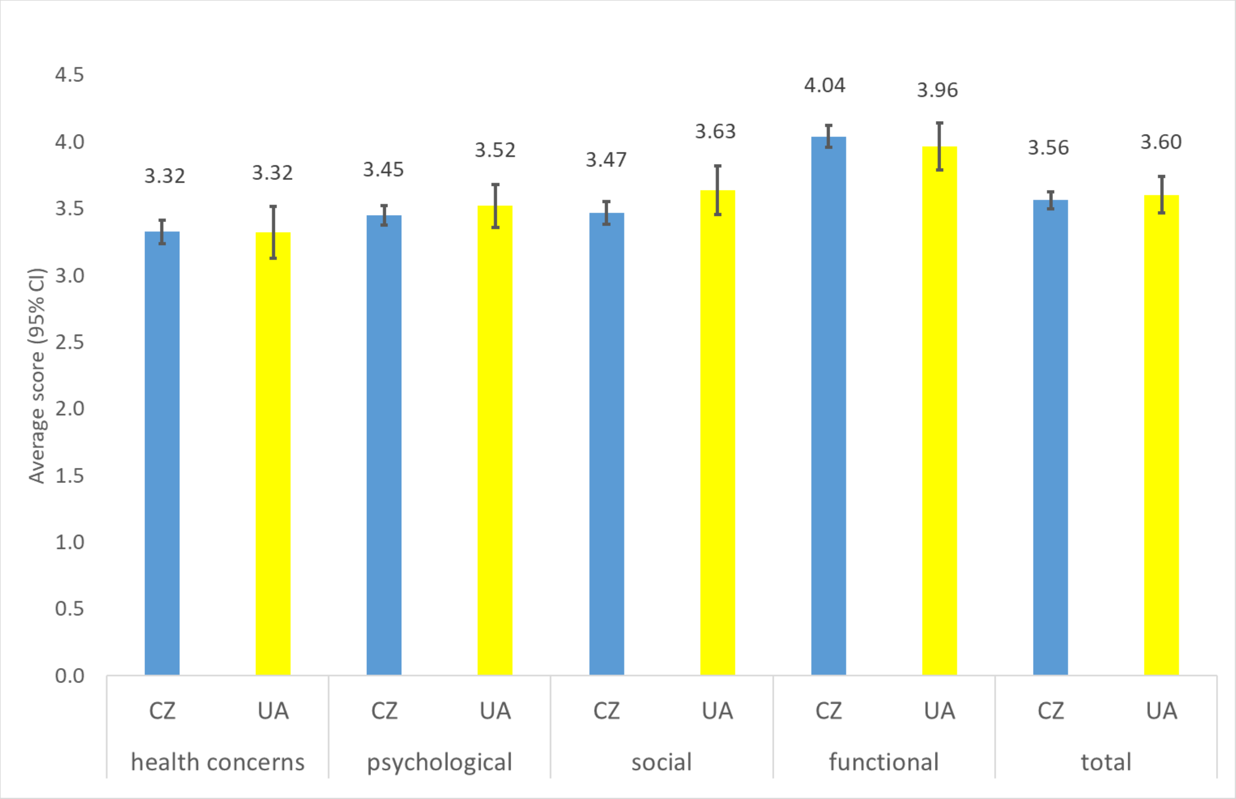
Table 7 Internal consistency of the PozQoL scale and its subscales – Czech sample

| Scale/subscale | Number of items | Cronbach's alpha | N |
|---|---|---|---|
| PozQoL (total score) | 13 | 0.89 | 431 |
| Health concerns | 3 | 0.84 | 458 |
| Psychological | 4 | 0.81 | 454 |
| Social | 3 | 0.71 | 453 |
| Functional | 3 | 0.81 | 450 |

## Comparison of group means for the Czech and Ukrainian samples on the PozQoL

Figure 1 summarizes the comparison of group means on the PozQoL for the Czech and Ukrainian samples. Means are presented with 95% confidence intervals (CIs). In terms of the overall score, the samples do not differ statistically significantly – the Czech sample has an average of 3.56 and the Ukrainian sample 3.60. Similarly, the means on the subscales differ statistically insignificantly. The degree of agreement between the two samples is surprising. It seems that the similarity in results may be the result of similar living conditions and high-quality healthcare.

Figure 1 Mean values on PozQoL for the Czech and Ukrainian sample (total scale and subscales)



The average scores on the PozQoL subscales were slightly lower for women than for men (see Table 8). However, these differences were not statistically significant in the Ukrainian sample. In the Czech sample, there were statistically significant differences on the Health Concerns and Functional subscales, which were then reflected in the overall score. Women in the Czech sample had a lower subjectively perceived quality of life compared to men, and this difference was also substantively significant (Cohen's d = 0.47).

Table 8 Mean values and standard deviation (SD) on the PozQoL subscales by gender, separately for the Czech and Ukrainian sample

| PozQoL Scales | CZ Sample | | UA Sample | |
|---|---|---|---|---|
| | Males | Females | Males | Females |
| Health Concerns | **3.36 (0.97)** | **3.00 (0.96)*** | 3.35 (1.05) | 3.30 (1.13) |
| Psychological | 3.47 (0.79) | 3.23 (0.62) | 3.53 (0.89) | 3.49 (0.91) |
| Social | 3.48 (0.95) | 3.32 (0.93) | 3.72 (1.08) | 3.54 (0.98) |
| Functional | **4.09 (0.92)** | **3.55 (0.94)*** | 4.04 (1.05) | 3.87 (0.93) |
| Total | **3.59 (0.71)** | **3.27 (0.64)*** | 3.65 (0.72) | 3.54 (0.79) |

*Results in bold are statistically significantly different between males and females (P < 0.05).

The overall mean score is a good indicator of differences between the samples studied, but to assess the quality of life of a specific individual, it is advisable to use the recommended interpretation of the scores achieved, as determined by the authors of the test. Table 9 shows that 18.5% of the Czech patients have a low quality of life, compared to 19.5% of the Ukrainian group. Individuals with this score would therefore need increased psychosocial support.

Almost half of the respondents fall into the category of medium quality of life (score 3.00 to 3.99). The Australian authors of PozQoL state that even for the group of people with these values, there is potential for improvement in their quality of life. Patients with a good and very good quality of life represent approximately one-third of the respondents. The interpretation of the categorized scores suggests that for one-fifth of patients living with HIV, appropriate interventions should be considered. A more detailed analysis of the characteristics of this group may reveal the context of their poor quality of life and assist in the development of appropriate procedures.

Table 9 Categorised Scores on PozQoL (values are given in percentages)

| PozQoL Score Categories | CZ Sample | UA Sample |
|---|---|---|
| <3.00<br>Low QoL | 18.5 | 19.5 |
| 3.00–3.99<br>Moderate QoL | 47.2 | 46.3 |
| ≥4.00<br>Good and very good QoL | 34.3 | 34.1 |

## Psychological scales measuring depression and anxiety

The study included two short psychological scales in the questionnaire. These were the GAD-7, a scale measuring generalized anxiety, and the PHQ-9, a scale measuring the presence of depressive symptoms. The results of the group comparison on these scales are shown in Figure 2 and 3. The results show that the Ukrainian and Czech samples do not differ in these psychological indicators.

Figure 2 Comparison of the Czech and Ukrainian sample in level of anxiety (GAD-7), percentage distribution across categories

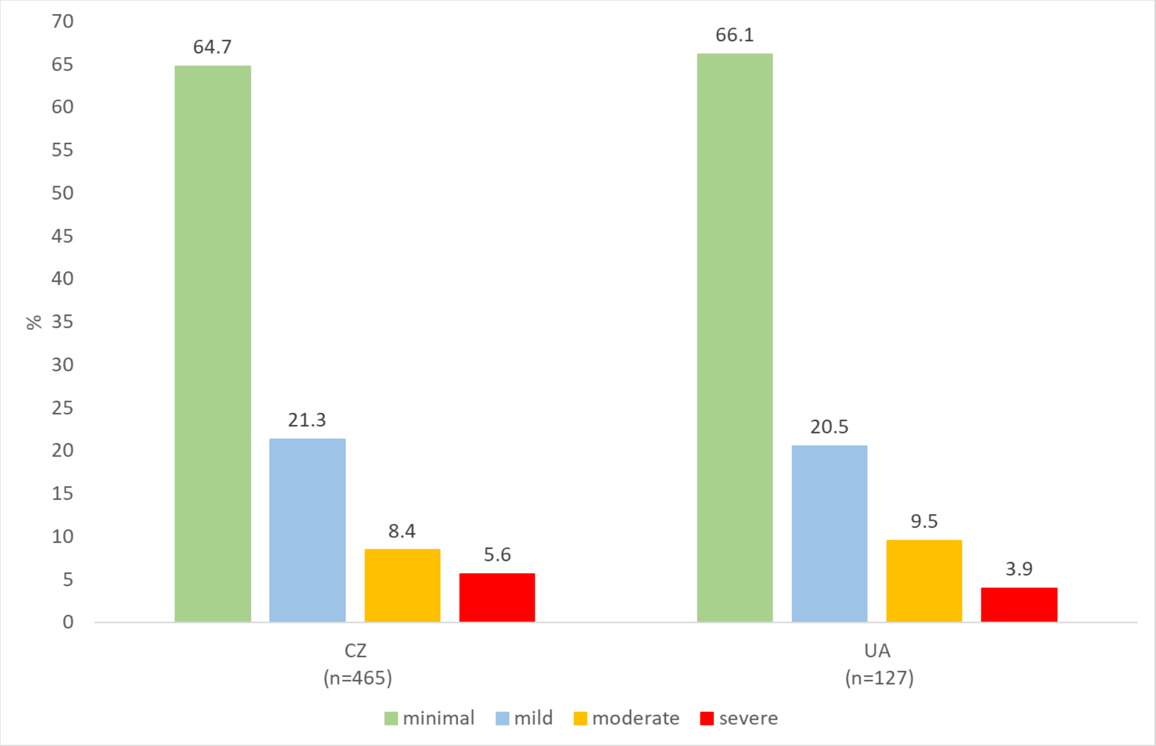
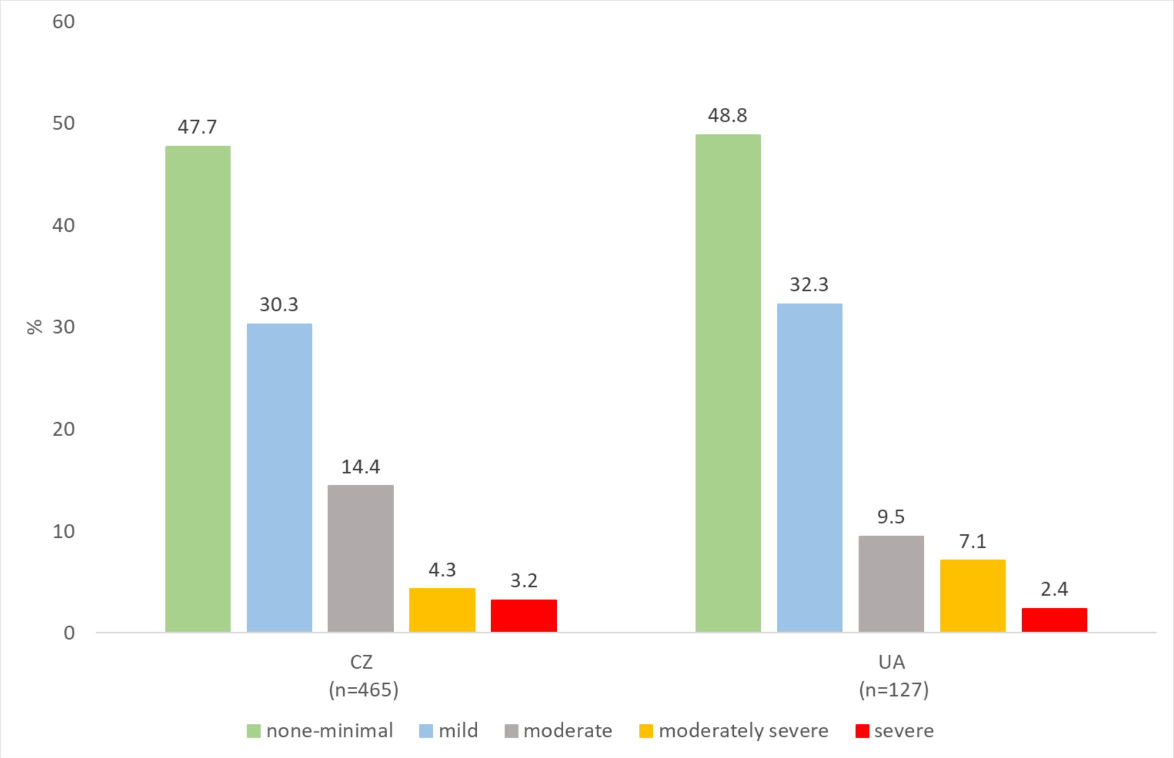
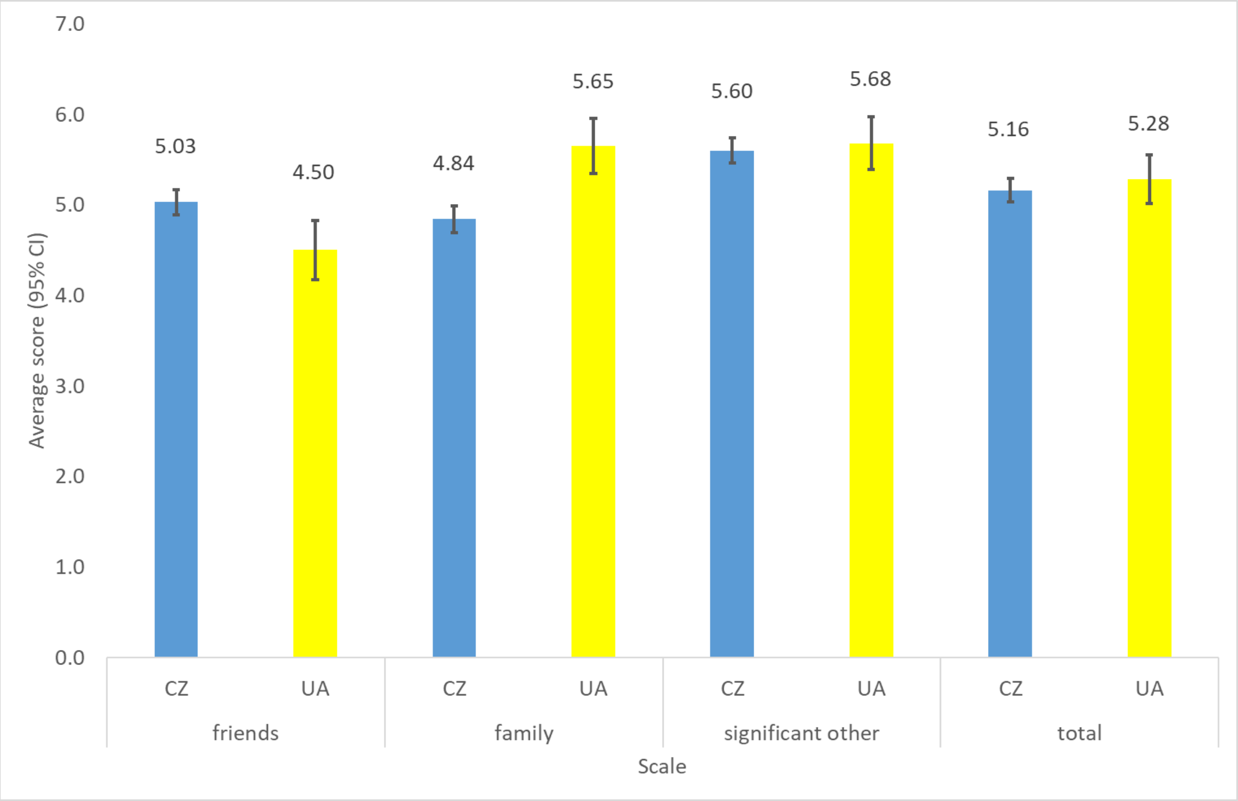


Figure 3 Comparison of the Czech and Ukrainian sample in terms of depression severity (PHQ-9), percentage distribution across categories



The importance of social support for shaping the quality of life was mentioned in the introduction to this report. The inclusion of the MSPSS scale (multidimensional scale of perceived social support) in the pilot study was therefore logical and theoretically justified. The differences between the Czech and Ukrainian samples are not statistically significant in this case either, with the exception of the family subscale. This domain is more important for the Ukrainian sample than for the Czech sample in terms of social support (see Fig. 4).

Figure 4 Mean values on the Multidimensional Scale of Perceived Social Support (MSPSS) for the Czech and Ukrainian sample (total scale and subscales)



We examined the relationship between the PozQoL score and the aforementioned GAD-7, PHQ-9, and MSPSS scales. Correlation analysis revealed a strong statistically significant inverse association between the total PozQoL score and GAD-7 and PHQ-9 scores, as well as a strong positive correlation between PozQoL and MSPSS scores (see Table 10). This confirms the fact known from the literature that lower quality of life is associated with higher anxiety and depression, and that, conversely, a good level of social support is associated with a good quality of life. The associations found suggest that mental health care and good social contacts and family relationships can significantly affect the quality of life of patients living with HIV.

Table 10 Spearman's correlation coefficients between total scores on PozQoL, GAD-7, PHQ-9 and MSPSS

| | PozQoL | GAD-7 | PHQ-9 | MSPSS |
|---|---|---|---|---|
| PozQoL | 1 | | | |
| GAD-7 | -0.55 | 1 | | |
| PHQ-9 | -0.60 | 0.74 | 1 | |
| MSPSS | 0.50 | -0.36 | -0.41 | 1 |

# 6. Conclusion and future perspectives

## Summary of key findings

In an era of widely available and effective antiretroviral treatment, the definition of successful HIV care is changing—it is no longer enough to achieve and maintain viral suppression; attention must also be paid to patients' quality of life. HRQoL is becoming the fourth “90”, a metric that complements the original 90–90–90 targets and reflects the overall health, mental, and social status of people living with HIV (Lazarus et al., 2016). In this text, we have presented arguments why focusing on the quality of life of PLHIV is justified and supported by the literature: a number of studies clearly show that even with successful treatment, many PLHIV suffer from problems such as stigmatization, depression, anxiety, or social isolation, which significantly reduce their life satisfaction and may indirectly jeopardize treatment outcomes (Rueda et al., 2016; Slater et al., 2015).

HIV stigma is a complex phenomenon closely linked to quality of life. Its presence undermines the mental well-being, interpersonal relationships, and self-esteem of PLHIV and, in the long term, prevents these people from fully participating in society (Fuster-Ruizdeapodaca et al., 2014; Holzemer et al., 2009). At the same time, stigma acts as a barrier to prevention and care, which ultimately complicates purely medical goals (Gesesew et al., 2017). The fight against stigmatization is therefore not only an ethical issue, but also a pragmatic part of efforts to improve health outcomes and quality of life; without a comprehensive destigmatization policy, the "fourth 90" target cannot be met (Andersson et al., 2020).

The Czech Republic reflects this shift in emphasis on HRQoL in its National Program for Addressing HIV/AIDS in the Czech Republic for the period 2023–2027. In this pilot study, we have outlined how HRQoL can be measured and monitored and have shown the validity and practicality of the proposed HRQoL measurement methodology. By selecting a suitable questionnaire tool (PozQoL) and incorporating additional indicators (in the areas of depression, anxiety, and social support), we have created a comprehensive framework that enables the quantification of the quality of life of PLHIV in the Czech Republic.

The administration of questionnaires via HIV centres and an online platform has proven to be feasible and well received by the target group. This paves the way for the regular inclusion of HRQoL in the evaluation of care effectiveness—in addition to indicators such as viral load or CD4 cell count, monitoring the average quality of life score of patients and its development over time may also become standard in the future (UNAIDS, 2019).

In summary, our pilot study has provided the first comprehensive picture of the quality of life of PLHIV in the Czech Republic. It has found no significant differences in overall quality of life, anxiety, or depressive symptoms between Czech and Ukrainian people living with HIV in the Czech Republic, despite significant differences in gender distribution and educational attainment. The PozQoL instrument has demonstrated excellent reliability in both samples. Approximately one-fifth of respondents in each group have reported low quality of life, indicating a clear need for targeted psychosocial support. Quality of life has been strongly negatively associated with anxiety and depressive symptoms and positively associated with perceived social support. These findings highlight the crucial role of mental health care and social support—particularly family support—in improving the well-being of people living with HIV.

## Future outputs and use of results

This text provides a professional basis for regular periodical monitoring the HRQoL among people living with HIV in the Czech Republic. From a practical point of view, the results may help the Ministry of Health of the Czech Republic and the National HIV Commission make informed decisions based on HRQoL as a supplementary indicator of quality of care and guide further steps within the National HIV/AIDS Program.

If certain factors (e.g., stigma, depression) are found to critically reduce the quality of life of Czech PLHIV, it will be appropriate to strengthen the relevant interventions, for example, expand mental health services for HIV-positive individuals (psychotherapy, peer mentoring). At the same time, it will be possible to reveal any previously hidden needs. For example, if it turns out that certain subpopulations (young vs. older patients, women vs. men, or non-native residents) have systematically poorer HRQoL, it will be possible to tailor support services specifically for these groups.

The data from the pilot study will also serve as a baseline for future comparisons – it will be possible to periodically repeat HRQoL measurements and monitor whether the implemented changes lead to improvement (the PozQoL scale was designed to be sensitive to changes over time; Brown et al., 2018).

The concept of "quality of life" thus becomes another logical milestone in the evolution of HIV care. After successfully prolonging and saving lives thanks to ART, the new challenge is to ensure that PLHIV live these lives with dignity, satisfaction, and in good health. Achieving the fourth 90 target—90% of people with HIV in good health and quality of life—is certainly ambitious but achievable, especially if medical, psychological, and social interventions are linked.

This expert report represents an open entry into the next phase of informed improvement in the quality of life of people living with HIV, a goal that should be the focus of attention for all stakeholders, from policymakers to care providers to PLHIV themselves.

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# 8. List of abbreviations

**AIDS** – Acquired Immune Deficiency Syndrome
**ART** – Antiretroviral Therapy
**CD4** – CD4+ T lymphocytes (immune marker)
**CZ** – Czech sample of respondents
**ČR** – Czech Republic
**ČSAP** – Czech AIDS Help Society
**DSM-IV** – Diagnostic and Statistical Manual of Mental Disorders, 4th edition
**GAD-7** – Generalized Anxiety Disorder-7
**GIPA** – Greater Involvement of People Living with HIV/AIDS
**HAT-QoL** – HIV/AIDS-Targeted Quality of Life Instrument
**HIV** – Human Immunodeficiency Virus
**HRQoL** – Health-Related Quality of Life
**MSM** – Men who have sex with men
**MSPSS** – Multidimensional Scale of Perceived Social Support
**NUDZ** – National Institute of Mental Health
**PHQ-9** – Patient Health Questionnaire-9
**PLHIV** – People Living with HIV
**PozQoL** – Positive Quality of Life Scale
**QoL** – Quality of Life
**SZÚ** – National Institute of Public Health
**STI** – Sexually Transmitted Infections
**U=U** – Undetectable = Untransmittable
**UA** – Ukrainian sample of respondents
**UNAIDS** – Joint United Nations Programme on HIV/AIDS
**WHO** – World Health Organization
**WHOQOL-HIV** – World Health Organization Quality of Life – HIV version

# 9. Attachments

## Questionnaire in Czech language

***Informace o výzkumu a Informovaný souhlas***
týkající se účasti ve výzkumu *Kvalita života osob žijících s HIV*

Vážená paní, vážený pane,
Státní zdravotní ústav a Národní ústav duševního zdraví řeší výzkum zaměřený na kvalitu života osob žijících s HIV. Cílem výzkumu je získat vědecké poznatky o kvalitě života osob s HIV, a poznatky o tom, jak subjektivně posuzovaná kvalita jejich života souvisí s dalšími faktory (historie léčení, některé životní okolnosti). Na základě výsledků výzkumu by měla být přijata doporučení k opatřením, která by vedla ke zlepšení kvality života a wellbeingu osob s HIV. Způsob řešení výzkumu byl posouzen a schválen Etickou komisí Státního zdravotního ústavu. Touto formou Vás chceme seznámit s tím, co pro Vás účast na výzkumu obnáší.

- Výzkum probíhá on-line formou, a to tak, že jím není nijak ovlivněna vaše současná léčba ani vaše životní situace. Na základě dobrovolnosti se mohou výzkumu účastnit osoby starší 18 let, které vyjádří souhlas s účastí na výzkumu zaškrtnutím políčka na konci Informovaného souhlasu. Účast na výzkumu je možné kdykoli odvolat bez udání důvodu.
- Osoby, které souhlasí s účastí ve výzkumu, budou požádány o vyplnění on-line dotazníku. Dotazníkové šetření se skládá ze škál zaměřených na kvalitu života, duševní zdraví, dále otázek na okolnosti léčení HIV a obecných osobních údajů (např. věk, pohlaví, vzdělání). Zodpovězení dotazníku trvá přibližně 10 až 15 minut.
- Zajištění ochrany osobních údajů odpovídá platným zákonům (Zákon č. 101/2000 Sb). Účast na výzkumu je zcela anonymní. Shromážděné informace nebudou spojovány s žádnými konkrétními osobními údaji, jakými jsou jméno, datum narození, rodné číslo, adresa bydliště. Výzkumná data jsou organizována a zpracovávána tak, že je vyloučena identifikace konkrétní osoby. Přístup k datům je omezen na řešitele výzkumného úkolu. Na vyžádání je přístup k podkladům umožněn zadavateli výzkumu, etické komisi a regulačnímu orgánu. Výsledky výzkumu budou publikovány formou agregovaných dat.
- Další informace o výzkumu a etických aspektech může podat řešitel projektu PhDr. Ladislav Csémy (mail csemy@nudz.cz).

Potvrzuji, že jsem se seznámil/a s informacemi o výzkumu a s podmínkami, za nichž se výzkum uskutečňuje, a souhlasím s účastí.

*Zaškrtávací políčko* ☐ ANO – Pokračujte ve vyplňování dotazníku
☐ NE

**Tento výzkum je určen pro osoby žijící s HIV. Rádi bychom se vás zeptali na vaše zdraví, vztahy, životní spokojenost a pohodu.**

***Na stupnici od 1 (vůbec ne) do 5 (extrémně) prosím uveďte, nakolik se vás týkají následující výroky.***

| | | Vůbec ne | Trochu | Středně | Velmi | Extrémně |
|---|---|---|---|---|---|---|
| 1 | Užívám si života. | 1 | 2 | 3 | 4 | 5 |
| 2 | Mám obavy o své zdraví. | 1 | 2 | 3 | 4 | 5 |
| 3 | Chybí mi pocit sounáležitosti s lidmi kolem mě. | 1 | 2 | 3 | 4 | 5 |
| 4 | Mám pocit, že mi HIV brání dělat tolik, kolik bych chtěl/a. | 1 | 2 | 3 | 4 | 5 |
| 5 | Mám ze sebe dobrý pocit. | 1 | 2 | 3 | 4 | 5 |
| 6 | To, že mám HIV, omezuje mé životní příležitosti. | 1 | 2 | 3 | 4 | 5 |
| 7 | Mám obavy z dopadu HIV na mé zdraví. | 1 | 2 | 3 | 4 | 5 |
| 8 | Mám pocit, že mám svůj život pod kontrolou. | 1 | 2 | 3 | 4 | 5 |
| 9 | Bojím se, že mě lidé odmítnou, když zjistí, že mám HIV. | 1 | 2 | 3 | 4 | 5 |
| 10 | Zvládání HIV mě vyčerpává. | 1 | 2 | 3 | 4 | 5 |
| 11 | Mám pocit, že HIV omezuje mé osobní vztahy. | 1 | 2 | 3 | 4 | 5 |
| 12 | Mám strach ze zdravotních dopadů HIV se zvyšujícím věkem. | 1 | 2 | 3 | 4 | 5 |
| 13 | Ohledně své budoucnosti jsem optimistický/á. | 1 | 2 | 3 | 4 | 5 |

***Jak často Vás trápil některý z uvedených problémů v posledních 2 týdnech?***

| | | Vůbec ne | Několik dní | Více než polovinu dní | Téměř každý den |
|---|---|---|---|---|---|
| 1 | Malý zájem nebo potěšení z věcí, které děláte | 0 | 1 | 2 | 3 |
| 2 | Pocit, že jste na dně, pocit deprese nebo beznaděje | 0 | 1 | 2 | 3 |
| 3 | Potíže s usínáním, přerušovaným spánkem nebo s přílišným spaním | 0 | 1 | 2 | 3 |
| 4 | Pocit únavy nebo málo energie | 0 | 1 | 2 | 3 |
| 5 | Malá chuť k jídlu nebo přejídání | 0 | 1 | 2 | 3 |
| 6 | Měl/a jste ze sebe špatný pocit, že se Vám život nevydařil nebo že jste zklamal/a sám/sama sebe nebo svou rodinu | 0 | 1 | 2 | 3 |
| 7 | Potíže se soustředěním, např. na čtení novin nebo sledování televize | 0 | 1 | 2 | 3 |
| 8 | Pohyboval/a jste se nebo mluvil/a tak pomalu, že si toho druzí mohli povšimnout? Nebo naopak – byl/a jste tak nepokojný/á a neklidný/á, že jste se pohyboval/a mnohem víc než obvykle | 0 | 1 | 2 | 3 |
| 9 | Myšlenky, že by vám bylo lépe, kdybyste byl/a mrtev/mrtva nebo si nějakým způsobem ublížil/a | 0 | 1 | 2 | 3 |

***Jak často Vás trápil některý z uvedených problémů v posledních 2 týdnech?***

| | | Vůbec ne | Několik dní | Více než polovinu dní | Téměř každý den |
|---|---|---|---|---|---|
| 1 | Nervozita, úzkost nebo pocit, že jsem na hraně | 0 | 1 | 2 | 3 |
| 2 | Nemožnost přestat se obávat nebo dostat obavy pod kontrolu | 0 | 1 | 2 | 3 |
| 3 | Přílišné obavy kvůli různým věcem | 0 | 1 | 2 | 3 |
| 4 | Potíže se uvolnit | 0 | 1 | 2 | 3 |
| 5 | Takový neklid, že těžko dokážu klidně sedět | 0 | 1 | 2 | 3 |
| 6 | Snadno se rozzlobím nebo jsem podrážděný/á | 0 | 1 | 2 | 3 |
| 7 | Strach, jako kdyby se mělo stát něco hrozného | 0 | 1 | 2 | 3 |

***Pomocí následující škály prosím označte, jak moc souhlasíte či nesouhlasíte s následujícími výroky. Prosím zvolte vhodnou odpověď pro každou z položek (od 1=velmi silně nesouhlasím … po 7=velmi silně souhlasím)***

| | | Velmi silně nesouhlasím | Silně nesouhlasím | Spíše nesouhlasím | Něco mezi | Spíše souhlasím | Silně souhlasím | Velmi silně souhlasím |
|---|---|---|---|---|---|---|---|---|
| 1 | Mám v blízkosti důvěrnou osobu, která mi vždy pomůže, když to potřebuji. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 2 | Mám v blízkosti důvěrnou osobu, s níž mohu sdílet své radosti i strasti. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 3 | Má rodina se mi skutečně snaží pomáhat. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 4 | Od své rodiny dostávám citovou podporu a pomoc, jakou potřebuji. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 5 | Mám v blízkosti důvěrnou osobu, která je pro mě opravdovým zdrojem útěchy. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 6 | Moji přátelé se mi skutečně snaží pomáhat. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 7 | Mohu se v případě potíží spolehnout na své přátele. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 8 | O svých problémech mohu mluvit se svou rodinou. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 9 | Mám přátele, s nimiž mohu sdílet své radosti i strasti. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 10 | Mám v blízkosti důvěrnou osobu, které záleží na mých pocitech. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 11 | Má rodina je ochotná mi pomáhat s rozhodováním. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 12 | O svých problémech mohu mluvit se svými přáteli. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

***Prosíme vás ještě o několik údajů, které potřebujeme pro vyhodnocení výzkumu***

**Jaké pohlaví vám bylo připsáno při narození?**
☐ mužské
☐ ženské
☐ nevím
☐ nechci uvádět

**Jaká je vaše genderová identita?**
☐ muž
☐ žena
☐ trans muž
☐ trans žena
☐ nebinární / genderqueer / agender / genderfluidní / polygender
☐ neidentifikuji se jako muž, žena, trans nebo nebinární – uveďte prosím, jak se identifikujete:

**Která z následujících kategorií nejlépe definuje vaši sexualitu / sexuální orientaci?**
☐ lesba (homosexuální)
☐ gay (homosexuální)
☐ bisexuální
☐ heterosexuální
☐ queer
☐ pansexuální
☐ asexuální
☐ nevím, nejsem si jistý/jistá
☐ nic z výše uvedeného

**Věk:** |__|__|

**Vzdělání:**
☐ Základní
☐ Střední odborné (vyučení, výuční list)
☐ Střední s maturitou
☐ Vysokoškolské (včetně Bc)

**Rodinný/partnerský stav:**
☐ svobodný/á
☐ ženatý/vdaná nebo žijící s partnerem/kou
☐ vdovec/vdova
☐ rozvedený/á
☐ je to jinak - prosím, popište:…………….

**Práce:**

☐ zaměstnání/práce na plný nebo částečný úvazek
☐ podnikání, OSVČ
☐ příležitostná práce/brigáda
☐ nezaměstnaný, v současnosti hledá práci
☐ důchod/renta
☐ je to jinak - prosím, popište:……………..

**Místo pobytu. Zaškrtněte, ve kterém kraji fakticky žijete**

☐ Hlavní město Praha
☐ Středočeský kraj
☐ Jihočeský kraj
☐ Plzeňský kraj
☐ Karlovarský kraj
☐ Ústecký kraj
☐ Liberecký kraj
☐ Královéhradecký kraj
☐ Pardubický kraj
☐ Kraj Vysočina
☐ Jihomoravský kraj
☐ Zlínský kraj
☐ Olomoucký kraj
☐ Moravskoslezský kraj.

***Historie léčby***

**Jak dlouho se léčíte s HIV?**

☐ do 1 roku
☐ 2 až 5 let
☐ 6 až 10 let
☐ více než 10 let
☐ neléčím se

**Měl/a jste někdy AIDS?**

☐ Ano
☐ Ne
☐ Nevím

**Máte nějaké dlouhodobé onemocnění, které Váš život ovlivňuje více než HIV?**

☐ Ano
☐ Ne

**Byl/a jste v posledních dvou letech hospitalizován/a kvůli zdravotnímu problému souvisejícímu s HIV?**

☐ Ano
☐ Ne

**Ve kterém HIV centru se aktuálně léčíte:**

☐ Praha, Nemocnice na Bulovce
☐ Praha, Ústřední vojenská nemocnice
☐ Plzeň
☐ Ostrava
☐ Brno
☐ Ústí nad Labem
☐ Hradec Králové
☐ České Budějovice
☐ Liberec
☐ Olomouc

**Zahájení léčby HIV proběhlo:**

☐ v ČR ve stejném HIV centru, kam nyní docházím

☐ v ČR v jiném HIV centru, zaškrtněte, ve kterém:
    ☐ Praha, Nemocnice na Bulovce
    ☐ Praha, Ústřední vojenská nemocnice
    ☐ Plzeň
    ☐ Ostrava
    ☐ Brno
    ☐ Ústí nad Labem
    ☐ Hradec Králové
    ☐ České Budějovice
    ☐ Liberec
    ☐ Olomouc
☐ v zahraničí

**Cesta z místa bydliště do HIV centra vám trvá:**

☐ méně než 1 hodinu
☐ alespoň 1 hodinu, ale méně než 2 hodiny
☐ alespoň 2 hodiny, ale méně než 3 hodiny
☐ 3 hodiny či více

DĚKUJEME VÁM ZA VYPLNĚNÍ DOTAZNÍKU!

## Questionnaire in Ukrainian language

### *Інформація про дослідження та Інформована згода*

щодо участі у дослідженні *Якість життя людей, які живуть з ВІЛ*

Шановна пані, шановний пане,

Державний інститут охорони здоров’я та Національний інститут психічного здоров’я проводять дослідження, спрямоване на оцінку якості життя людей, які живуть з ВІЛ. Мета дослідження – отримати наукові знання про якість життя людей з ВІЛ, а також про те, як суб’єктивно оцінювана якість їхнього життя пов’язана з іншими факторами (історія лікування, певні життєві обставини). На основі результатів дослідження мають бути прийняті рекомендації щодо заходів, які б сприяли покращенню якості життя та добробуту людей з ВІЛ. План дослідження було розглянуто та схвалено Етичною комісією Державного інституту охорони здоров’я.

Цим документом ми хочемо ознайомити Вас із тим, що передбачає для Вас участь у дослідженні.

- Дослідження проводиться онлайн і жодним чином не впливає на Ваше поточне лікування чи життєву ситуацію. Добровільно у ньому можуть брати участь особи віком від 18 років, які погодяться на участь, позначивши відповідне поле наприкінці Інформованої згоди. У будь-який момент можна відкликати свою участь без пояснення причин.

- Особи, які погодяться взяти участь у дослідженні, будуть запрошені заповнити онлайн-анкету. Анкета складається зі шкал, спрямованих на оцінку якості життя, психічного здоров’я, а також питань, що стосуються лікування ВІЛ та загальних персональних даних (наприклад, вік, стать, освіта). Заповнення анкети займає приблизно 10–15 хвилин.

- Захист персональних даних здійснюється відповідно до чинного законодавства (Закон № 101/2000 Зб. законів). Участь у дослідженні є повністю анонімною. Зібрана інформація не буде пов’язана з будь-якими конкретними особистими даними, такими як ім’я, дата народження, ідентифікаційний номер чи адреса проживання. Дослідницькі дані організовані та обробляються таким чином, щоб виключити можливість ідентифікації конкретної особи. Доступ до даних мають лише виконавці дослідницького проєкту. За запитом доступ до матеріалів може бути наданий замовнику дослідження, етичній комісії та регуляторному органу. Результати дослідження будуть опубліковані у вигляді зведених даних.

- Додаткову інформацію про дослідження та етичні аспекти може надати керівник проєкту доктор філософії Ладислав Чсеми (e-mail csemy@nudz.cz).

Підтверджую, що я ознайомився/ознайомилася з інформацією про дослідження та з умовами, за яких воно проводиться, і погоджуюся взяти у ньому участь.

Прапорець для відмітки

☐ ТАК – Продовжуйте заповнення анкети

☐ НІ

**Це дослідження призначене для людей, які живуть з ВІЛ. Ми хотіли б запитати вас про ваше здоров'я, стосунки, задоволеність життям та благополуччя.**

***За шкалою від 1 (зовсім ні) до 5 (дуже) просимо зазначити, наскільки вас стосуються наведені нижче твердження.***

| | | Зовсім | Трохи | Помірно | Значною мірою | Дуже |
|---|---|---|---|---|---|---|
| 1 | Я насолоджуюсь життям. | 1 | 2 | 3 | 4 | 5 |
| 2 | Мене непокоїть моє здоров'я. | 1 | 2 | 3 | 4 | 5 |
| 3 | Мені не вистачає відчуття єдності з людьми навколо мене. | 1 | 2 | 3 | 4 | 5 |
| 4 | Я відчуваю, що через ВІЛ я не можу робити багато з того, що мені б хотілося. | 1 | 2 | 3 | 4 | 5 |
| 5 | Я вважаю себе хорошою людиною. | 1 | 2 | 3 | 4 | 5 |
| 6 | ВІЛ обмежує мої життєві можливості. | 1 | 2 | 3 | 4 | 5 |
| 7 | Мене непокоїть те, як ВІЛ впливає на моє здоров'я. | 1 | 2 | 3 | 4 | 5 |
| 8 | Я маю відчуття контролю над власним життям. | 1 | 2 | 3 | 4 | 5 |
| 9 | Я боюся, що, дізнавшись про мій ВІЛ-статус, люди можуть мене цуратися. | 1 | 2 | 3 | 4 | 5 |
| 10 | Лікування ВІЛ мене виснажує. | 1 | 2 | 3 | 4 | 5 |
| 11 | Я відчуваю, що ВІЛ обмежує мої особисті стосунки. | 1 | 2 | 3 | 4 | 5 |
| 12 | Я боюся, що з віком ВІЛ матиме серйозні наслідки для мого здоров'я. | 1 | 2 | 3 | 4 | 5 |
| 13 | Я з оптимізмом дивлюся в майбутнє. | 1 | 2 | 3 | 4 | 5 |

**Як часто вас турбувала якась із наведених проблем протягом останніх 2 тижнів?**

| | | Зовсім ні | Декілька днів | Більше половини днів | Майже щодня |
|---|---|---|---|---|---|
| 1 | Невеликий інтерес або задоволення від того, що ви робите | 0 | 1 | 2 | 3 |
| 2 | Почуття пригніченості, депресії або безнадії | 0 | 1 | 2 | 3 |
| 3 | Труднощі із засинанням, переривчастим сном або надмірним сном | 0 | 1 | 2 | 3 |
| 4 | Відчуття втоми або брак енергії | 0 | 1 | 2 | 3 |
| 5 | Поганий апетит або переїдання | 0 | 1 | 2 | 3 |
| 6 | Ви думали про себе погано, відчували, що ваше життя не склалося, або що ви розчарували себе чи свою сім’ю | 0 | 1 | 2 | 3 |
| 7 | Труднощі з концентрацією, наприклад, під час читання газети чи перегляду телевізора | 0 | 1 | 2 | 3 |
| 8 | Ви рухалися або говорили настільки повільно, що це могли помітити інші? Або навпаки – були настільки знервовані та занепокоєні, що рухалися значно більше, ніж зазвичай | 0 | 1 | 2 | 3 |
| 9 | Думки, що вам було б краще, якби ви померли або якимось чином собі зашкодили | 0 | 1 | 2 | 3 |

**Як часто протягом останніх двох тижнів вас непокоїла будь-яка з перелічених проблем?**

| | | Зовсім ні | Декілька днів | Більше половини днів | Майже |
|---|---|---|---|---|---|
| 1 | Нервозність, тривога або відчуття, що я «на межі» | 0 | 1 | 2 | 3 |
| 2 | Неможливість перестати хвилюватися або взяти свої хвилювання під контроль | 0 | 1 | 2 | 3 |
| 3 | Надмірні хвилювання з приводу різних речей | 0 | 1 | 2 | 3 |
| 4 | Труднощі з розслабленням | 0 | 1 | 2 | 3 |
| 5 | Такий неспокій, що важко всидіти на місці | 0 | 1 | 2 | 3 |
| 6 | Легко можете розсердитися або роздратуватися | 0 | 1 | 2 | 3 |
| 7 | Страх, ніби має статися щось жахливе | 0 | 1 | 2 | 3 |

**Використовуючи наведену нижче шкалу, позначте, будь ласка, наскільки ви згодні або не згодні з наведеними твердженнями. Оберіть відповідь для кожного пункту (від 1 = зовсім не згоден/згодна … до 7 = повністю згоден/згодна).**

| | | Зовсім не згоден(на) | Не згоден(на) | Скоріше не згоден(на) | Не певен(на) | Скоріше згоден(на) | Згоден(на) | Повністю згоден(на) |
|---|---|---|---|---|---|---|---|---|
| 1 | У мене поруч є близька людина, яка завжди допоможе, коли мені це потрібно. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 2 | У мене поруч є близька людина, з якою я можу поділитися своїми радощами та прикрощами. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 3 | Моя родина справді намагається мені допомагати. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 4 | Від своєї родини я отримую емоційну підтримку та допомогу, які мені потрібні. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 5 | У мене поруч є близька людина, яка є для мене справжнім джерелом розради. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 6 | Мої друзі справді намагаються мені допомагати. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 7 | У разі труднощів я можу покластися на своїх друзів. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 8 | Про свої проблеми я можу поговорити з родиною. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 9 | У мене є друзі, з якими я можу поділитися своїми радощами та прикрощами. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 10 | У мене поруч є близька людина, якій небайдужі мої почуття. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 11 | Моя родина готова допомагати мені з прийняттям рішень. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 12 | Про свої проблеми я можу поговорити з друзями. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

**Просимо вас про надання ще кількох відомостей, які нам потрібні для оцінки дослідження**

**Яка стать була вам приписана при народженні?**

☐ чоловіча
☐ жіноча
☐ не знаю
☐ не хочу вказувати

**Яка ваша гендерна ідентичність?**

☐ чоловік
☐ жінка
☐ транс-чоловік
☐ транс-жінка
☐ небінарна / гендерквір / агендер / гендерфлюїдна / полігендер

☐ я не ідентифікую себе як чоловік, жінка, транс чи небінарна особа – будь ласка, вкажіть, як ви себе ідентифікуєте:

**Яка з наведених нижче категорій найкраще визначає вашу сексуальну орієнтацію?**
☐ лесбійка (гомосексуальна)
☐ гей (гомосексуальний)
☐ бісексуальний/а
☐ гетеросексуальний/а
☐ квір
☐ пансексуальний/а
☐ асексуальний/а
☐ не знаю, я не впевнений/впевнена
☐ нічого з вищенаведеного

**Вік:** |__|__|

**Освіта:**
☐ Початкова
☐ Середня професійна (професійно-технічна освіта, свідоцтво про кваліфікацію)
☐ Середня з атестатом зрілості
☐ Вища освіта (включно з бакалавріатом)
**Сімейний/партнерський стан:**
☐ неодружений/незаміжня
☐ одружений/заміжня або проживаю з партнером/кою
☐ вдівець/вдова
☐ розлучений/а
☐ інше – будь ласка, вкажіть:…………….

**Робота:**
☐ робота/зайнятість на повний або неповний робочий день
☐ підприємництво, ФОП
☐ нестабільна робота/підробіток
☐ безробітний/а, наразі шукаю роботу
☐ пенсія/рента
☐ інше – будь ласка, вкажіть:……………..

**Місце проживання. Позначте, в якому краї ви фактично проживаєте**

☐ місто Прага
☐ Середньочеський край
☐ Південночеський край
☐ Плзенський край
☐ Карловарський край
☐ Устецький край

☐ Ліберецький край
☐ Краловоградецький край
☐ Пардубіцький край
☐ Край Височина
☐ Південноморавський край
☐ Злінський край
☐ Оломоуцький край
☐ Моравськосілезький край

***Історія лікування***

**Як довго ви лікуєтеся від ВІЛ?**

☐ до 1 року
☐ від 2 до 5 років
☐ від 6 до 10 років
☐ більше ніж 10 років
☐ не лікуюсь

**Чи мали ви коли-небудь СНІД?**

☐ Так
☐ Ні
☐ Не знаю

**Чи маєте ви хронічне захворювання, яке впливає на ваше життя більше, ніж ВІЛ?**

☐ Так
☐ Ні

**Чи були ви впродовж останніх двох років госпіталізовані через проблеми зі здоров'ям, пов'язані з ВІЛ?**

☐ Так
☐ Ні

**У якому ВІЛ-центрі ви наразі лікуєтеся:**

☐ Прага, Лікарня на Буловці (Nemocnice na Bulovce)
☐ Прага, Центральний військовий госпіталь (Ústřední vojenská nemocnice)
☐ Плзень
☐ Острава
☐ Брно
☐ Усті-над-Лабем
☐ Градець-Кралове
☐ Чеські Будейовиці
☐ Ліберець
☐ Оломоуць

**Початок лікування ВІЛ відбувся:**

☐ у Чехії в тому самому ВІЛ-центрі, куди я зараз ходжу
☐ у Чехії в іншому ВІЛ-центрі, позначте, у якому:

  - ☐ Прага, Лікарня на Буловці (Nemocnice na Bulovce)
  - ☐ Прага, Центральний військовий госпіталь (Ústřední vojenská nemocnice)
  - ☐ Плзень
  - ☐ Острава
  - ☐ Брно
  - ☐ Усті-над-Лабем
  - ☐ Градець-Кралове
  - ☐ Чеські Будейовиці
  - ☐ Ліберець
  - ☐ Оломоуць
- ☐ за кордоном

**Дорога від місця проживання до ВІЛ-центру у вас займає:**
- ☐ менше ніж 1 годину
- ☐ принаймні 1 годину, але менше ніж 2 години
- ☐ принаймні 2 години, але менше ніж 3 години
- ☐ 3 години чи більше

ДЯКУЄМО ВАМ ЗА ЗАПОВНЕННЯ АНКЕТИ!