


SPECIAL REPORT



Stigma: survey of people living with HIV

Monitoring implementation of the Dublin
Declaration on partnership to fight HIV/AIDS in
Europe and Central Asia: 2022 progress report

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This report of the European Centre for Disease Prevention and Control (ECDC) was coordinated by Teymur Noori, with technical input from Jasleen Singh, Emma Cattermole, Ana Paula Finatto-Canabarro and Anastasia Pharris.

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Abbreviations

AAE	AIDS Action Europe
EATG	European AIDS Treatment Group
HIV	Human immunodeficiency virus
LSS	Life satisfaction score
NGO	Non-governmental organisation
OECD	Organisation for Economic Co-operation and Development
PLHIV	People living with HIV
Trans AMAB	Trans assigned male at birth
U=U	Undetectable=Untransmissible
WHO	World Health Organization

Executive summary

HIV-related stigma and discrimination remain major barriers to accessing HIV services for people living with HIV worldwide. In this context, stigma can be understood as the negative perception of people living with HIV based solely on their HIV status. Experienced stigma, or discrimination, occurs when people living with HIV experience negative or unfair treatment based on these perceptions. An estimated one in eight people living with HIV are denied health services because of stigma and discrimination, and research shows that over 50% of people report having discriminatory attitudes towards people living with HIV [1]. Understanding and addressing stigma is critical to achieving the zero discrimination element of UNAIDS vision and successive strategies to end the AIDS epidemic by 2030.

To improve the understanding of experienced HIV stigma in the community, ECDC — in collaboration with the European AIDS Treatment Group (EATG) and AIDS Action Europe (AAE) — initiated an exploratory survey in 2021 to measure HIV-related stigma across Europe and Central Asia. The objective of this survey was to examine the experience of HIV-related stigma in the region and to establish a benchmark measure of perceived and experienced HIV-related stigma among the most affected communities in order to assess progress toward the UNAIDS target of zero discrimination by 2030 [1].

A total of 3 272 people living with HIV from 54 of the 55 countries in Europe and Central Asia responded to the survey. Nearly one in three (30%) respondents had not told a single family member that they were living with HIV, and one in five had not told a single friend or a current sexual partner (19% and 22%, respectively). A large proportion of respondents (59%) either agreed or strongly agreed that it is difficult to tell others about living with HIV.

Rejection by friends was the most frequently experienced stigmatising practice, with 24% of respondents reporting ever having experienced this form of stigma, 6% of these in the last year. One in six (17%) respondents reported ever having experienced being threatened, verbally abused or physically harmed by a sexual partner, 4% of these in the last year.

One in four (26%) respondents indicated that they were worried about being treated differently by healthcare staff within the last year. Also within the last year, one in five (21%) respondents were afraid to go to healthcare services for fear of having their HIV status disclosed and one in seven (16%) avoided healthcare services altogether for fear of being treated differently. One in three (33%) respondents reported ever generally feeling that they were treated poorly in a healthcare setting (11% in the last year) and one in four (23%) reported ever being refused healthcare or experiencing a delay in treatment due to their HIV status (7% in the last year).

One in seven (15%) respondents reported that they were afraid to go to dental services within the last year for fear of having their HIV status disclosed. Nearly one in six (12%) respondents avoided dental services for fear of being treated differently, while 6% reported actually being treated differently by a dentist or dental healthcare staff.

One in seven (15%) respondents had ever felt scared to be in public (7% in the last year), which may be related to the proportion of respondents that had been subjected to such stigmatising practices as being verbally harassed (20%) or being threatened, verbally abused or physically harmed by someone other than friends or family (15%).

It is important to note that this exploratory survey recruited a convenience sample of people living with HIV from across Europe and Central Asia, with the vast majority of respondents identifying as gay, bisexual or other men who have sex with men. The survey also had a limited sample size. For these reasons, the findings in this report are not representative of the mix of exposure categories within the broader population of people living with HIV. Furthermore, the results do not allow for further assessment as to whether there are statistically significant differences in experiences between exposure categories (e.g. those diagnosed decades ago versus those diagnosed more recently) or if there are statistically significant differences between countries.

These data illustrate the need to ensure that education, awareness and other interventions around stigma meet the needs of all people living with HIV, including genders other than male or female, sexual orientations other than heterosexual and key populations such as ethnic minorities, prisoners, people who inject drugs and people who have sex in exchange for money or other goods.

Countries are strongly encouraged to collect more data around stigma and discrimination at the national level, including qualitative data, to explore how HIV-related stigma operates in different settings and across population groups, as well as to strengthen education programmes and raise awareness of HIV within all facets of their communities. While reducing transmission of HIV and eliminating new infections are critical components of ending the HIV/AIDS epidemic by 2030, this goal will not be entirely successful without also addressing the HIV-associated stigma and discrimination that are still very present across Europe and Central Asia.

1 Introduction

The Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia [2], adopted in 2004, was the first in a series of regional and global declarations that emphasised HIV as an important political priority for the countries of Europe and Central Asia. Combined, these declarations state the commitment of all signatories to act collectively in tackling the HIV/AIDS epidemic and set out several actions to accelerate the achievement of the targets now included in the Sustainable Development Goals [3].

HIV-related stigma and discrimination remain major barriers to accessing HIV services among people living with HIV worldwide. An estimated one in eight people living with HIV are denied health services because of stigma and discrimination, and research shows that over 50% of people report having discriminatory attitudes towards people living with HIV [4]. For this reason, zero discrimination is an essential element of UNAIDS vision and successive strategies to end the AIDS epidemic by 2030, including a target that less than 10% of people living with HIV should report internalised or experienced HIV-related stigma and discrimination by 2025 [1].

As part of annual Dublin Declaration monitoring coordinated by ECDC for all countries in Europe and Central Asia, national public health bodies are asked to cooperate with in-country, non-governmental organisations (NGOs) to supply data on a variety of HIV-related indicators, including stigma. Although some countries conduct stigma surveys — often led by NGOs — these surveys (e.g. The People Living with HIV Stigma Index) [5] are either not implemented in most countries or are not standardised in a way that would allow for national benchmarking or comparison across countries, which has resulted in very little data available at the regional level (i.e. Europe and Central Asia).

In an effort to improve the understanding of experienced HIV stigma in the community, ECDC — in collaboration with the European AIDS Treatment Group (EATG) [6] and AIDS Action Europe (AAE) [7] — initiated an exploratory survey in 2021 to measure HIV-related stigma across Europe and Central Asia. The objective of this survey was to examine the experience of HIV-related stigma in the region and to establish a benchmark measure of perceived and experienced HIV-related stigma among the most affected communities in order to assess progress towards the UNAIDS target of zero stigma and discrimination by 2030.

2 Methods

Between 3 November 2021 and 31 January 2022, a survey (Annex 1) developed by ECDC, EATG and AAE was used to collect data on the experience of HIV-related stigma among people living with HIV in Europe and Central Asia.

The survey was designed in collaboration with a steering group (see Acknowledgments) that included representatives from the HIV community, public health specialists and survey experts. The survey drew upon two existing validated HIV stigma instruments, the People Living with HIV Stigma Index [5], conducted in 16 European countries to date, and the Positive Voices 2017 survey conducted in England and Wales [8]. In addition to questions on basic demographic information, the survey included questions regarding current life satisfaction, self-perceived health, and depression, as well as self-stigma markers and experiences of stigma in four different settings: among friends, family and sexual partners; in healthcare; in dental care; and in society and state-based systems. In October 2021, the survey was piloted and validated in 20 countries by the EATG and AAE country focal points. These focal points, drawn from NGOs, were nominated by EATG and AAE. Meetings were held with the focal points to explain the purpose and practicalities of the survey. Each focal point reviewed the survey to ensure that translations were correct and that all response options were functional. The findings of this validation step were used to inform the final survey.

The country focal points also supported the translation of the survey into participating countries' official languages, as well as its dissemination through their in-country networks. The focal points were crucial to ensure reach into the communities of people living with HIV who could provide responses. However, the success of the survey was also dependent on local organisations with limited capacities and without specific funding for this activity.

Potential survey respondents were informed that their participation was voluntary, anonymous and confidential. No information was collected that allowed for the identification of participants, including IP addresses, and consent was explicitly sought. Country focal points were instructed to determine if ethical approval was needed at the national level. To our knowledge, only two focal points sought ethical approval, in one case because recruitment to the survey was conducted at the clinic level in that specific country.

Not all NGOs were in a position to commit resources to this survey, and this may be reflected in the variation in response rates between countries. Individual countries were at liberty to collect data in any way they deemed suitable. The survey was conducted electronically via the EUSurvey tool [9] and was disseminated via the country focal points and through existing in-country networks. People living with HIV in the 55 countries in Europe and Central Asia were also invited to complete the survey via the social media platforms of ECDC, EATG and AAE. The survey was also advertised twice via Hornet (a queer tech platform) [10], which produced corresponding spikes in responses. However, this approach skewed the responses towards gay, bisexual and other men who have sex with men.

Data were cleaned from February to June 2022, and were subsequently analysed by the project team using Microsoft Excel to summarise the main results in numbers or proportions overall for the region. The analysis objective was to examine the experience of HIV-related stigma in the region and to explore an approach to collect robust data on HIV-related stigma for repeated monitoring leading up to the 2025 and 2030 targets.

For most questions, non-responses (or the response 'prefer not to say') were excluded from the analysis of that question. Such responses did not constitute a large proportion of the replies to any question.

The ages of respondents were split into four categories: under 20 years, 21 to 40 years, 41 to 60 years, and 61 years and above. Demographic indicators such as age, gender and key populations were considered in relation to the types of stigma ever experienced by respondents and, where differences existed, these are reported.

Respondents were asked to score their life satisfaction on a scale of zero to 10, which can be split into low satisfaction (a life satisfaction score (LSS) of zero to three), medium satisfaction (an LSS of four to six) and high satisfaction (an LSS of seven to 10).

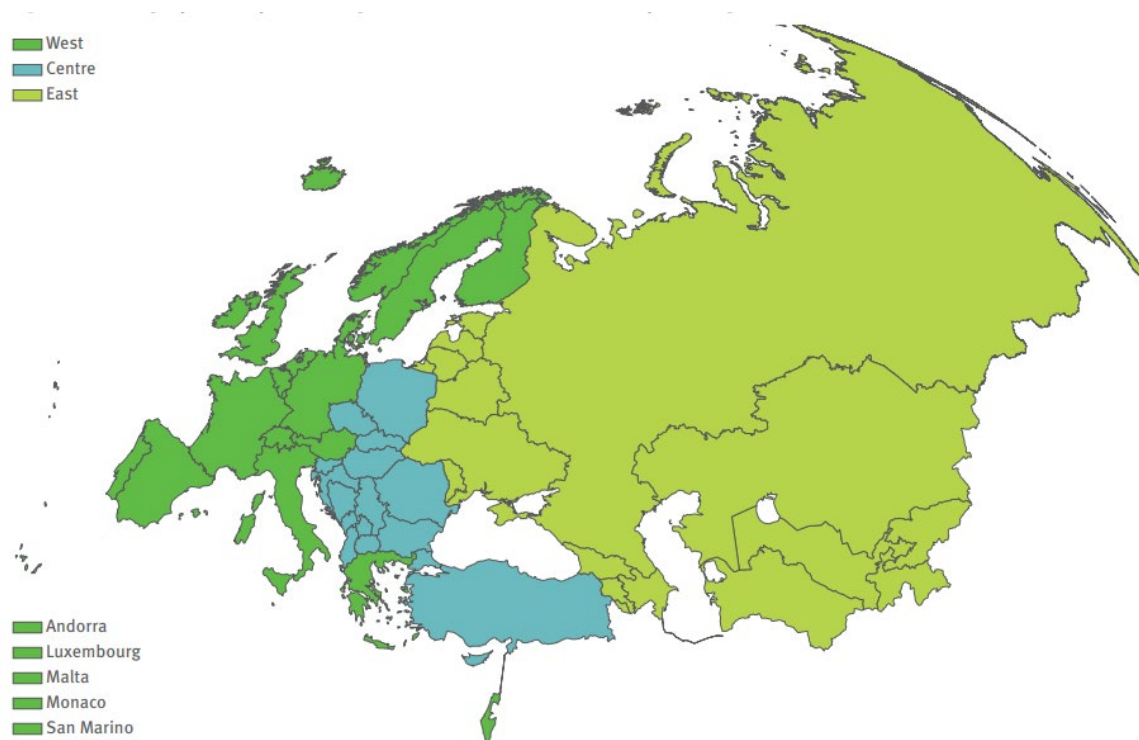
Respondents were asked to report the date of their HIV diagnosis and were grouped together to represent arguably discrete eras in the history of HIV:

- **Pre-1996:** those diagnosed before effective antiretroviral treatment became available.
- **1996 to 2007:** those diagnosed since treatment was available but before the Swiss statement in 2008 [11], which drew attention to the ability of HIV treatment to reduce transmission.
- **2008 to 2014:** those diagnosed since the Swiss statement but before the era of 'undetectable=untransmissible' (U=U) and the Strategic Timing of Antiretroviral Therapy (START) trial, which recommended starting antiretroviral therapy regardless of CD4+ count [12].
- **2015 to present:** those diagnosed since U=U and the START trial.

The data in this report are not presented by country due to the variation in the number of responses received. Some countries produced hundreds of responses, while others generated very few (range: 1–428 responses). Individual datasets were provided to each country to conduct their own national analyses.

In addition to considering the picture for the overall European and Central Asian region, this report presents data by World Health Organization (WHO) European Region subregions (West, Centre and East), which broadly groups areas of Europe and Central Asia by geography (Figure 1).

Figure 1. Geographical and epidemiological division of the WHO European Region into subregions



Source: WHO Regional Office for Europe (WHO/Europe), European Centre for Disease Prevention and Control (ECDC). HIV/AIDS surveillance in Europe 2022 – 2021 data. Copenhagen, Stockholm: WHO/Europe, ECDC; 2023. Available at: <http://www.ecdc.europa.eu/en/publications-data/hiv-aids-joint-report-surveillance-2021-data>

The countries covered by the report are grouped according to the WHO European Region subregions, as follows:

- **West (24 countries):** Andorra, Austria, Belgium, Denmark, Finland, France, Germany, Greece, Iceland, Ireland, Israel, Italy, Luxembourg, Liechtenstein, Malta, Monaco, the Netherlands, Norway, Portugal, San Marino, Spain, Sweden, Switzerland and the United Kingdom.
- **Centre (16 countries):** Albania, Bosnia and Herzegovina, Bulgaria, Croatia, Cyprus, Czechia, Hungary, Kosovo¹, Montenegro, North Macedonia, Poland, Romania, Serbia, Slovakia, Slovenia and Türkiye.
- **East (15 countries):** Armenia, Azerbaijan, Belarus, Estonia, Georgia, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, Moldova, Russia, Tajikistan, Turkmenistan, Ukraine and Uzbekistan.

Limitations

It is important to note that this study recruited a convenience sample of people living with HIV from across Europe and Central Asia, resulting in different proportional sample sizes across countries. The vast majority of respondents identified as gay, bisexual or men who have sex with men. Migrants were the second largest key population group surveyed, but only made up 6% of the entire sample. One explanation for the low sample size of migrants could be that the survey was only translated into the official languages of the countries in the European and Central Asian region. While it is useful to investigate trends in stigma relating to key populations, further studies with larger sample sizes from across the region will be needed — with more individuals surveyed from groups other than gay, bisexual or men who have sex with men — to ensure that patterns are proportionally representative of the overall population of people living with HIV. Although individual countries were at liberty to collect data in any way they deemed suitable, the lack of capacity to commit to coding paper-based responses meant that this survey could only be conducted electronically.

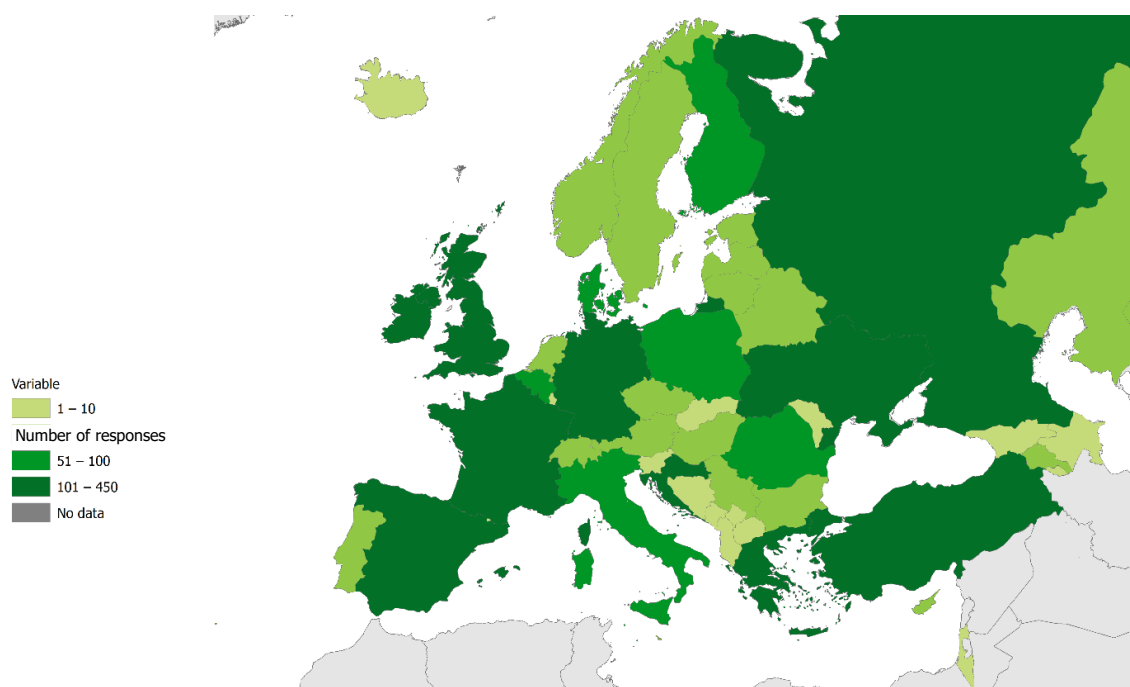
¹ This designation is without prejudice to positions on status, and is in line with UNSCR 1244 and the ICJ Opinion on the Kosovo Declaration of Independence.

For the reasons mentioned previously, including the study's limited sample size, the findings in this report are not representative of the mix of exposure categories within the broader population of people living with HIV. Furthermore, the results do not allow for further assessment as to whether there are statistically significant differences in experiences between exposure categories (e.g. those diagnosed decades ago versus those diagnosed more recently), between the major fraction of the sample (i.e. gay, bisexual and men who have sex with men) and other exposure categories, or between countries. Age and time since diagnosis are likely important determinants of how recently the reported stigma was experienced. Despite a strong relationship between these background determinants, these elements have not been explored in this analysis. Results presented herein are descriptive in nature and no inferential statistical analysis or statistical testing for significance was performed. Consequently, the results presented in this report should be interpreted with great caution.

3 Survey responses

There were a total of 3 272 responses to the survey, with considerable variation in the number of responses reported by each country (Figure 2). Responses were received from 54 of the 55 countries in Europe and Central Asia (Turkmenistan did not report any responses). The greatest number of responses was from Russia ($n = 428$), while 19 countries had fewer than 10 responses. This variation in number of responses is undoubtedly affected by variation in HIV prevalence (Annex 2), but prevalence alone is not a sufficient explanation. As a proportion of the number of estimated people living with HIV in the country, Croatia (7%) had the highest response rate, followed by Kosovo (4%). Due to the low response rate in many countries, the data in this report are presented in aggregate and not by country.

Figure 2. Number of survey respondents by country



Almost half of respondents ($n = 1\ 575$) currently live in the West subregion, while roughly one quarter live in the Centre ($n = 725$) and roughly another quarter in the East ($n = 935$). There were 37 (1%) respondents who did not respond to the question on country of current residence; these responses are included in the results presented for the whole European and Central Asian region.

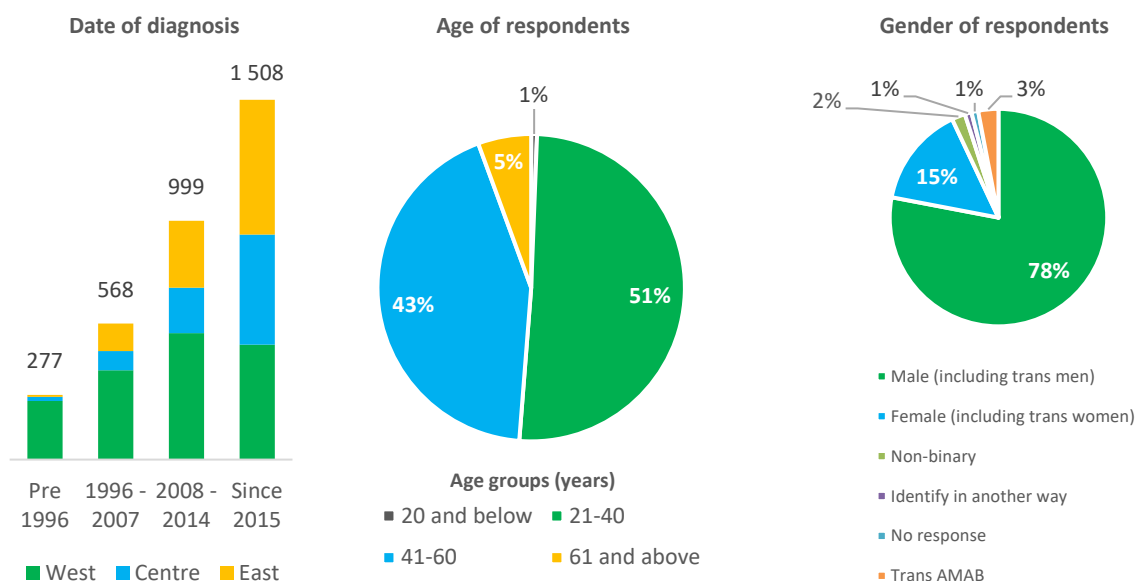
Demographics of respondents

The respondents were predominantly gay, bisexual or men who have sex with men (2022 respondents, 62%), as predicted by the spikes in responses following advertisements via Hornet. The response rates for other key populations was low, with migrants (184 respondents, 6%) having the next strongest representation, and lower proportions self-identifying as people who currently or in the past injected drugs (139 respondents, 4%), ethnic minorities (125 respondents, 3%), people who have or have had sex in exchange for money or goods (66 respondents, 2%) and prisoners (23 respondents, 0.7%). Some respondents belonged to multiple key populations. Nearly one third (956 respondents, 29%) of respondents did not identify with any of the key population groups. Overall, the predominance of gay, bisexual or men who have sex with men in this survey sample should be kept in mind when interpreting data on the experiences of stigma reported overall.

The majority of individuals diagnosed before 2008 were from the West subregion; therefore, this subregion is disproportionately represented in data from those diagnosed before 2008. Conversely, respondents diagnosed after 2015 were mainly from the East and Centre subregions (Figure 3).

The age category with the greatest number of respondents was aged 21 to 40 years (51%), with very few responses from those aged under 20 years or over 60 years (Figure 3). The majority of respondents identified as male (including trans men) (78%), with the remaining respondents identifying as female (including trans women) (16%), trans assigned male at birth (3%), non-binary (2%) and in another way (1%) (Figure 3). Nearly all survey respondents (98%) were on antiretroviral therapy at the time of their response.

Figure 3. Date of diagnosis by World Health Organization European Region subregion, age and gender of respondents

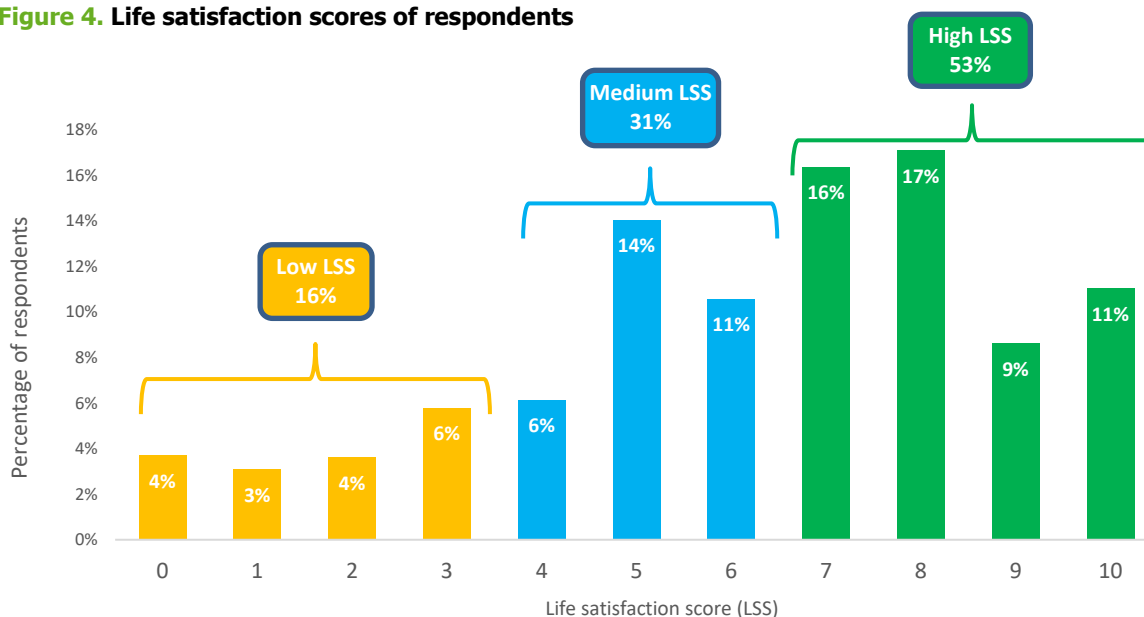


Trans AMAB: trans (assigned male at birth). West, Centre and East refer to the World Health Organization European Region subregions. Due to rounding totals, percentages may not always equal the sum of each of the values.

Quality of life

Survey respondents were asked to provide a life satisfaction score (LSS) between zero and 10 (where zero is not at all satisfied and 10 is completely satisfied) in response to the question: 'Overall, how satisfied are you with your life at the moment?' More than half of the respondents (1 734 respondents, 53%) rated their life satisfaction as high (an LSS of seven to 10), while 31% (1 014 respondents) rated their life satisfaction as medium (an LSS of four to six), and 16% (524 respondents) as low (an LSS of zero to three) (Figure 4). The average LSS across the full sample was 6.2, which can be compared to an average of 6.7 across Organisation for Economic Co-operation and Development (OECD) countries for the general population [13].

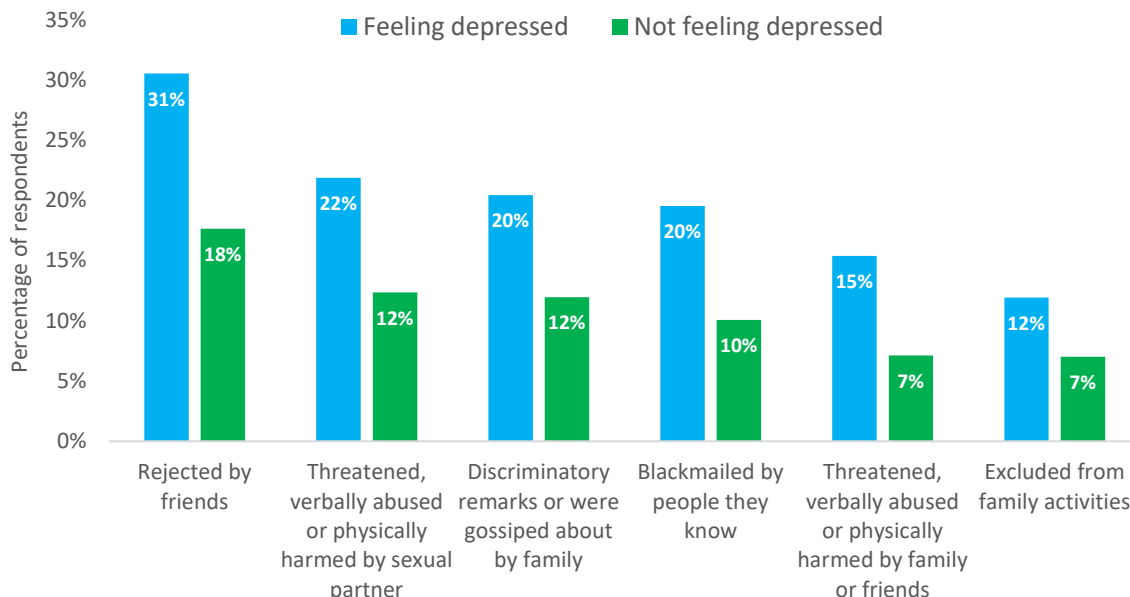
Figure 4. Life satisfaction scores of respondents



LSS: life satisfaction score. The LSS scale is from zero to 10, where zero is not at all satisfied and 10 is completely satisfied. Due to rounding totals, percentages may not always equal the sum of each of the values.

Respondents reported their health at the time of completing the survey as good or very good (69%), fair (25%) or bad or very bad (6%). In addition to their responses about their general health status, over 25% of respondents reported that they had markers of depression (e.g. feeling down, depressed or hopeless) during the two weeks prior to completing the survey. Across all categories of stigma, those who reported feeling depressed all experienced higher levels of stigma than those who did not report this feeling (Figure 5).

Figure 5. Experiences of stigma by markers of depression in the two weeks prior to completing the survey

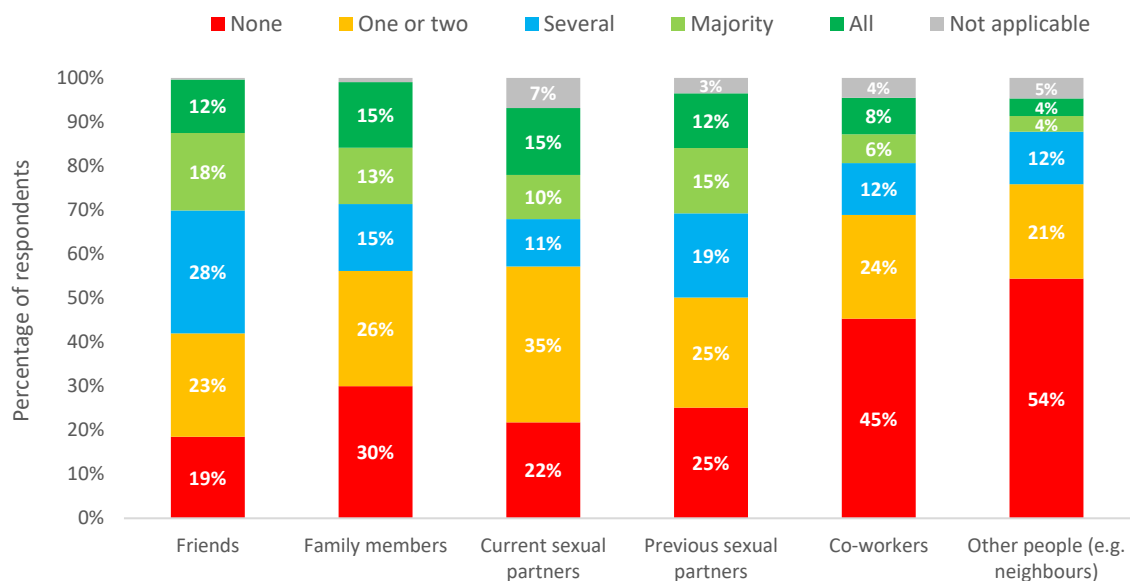


Due to rounding totals, percentages may not always equal the sum of each of the values.

Self-stigma

Nearly one in three (30%) respondents had not told a single family member that they were living with HIV. Approximately one in five (19% and 22%, respectively) had not told a single friend or a current sexual partner that they were living with HIV (Figure 6).

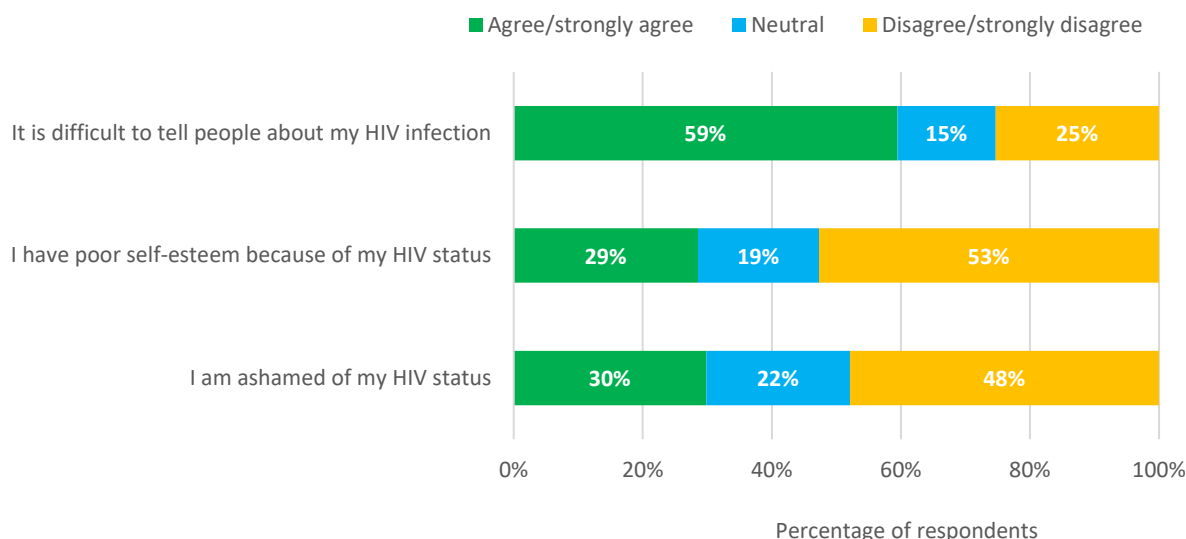
Figure 6. Proportion of respondents who have ever told people in their life about their HIV status



Due to rounding totals, percentages may not always equal the sum of each of the values.

More than half of the respondents (59%) either agreed or strongly agreed that it is difficult to tell others about living with HIV. Nearly one third of respondents agreed or strongly agreed that they had poor self-esteem related to their HIV status (29%) or were ashamed of their HIV status (30%) (Figure 7).

Figure 7. Self-stigma of respondents

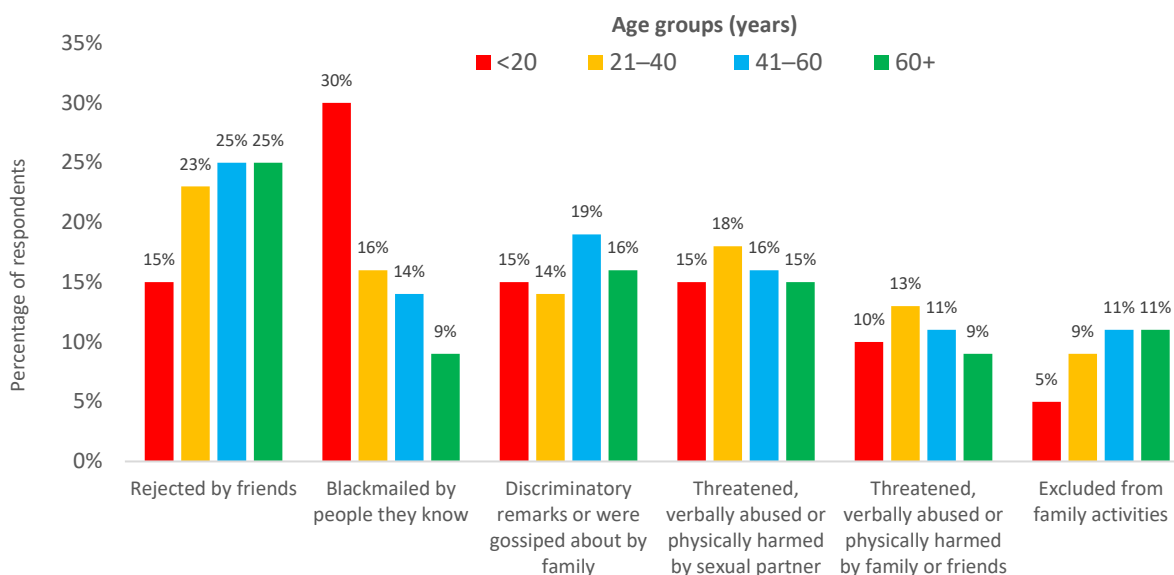


Due to rounding totals, percentages may not always equal the sum of each of the values.

Experiences of stigma: friends, family and sexual partners

Rejection from friends was the most commonly reported type of experienced stigma, while exclusion from family activities was the least commonly reported (Figure 8). Of all the age groups, those aged 21 to 40 years were mostly likely to experience threats, verbal abuse or physical harm from family, friends or sexual partners. The group aged 61 years and above was most likely to experience rejection from friends or exclusion from family activities. Generally, experiences of blackmail were low, but the age group below 20 years experienced much more of this type of stigma than other age groups, with 30% of this group reporting blackmail from people they know.

Figure 8. Experiences of stigma ever by age group

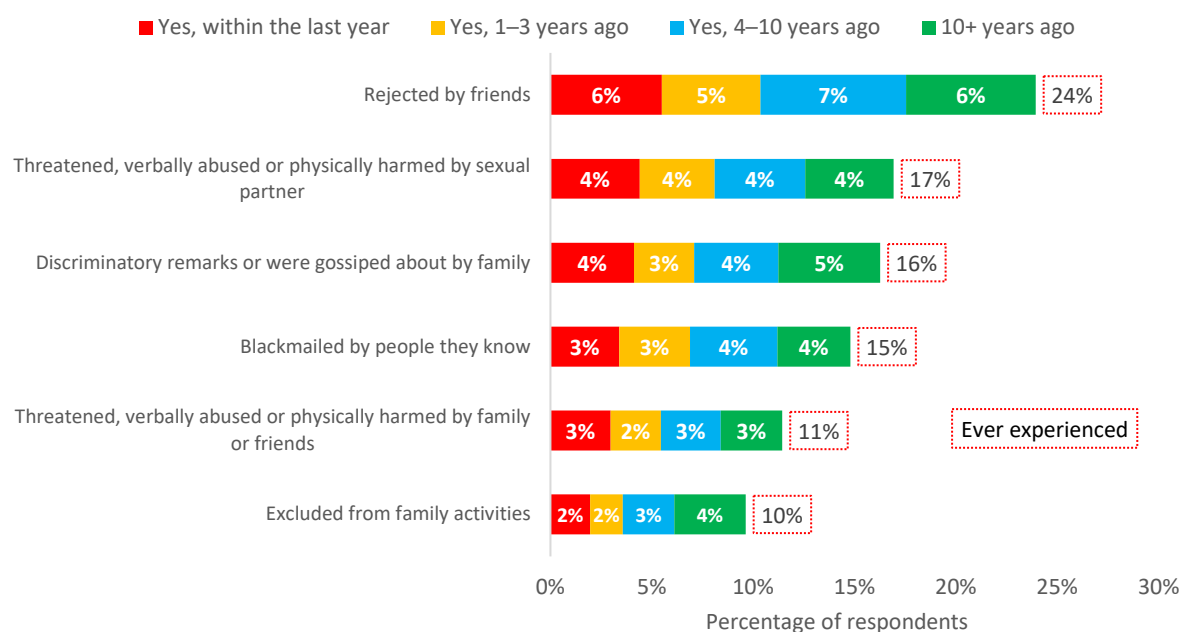


Due to rounding totals, percentages may not always equal the sum of each of the values.

Respondents identifying as non-binary experienced the highest levels of stigma in four of the six stigma categories. Rejection from friends was experienced by 41% of non-binary respondents. Female (including trans women) respondents experienced the highest levels of discriminatory remarks or being gossiped about by family, as well as exclusion from family activities. Male (including trans men) respondents reported the lowest levels of stigma of all genders, across all but one stigma category.

Figure 9 shows how recently stigmatising experiences by friends, family or sexual partners occurred. Rejection by friends was the most commonly experienced stigmatising practice in this category, with 24% of respondents ever having experienced this form of stigma, 6% of these within the last year. One in six (17%) respondents had ever experienced being threatened, verbally abused or physically harmed by a sexual partner, 4% of these within the last year. Exclusion from family activities was the least commonly experienced stigmatising practice, with 11% of respondents ever having been excluded from family activities, 2% of these within the last year. Age and time since diagnosis are likely important determinants of how recently the reported stigma was experienced, but these elements have not been explored in this analysis.

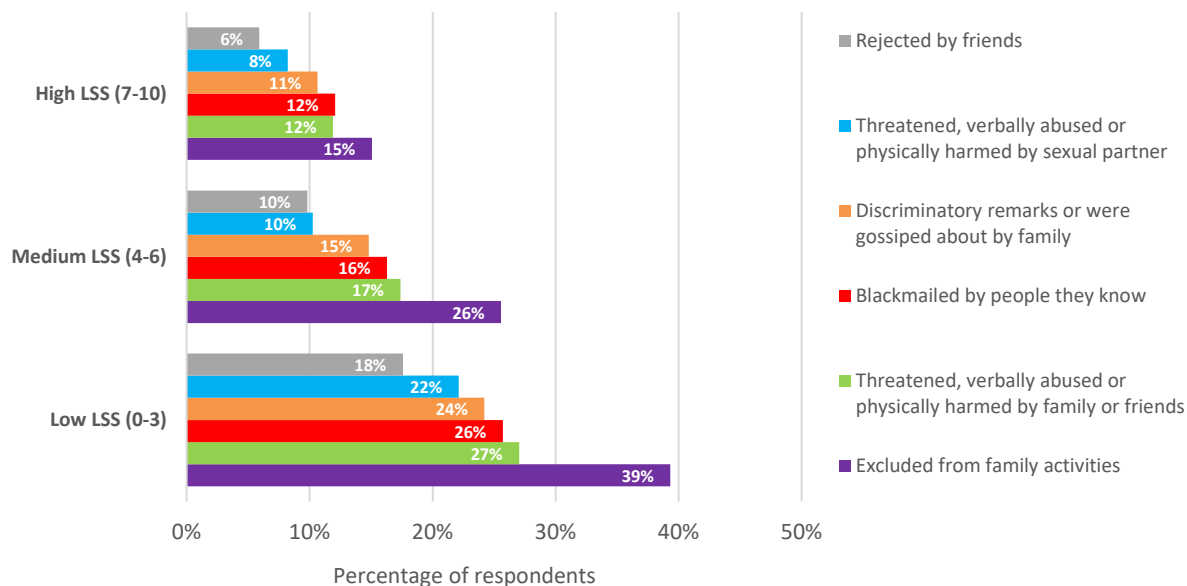
Figure 9. Experiences of stigma from friends, family or sexual partners, by how recently the experience occurred



Due to rounding, total percentages may not always equal the sum of each of the values.

Those with low life satisfaction (an LSS of zero to three) were more than twice as likely to have experienced stigma from friends, family or sexual partners — in all categories — than those with high life satisfaction (an LSS of seven to 10) (Figure 10). More than one third (39%) of those with low life satisfaction reported being rejected by friends; this was the highest level of stigma reported in this question.

Figure 10. Experiences of stigma ever by friends, family or sexual partners, by life satisfaction score



LSS: life satisfaction score.

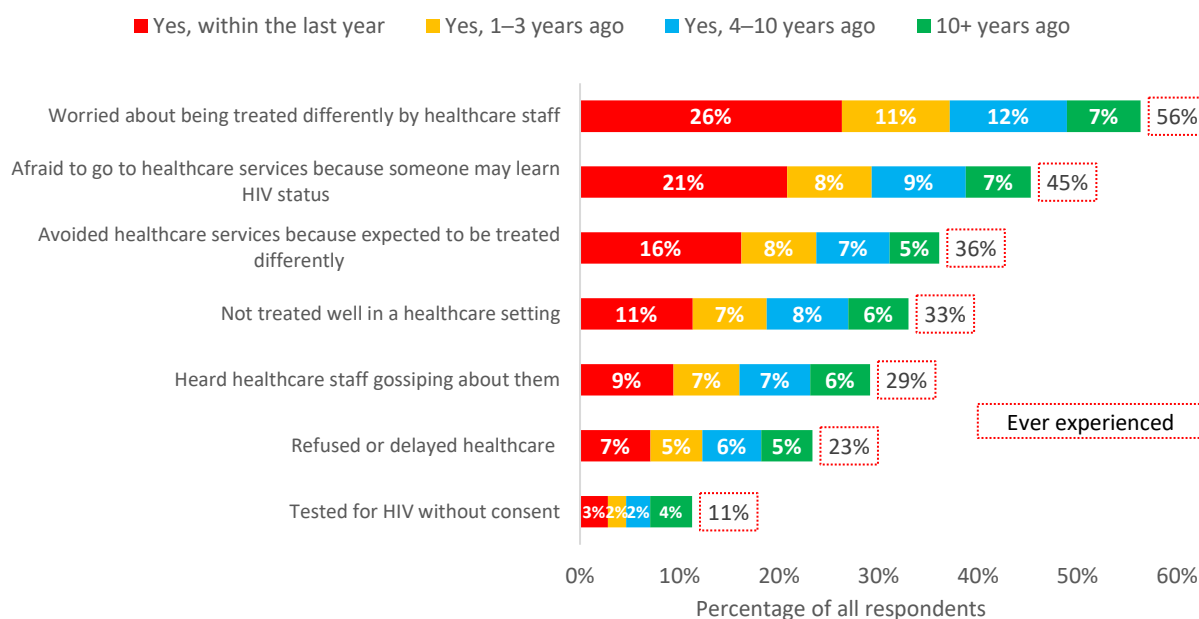
The LSS scale is from zero to 10, where zero is not at all satisfied and 10 is completely satisfied. LSS is given here as high (LSS of seven to 10), medium (LSS of four to six) or low (LSS of zero to three).

Due to rounding totals, percentages may not always equal the sum of each of the values.

Experiences of stigma: healthcare settings

One in four (26%) respondents indicated that they were worried about being treated differently by healthcare staff within the last year (Figure 11). Also within the last year, one in five (21%) were afraid to go to healthcare services for fear of having their HIV status disclosed and one in seven (16%) avoided healthcare services altogether for fear of being treated differently. One in three (33%) reported ever generally feeling that they were not treated well in a healthcare setting (11% in the last year) and one in four (23%) reported ever being refused healthcare or experiencing a delay in treatment due to their HIV status (7% in the last year). Age and time since diagnosis are likely important determinants of how recently the reported stigma was experienced, but these elements have not been explored in this analysis.

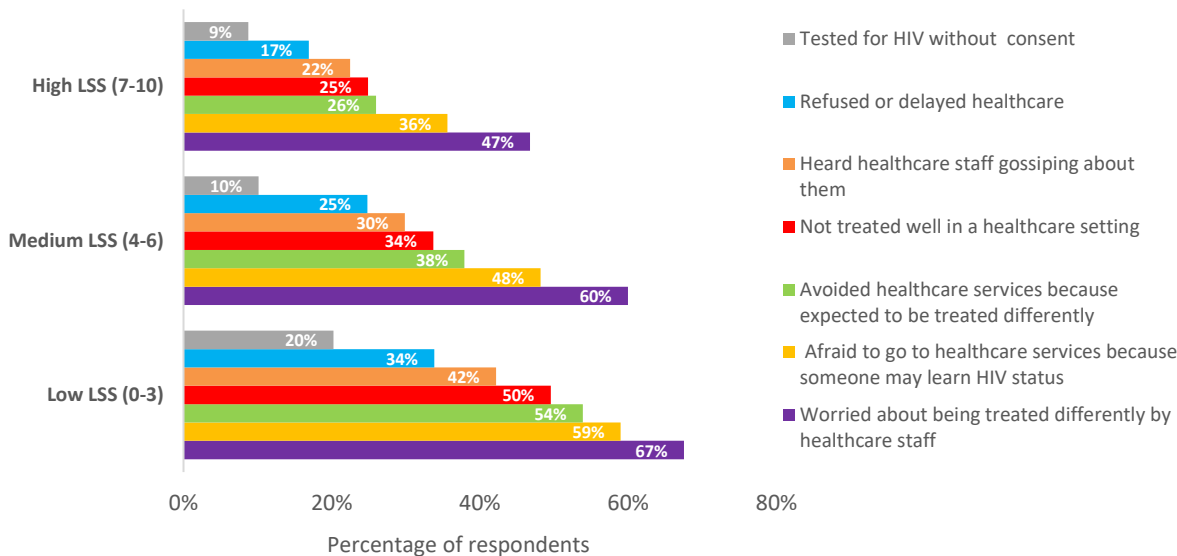
Figure 11. Experiences of stigma in healthcare settings by how recently the experience occurred



Due to rounding, totals percentages may not always equal the sum of each of the values.

Respondents who reported low life satisfaction (LSS of zero to three) reported the highest levels of experienced stigma in healthcare settings (Figure 12). While 67% of those with low life satisfaction were worried about being treated differently by healthcare staff, only 47% of those with high life satisfaction (LSS of seven to 10) were concerned about this. Regardless of their LSS, a large proportion of respondents were afraid to seek healthcare services for fear of having their HIV status disclosed or avoided healthcare services altogether out of fear of being treated differently. This is worrying, as people living with HIV need to have regular contact with healthcare services.

Figure 12. Experiences of stigma ever in healthcare settings by life satisfaction score

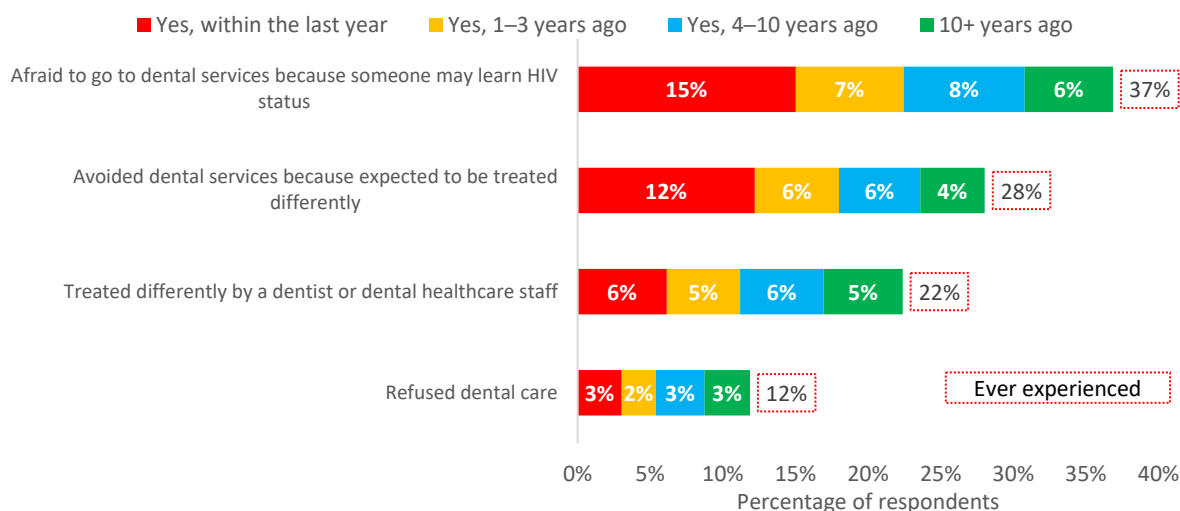


LSS: life satisfaction score.
 The LSS scale is from zero to 10, where zero is not at all satisfied and 10 is completely satisfied. LSS is given here as high (LSS of seven to 10), medium (LSS of four to six) or low (LSS of zero to three).
 Due to rounding totals, percentages may not always equal the sum of each of the values.

Experiences of stigma: dental care settings

One in seven (15%) respondents reported that they were afraid to go to dental services within the last year out of fear of having their HIV status disclosed (Figure 13). One in eight (12%) avoided dental services within the last year out of fear for being treated differently because of their HIV status, and 6% reported actually having been treated differently by a dentist or dental healthcare staff within the last year. Age and time since diagnosis are likely important determinants of how recently the reported stigma was experienced, but these elements have not been explored in this analysis.

Figure 13. Experiences of stigma in dental care, by how recently the experience occurred



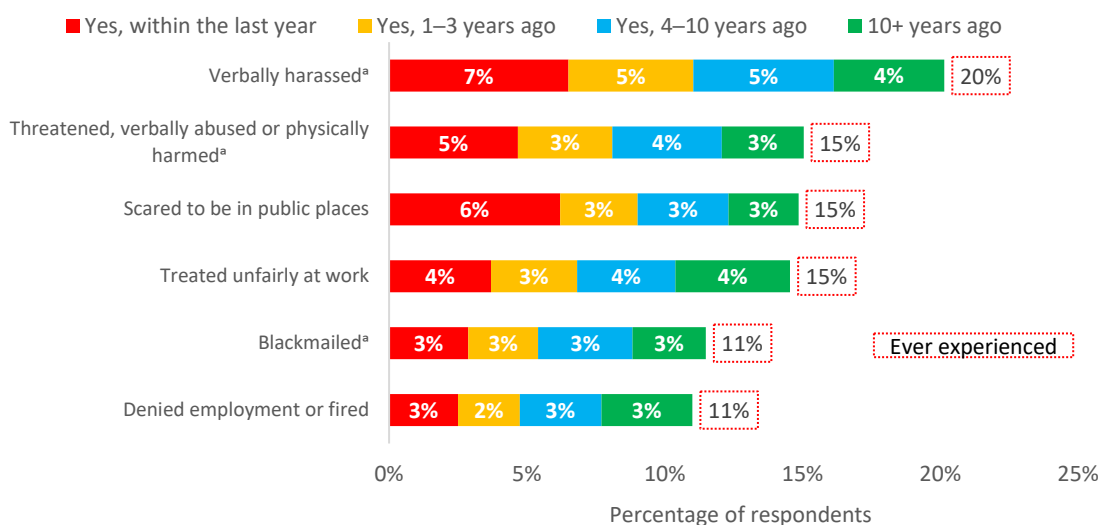
Due to rounding totals, percentages may not always equal the sum of each of the values.

Ethnic minorities reported more perceived stigma than other key populations: 50% of respondents from this group reported fear of someone learning their HIV status at dental services and 45% reported that they avoided dental services out of fear of being treated differently. However, they are not the group that reported the most experienced stigma: 29% of respondents who inject drugs reported being treated differently by a dentist or dental healthcare staff and 22% of prisoners reported being refused dental care.

Experiences of stigma: society and state-based systems

One in seven (15%) respondents had ever felt scared to be in public (7% in the last year), which may not be surprising given that many had been subjected to stigmatising practices including being verbally harassed (20%) or being threatened, verbally abused or physically harmed (15%) by someone other than friends or family (Figure 14). Moreover, 15% of respondents reported that they had ever felt unfairly treated at work because of their HIV status, and 11% had been denied employment or been fired. Age and time since diagnosis are likely important determinants of how recently the reported stigma was experienced, but these elements have not been explored in this analysis.

Figure 14. Experiences of stigma in society, by how recently the experience occurred

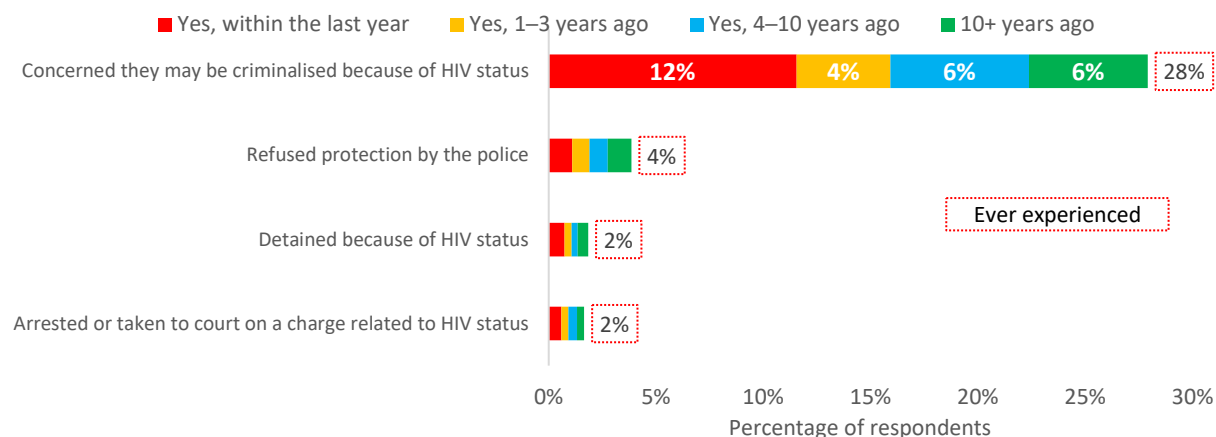


^a By someone other than friends or family.

Due to rounding totals, percentages may not always equal the sum of each of the values.

More than one quarter of respondents (28%) reported having been concerned at any point in their lives that they may be criminalised due to their HIV status (12% in the last year), and 4% have been refused protection by the police (Figure 15). This illustrates how unsafe people living with HIV can feel as a result of stigma and discrimination.

Figure 15. Experiences of stigma within the justice system, by how recently the experience occurred



Due to rounding totals, percentages may not always equal the sum of each of the values.

4 Conclusions

Experiences of HIV-associated stigma and discrimination vary between groups of individuals and in different settings and environments. Stigma can be experienced internally (self-stigma), as well as with friends, family and sexual partners; in healthcare settings; in dental care settings; and in society and state-based systems. It is crucial to identify which forms of stigma are most prevalent in each of these domains so that efforts can be made to eliminate both perceived and experienced stigma for people living with HIV. This step is integral to achieving zero discrimination and the ultimate goal of ending the AIDS epidemic by 2030.

Among friends, family and sexual partners, the most commonly reported experience of stigma for the respondents as a whole was rejection from friends. More than half of respondents reported that it was difficult to tell others about their HIV infection, indicating that stigmatisation of HIV among social groups may be the greatest concern in this area. However, if respondents are broken down by characteristics like age and gender, concerns and experiences around stigma change and new patterns emerge. For example, nearly one in three respondents aged 20 years or younger reported being blackmailed by people they know, which was substantially higher than for any other age group, potentially indicating forms of bullying that have emerged in more recent years.

Within healthcare and dental care settings, it is apparent that perceived stigma — the fear of stigmatising experiences — is more common than direct experiences of discrimination. However, this demonstrates that there is still a lot of work to be done to make people living with HIV feel safe in these settings, in order to ensure that they receive the regular healthcare services that they need.

These data illustrate the need to ensure that education, awareness and other interventions around stigma meet the needs of marginalised groups, including genders other than male or female, sexual orientations other than heterosexual, and key populations such as ethnic minorities, prisoners, people who inject drugs, and people who have sex in exchange for money or other goods. It is also crucial to acknowledge the intersections of these groups and how stigma can intensify for individuals who may align with more than one of these identities.

It is important to restate that our findings are not representative of the mix of exposure categories within the broader population of people living with HIV, and not representative of any particular key population, because of the sample and data collection methods underlying this study. It is also likely that HIV-related experienced stigma varies substantially based on time since diagnosis, as well as region or place of residence.

Countries are strongly encouraged to collect more data around stigma and discrimination at the national level, including qualitative data, to explore how HIV-related stigma operates in different settings and across population groups, as well as to strengthen education programmes and raise awareness of HIV within all facets of their communities. While reducing transmission of HIV and eliminating new infections are critical components of ending the HIV/AIDS epidemic by 2030, this goal will not be entirely successful without also addressing the HIV-associated stigma and discrimination that are still very present across Europe and Central Asia.

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Annex 1. ECDC/EATG/AAE/CSF Survey of stigma among people living with HIV

The European AIDS Treatment Group (EATG), AIDS Action Europe (AAE) and the EU HIV/AIDS, Hepatitis and TB Civil Society Forum (CSF) are working with the European Centre for Disease Prevention and Control (ECDC) to understand the experience of stigma for people living with HIV in Europe and Central Asia. If you are living with HIV, you can help by answering this survey.

The survey is anonymous, confidential, and no information will be collected that allows for the identification of participants. IP addresses will also not be recorded.

The survey should take between 10-20 minutes to complete, and questions are focused on your experience of HIV related stigma and discrimination.

As some of the situations mentioned in the questions are sensitive, may constitute breaches of your rights, or have negative impacts on your wellbeing, in the link below you can find a list of contacts of organizations working with people living with HIV in European countries, which can either provide you with support, or assist you in seeking support. Should you require assistance, please do not hesitate to contact them. This link will also be available at the end of the survey.

Do you accept to participate in this survey? Yes (enter survey) / no (exit survey)

Section A	
A1: Are you living with HIV?	Yes <input type="checkbox"/> No <input type="checkbox"/> Prefer not to say <input type="checkbox"/> If no or prefer not to say, exit survey
A2: In which YEAR were you first diagnosed with HIV?	Drop down
A3: Are you currently taking medication to treat your HIV infection (also known as antiretroviral drugs)?	Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Prefer not to say <input type="checkbox"/>
Section B	
B1: How old are you?	10 year AGE Groups
B2: How do you identify your gender:	Female (including trans woman) <input type="checkbox"/> Male (including trans man) <input type="checkbox"/> Non-binary <input type="checkbox"/> Trans assigned male at birth <input type="checkbox"/> In another way <input type="checkbox"/> Prefer not to say <input type="checkbox"/>
B3: Is this the same gender you were assigned at birth?	Yes <input type="checkbox"/> No, it was female <input type="checkbox"/> No, it was male <input type="checkbox"/> Prefer not to say <input type="checkbox"/>
B4: Which of the following best describes how you think of yourself?	Straight / Heterosexual <input type="checkbox"/> Gay or Lesbian / Homosexual <input type="checkbox"/> Bisexual <input type="checkbox"/> Other <input type="checkbox"/> Prefer not to say <input type="checkbox"/>
B5: what is your country of birth?	Drop down menu

B6: Where do you live now?	Drop down menu
B7: How long have you lived in this country?	All my life <input type="checkbox"/> <2 years <input type="checkbox"/> 2-5 years <input type="checkbox"/> 6-9 <input type="checkbox"/> 10 years or more <input type="checkbox"/>
B8: Do you self-identify as part of any of these key population groups?	Migrants <input type="checkbox"/> Ethnic minorities <input type="checkbox"/> People who inject drugs <input type="checkbox"/> Prisoners <input type="checkbox"/> People who have sex in exchange for money or other goods <input type="checkbox"/> None of the above <input type="checkbox"/> Other group, please state <input type="checkbox"/> Prefer not to say <input type="checkbox"/>
Section C	
C1: Overall, how satisfied are you with your life at the moment?	Scale 0-10 <i>Where 0 is not at all and 10 is completely</i>
C2: In general, how would you say your health is TODAY?	Very Good <input type="checkbox"/> Good <input type="checkbox"/> Fair <input type="checkbox"/> Bad <input type="checkbox"/> Very Bad <input type="checkbox"/>
C3: During the past two weeks, have you often been bothered by little interest or pleasure in doing things? feeling down, depressed or hopeless?	Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/>
C4: Apart from health care staff, who have you told that you have HIV?	Scale: None / one or two / several / the majority / all Current sexual partner(s) <input type="checkbox"/> Friend(s) <input type="checkbox"/> Family members <input type="checkbox"/> Co-workers <input type="checkbox"/> Previous/other Sexual partner(s) <input type="checkbox"/> Other people (e.g. neighbours, etc.) <input type="checkbox"/> Nobody <input type="checkbox"/>
C5: How does HIV make you feel? I am ashamed of my HIV status I have poor self-esteem because of my HIV status It is difficult to tell people about my HIV infection	Choice for each question: Strongly disagree <input type="checkbox"/> Disagree <input type="checkbox"/> Neutral <input type="checkbox"/> Agree <input type="checkbox"/> Strongly agree <input type="checkbox"/> Prefer not to say <input type="checkbox"/>

Section D	
<p>D1: Have you ever experienced any of the following because of your HIV status?</p> <p><i>Some of these questions are sensitive, remember that you do not have to answer any questions that you don't want to.</i></p> <p><u>Have you ever experienced any of the following from family and friends because of your HIV status?</u></p> <p>Been excluded from family activities.</p> <p>Had family members make discriminatory remarks or gossip (talk inappropriately) about you.</p> <p>Felt rejected by your friends.</p> <p>Been threatened, verbally abused or physically harmed by family or friends.</p> <p>Been threatened, verbally abused or physically harmed by a sexual partner.</p> <p>Been blackmailed by people you know.</p> <p><u>Have you had any of the following experiences with healthcare (excluding dental) because of your HIV status?</u></p> <p>Felt afraid to go to health care services because someone may learn your HIV status.</p> <p>Avoided going to health care services when you needed it because you expected to be treated differently.</p> <p>Been worried that you would be treated differently from other patients by healthcare staff.</p> <p>Heard health care staff gossiping (talking inappropriately) about you.</p> <p>Generally felt that you were not treated well in a healthcare setting.</p> <p>Been refused healthcare or had a delay in treatment or medical procedure.</p> <p>Been tested for HIV without your consent.</p> <p><u>Have you had any of the following experiences with dental care because of your HIV status?</u></p> <p>Felt afraid to go to dental services because someone may learn your HIV status.</p> <p>Avoided using dental services when you needed them because you expected to be treated differently.</p> <p>Been treated differently from others by a dentist or dental healthcare staff.</p> <p>Been refused dental care.</p> <p><u>Have you had any of the following experiences because of your HIV status?</u></p> <p>Felt that you were treated unfairly at work.</p> <p>Been denied employment or fired.</p> <p>Been refused protection by the police?</p> <p>Felt scared to be in public places</p> <p>Been verbally harassed by someone (other than friends or family).</p> <p>Been threatened, verbally abused or physically harmed by someone (other than friends or family).</p> <p>Been blackmailed by someone (other than friends and family)?</p> <p>Been detained because of your HIV status</p> <p>Been arrested or taken to court on a charge related to your HIV status</p> <p>Been concerned that you may be detained, charged or accused of exposing a sexual partner to HIV, transmitting HIV to a sexual partner, or of failing to disclose your HIV status to a partner</p>	<p>Choice for each question:</p> <p>No <input type="checkbox"/></p> <p>Yes, but more than 10 years ago <input type="checkbox"/></p> <p>Yes, but more than three years ago <input type="checkbox"/></p> <p>Yes, within the last three years <input type="checkbox"/></p> <p>Yes, within the last year <input type="checkbox"/></p> <p>Don't know <input type="checkbox"/></p> <p>Prefer not to say <input type="checkbox"/></p>
<p>D2: Has the way that people have behaved towards you as a person living with HIV been affected by COVID?</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p> <p>Prefer not to say <input type="checkbox"/></p> <p>If Yes:</p> <p>Please describe how the way people have behaved towards you has changed during COVID</p> <p>[text box – open response]</p>

Thank you very much for completing the survey. Your responses will be extremely useful to assess the burden of HIV related stigma and discrimination in Europe and Central Asia.

Annex 2. Estimated number of people living with HIV in the WHO European Region subregions, reported in 2022

West subregion		Centre subregion		East subregion	
Country	Number of PLHIV	Country	Number of PLHIV	Country	Number of PLHIV
Austria	7 652	Albania	1 433	Armenia	4 771
Belgium	18 620	Bulgaria	3 199	Azerbaijan	9 937
Denmark	6 800	Croatia	1 700	Belarus	28 315
Finland	3 473	Cyprus	1 325	Estonia	6 855
France	178 700	Czechia	3 674	Georgia	8 081
Germany	91 400	Montenegro	45	Kazakhstan	35 201
Greece	16 637	North Macedonia	352	Kyrgyzstan	9 222
Iceland	296	Poland	500	Lithuania	3 558
Ireland	7 200	Romania	18 923	Moldova	15 565
Israel	8 145	Serbia	20 130	Russia	1 000 000
Italy	140 730	Slovakia	3 200	Tajikistan	14 246
Luxembourg	1 365	Slovenia	19 415	Ukraine	244 877
Malta	814			Uzbekistan	57 555
Monaco	48				
Netherlands	24 000				
Norway	4 572				
Portugal	41 889				
San Marino	71				
Spain	151 387				
Sweden	9 184				
Switzerland	17 350				
United Kingdom	97 700				

PLHIV: people living with HIV

Latest available data reported by countries in 2022 (data can be reported for previous years). Data were not available for Andorra, Bosnia and Herzegovina, Hungary, Kosovo, Latvia, Liechtenstein, Turkmenistan or Türkiye.

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