

STIGMA INDEX 2.0: PEOPLE LIVING WITH HIV STIGMA INDEX

Final Report

**Portugal
2021-2022**



THE
PEOPLE
LIVING
WITH HIV
STIGMA
INDEX

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List of Acronyms and Abbreviations

AIDS	Acquired Immunodeficiency Syndrome
CAD	HIV Anti-Discrimination Centre (Centro Anti-Discriminação VIH)
CSO	Civil Society Organizations
DGS	Directorate General of Health (Direção-Geral da Saúde)
ENSP-NOVA	NOVA National School of Public Health, NOVA University Lisbon (Escola Nacional de Saúde Pública da Universidade Nova de Lisboa)
GAT	Portuguese Treatment Activists Group (Grupo de Ativistas em Tratamentos)
GIPA	Greater Involvement of People Living with HIV and AIDS
GNP+	Global Network of People Living with HIV
HCP	Healthcare Professionals
HIV	Human Immunodeficiency Virus
ICW	International Community of Women Living with HIV
INE	National Institute of Statistics (Instituto Nacional de Estatística)
INR	National Institute for Rehabilitation (Instituto Nacional para a Reabilitação)
IPPF	International Planned Parenthood Federation
KP	Key Populations
MA	Metropolitan Area
MIG	Immigrants, refugees, asylum seekers or people belonging to ethnic minorities
MSM	Men who have Sex with Men
NGO	Non-governmental Organization
NUTS	Nomenclature of Territorial Units for Statistical Purposes
PNISTVIH	National Program for Sexually Transmitted Infections and HIV infection (Programa Nacional para as Infeções Sexualmente Transmissíveis e infeção por VIH)
PWUD	People who Use or have used Drugs
PLHIV	People living with HIV
SDG	Sustainable Development Goals
SW	Sex Workers/People who do or have done sex work
Trans	Transgender/ non-Cis people/ people who do not identify with the gender assigned at birth
UNAIDS	Joint United Nations Program on HIV/AIDS
WSW	Women who have Sex with Women

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- AHSeAS - Associação Humanitária de Saúde e Apoio Social (Humanitarian Association of Health and Social Support)
- AJPAS - Associação de Intervenção Comunitária, Desenvolvimento Social e de Saúde (Association for Community Intervention, Social Development, and Health)
- APDES - Agência Piaget para o Desenvolvimento (GIRUGaia e Porto G projects) (Piaget Agency for Development)
- Associação para o Planeamento da Família - Norte (Espaço Pessoa) (Association for Family Planning - North)
- Abraço - Associação de Apoio a Pessoas com VIH/SIDA (Abraço Association - PLHIV Support Association)
- Associação Existências (Existências Association)
- Associação Plano i - Centro Gis (Plano i Association)
- Associação Positivo (Positivo Association)
- Cáritas Diocesana de Coimbra (Diocesan Caritas Coimbra)

- Cáritas Diocesana de Setúbal (Diocesan Caritas Setúbal)
- CASO - Consumidores Associados Sobrevivem Organizados (Associated Consumers Survive Organized)
- Centro Comunitário e Paroquial de Carcavelos - Casa Jubileu (Community and Parish Centre of Carcavelos)
- Centro Hospitalar Barreiro Montijo, E.P.E. (Barreiro Montijo Hospital Centre, EPE)
- Centro Hospitalar São João (São João Hospital Centre)
- Centro Hospitalar Universitário do Algarve – Hospitais de Faro e Portimão (Algarve University Hospital Centre – Faro and Portimão Hospitals)
- Centro Hospitalar Universitário Lisboa Central EPE - Hospitais Curry Cabral, Capuchos e S. José (Lisbon Centre University Hospital EPE - Curry Cabral, Capuchos and S. José Hospitals)
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- Hospital Professor Doutor Fernando Fonseca, EPE (Professor Dr. Fernando Fonseca Hospital, EPE)
- ILGA Portugal (ILGA Portugal)
- MAPS - Movimento de Apoio à Problemática da Sida (AIDS Support Movement)
- Médicos do Mundo (Lisboa e Porto) (Doctors of the World)
- Norte Vida - Associação para a Promoção da Saúde (Association for the Promotion of Health)
- Opus Diversidades (Opus Diversity)
- Passo a Passo - Associação de Ajuda Psicossocial (Association for Psychosocial Support)
- Unidade Local de Saúde de Matosinhos, EPE - Hospital Pedro Hispano (Matosinhos Local Health Unit, EPE - Pedro Hispano Hospital)

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Executive Summary

Introduction: Stigma and discrimination faced by people living with HIV (PLHIV) have been identified as important obstacles to eliminating the HIV epidemic. To better intervene in these phenomena, it is essential to know these factors. People Living with HIV Stigma Index (PLHIV *Stigma Index*) is an international project developed by four entities (GNP+, ICW, IPPF, and UNAIDS) that was implemented in Portugal in 2013 and replicated in 2021/22 using its most current version (PLHIV *Stigma Index 2.0*). Its implementation allowed measuring the stigma and discrimination experienced by PLHIV in this country, in different contexts of their lives, and to assess the evolutionary trend of these phenomena, by comparing these 2021/2 results with those of 2013, with the ultimate goal of advocating for the defence and promotion of human rights.

Methodology: The PLHIV *Stigma Index 2.0* questionnaire (standard instrument) was used through structured interviews applied by peers (other PLHIV) trained for the purpose. Data collection took place between October 2021 and March 2022, mostly in hospitals with specialist consultations for HIV and at community-based organizations monitoring PLHIV in Lisbon and Porto metropolitan areas, Coimbra and Algarve regions. A total of 1 095 questionnaires were applied to PLHIV diagnosed for HIV at least one year ago, over 18 years of age and living in Portugal, with quotas established by region to ensure sample representativeness. There was also a target to reach key populations (MSM, SW, PWUD, Transgender people) and vulnerable groups (immigrants/ethnic minorities), representing 73% of the sample.

Results: The results of the current 2021/2 study are presented and then compared with the 2013 results, although, for many of the data points it is not possible to undertake this comparison due to the deep restructuring that the questionnaire underwent in 2018 and due to the introduction of the new PLHIV Stigma Index 2.0 methodology in 2020. The main results of the 2021/2 PLHIV Stigma Index in Portugal are as follows:

- **Sociodemographic characteristics:** Respondents were predominantly men (62%), over 50 years old (49%), diagnosed with HIV more than 10 years ago (60%), with primary (40%) or secondary (36%) education.
- **Disclosure of HIV status:** Most respondents (88%) disclosed their HIV status to someone, primarily to those close to them. 16% of respondents have encountered this information being shared without their consent. Sharing one's serological status is usually felt as a positive experience with close people (72%), but not with people that respondent does not know well (33%).
- **Stigma and discrimination experiences:** 38% of respondents have experienced some kind of social discrimination (8.5% experienced it in the last 12 months), with people belonging to key and vulnerable populations and women being particularly affected. The most reported situations are being the target of discriminatory comments and being verbally assaulted. Considering the response categories from

the 2013 study that allow comparison, there is a decrease in people who report some kind of discrimination in the last 12 months (from 29% to 8.5%).

- **Internalized stigma and self-discrimination:** 90.5% of participants identified at least one manifestation of internalized stigma, and 30% reported some self-discriminatory behaviour in the last 12 months. These behaviours are more present among some vulnerable groups (immigrants) and key populations (SW and transgender people) and in women. Analysing only the comparable data points between 2013 and the current 2021/2 study, a decrease in both internalized stigma (from 68% to 40%) and self-discrimination (from 49% to 30%) is observed.
- **Interaction with health services:** Most respondents were tested for HIV voluntarily (54%), but the number of those tested without their knowledge increased (22% to 30%); 33% postponed or avoided receiving treatment for reasons related to stigma and discrimination; 22% reported some kind of discrimination in the last 12 months by health professionals - this most frequently occurring in non-HIV-related health services (16%) and experienced by SW, PWUD, and women. Comparing the results from the 2013 and 2021/2 PLHIV Stigma Index studies, there is a decrease in those who experienced stigma and discrimination in healthcare settings in the last 12 months (from 11% to 7%). On the other hand, respecting the principle of confidentiality has worsened, with more respondents reporting that their medical records are not kept confidential (from 5.3% to 9.5%). Concerning sexual and reproductive health, 27% of women reported some form of pressure regarding pregnancy, childbirth, and breastfeeding, and 7% of respondents identified situations of discrimination regarding access to family planning in the last 12 months.
- **Human rights and effective change:** 15% of respondents reported having already suffered some situations of violation of their rights due to living with HIV (3.5% in the last 12 months), this happening more frequently in SW, PWUD, MSM, and women. Considering the comparable data points between both studies, the percentage of people who reported at least one situation of violation of their rights in the last 12 months, decreased from 6.2% to 1%. However, the number of those who have experienced one of these situations (of violation of their rights), but took some action to seek justice, has decreased (from 32% to 19%), as well as there are less participants who reported that the issue was resolved after having sought justice.
- **Stigma and discrimination for non-HIV-related reasons:** Transgender people, PWUD, and MSM are the most likely to report being discriminated against, with 88%, 77%, and 65% (respectively) stating to have been the target of some of the situations of discrimination documented, due to belonging to vulnerable groups. However, they are also the ones who most often report that other people know that they belong to that vulnerable population.

Discussion and Conclusion: Although the results of this 2021/2 study seem to indicate a favourable evolution by showing a decrease in stigma and discrimination experienced by PLHIV in the various contexts of their lives, it appears that this remains a very relevant issue

in Portugal, especially in health services, disproportionately affecting people belonging to one or more key and vulnerable populations, as well as women. It should be noted that the data collected for this 2021/2 PLHIV Stigma Index 2.0 study may be biased by the COVID-19 pandemic, which caused a decrease in social interactions in the 12 months preceding the application of the questionnaire, which may have led to an artificial reduction in situations of discrimination. Aspects that seem to have worsened since 2013 include the respect of confidentiality of medical records and dealing with situations of discrimination.

Recommendations: Given the results obtained, a list of recommendations is drawn up at different levels:

Recommendations to the Parliament:

1. Review Law 46/2006, of August 28, on rights and discrimination, replacing “aggravated health risk” with “health condition” and including discrimination suffered in the family and social environment;
2. Reinforce the mandate of the INR – National Institute for Rehabilitation, for monitoring and acting in situations of discrimination based on health conditions.

Recommendations to the Government, DGS, and PNISTVIH:

3. Regulate Law No. 75/2021, of November 18, which prohibits discriminatory practices when accessing credit and insurance contracts;
4. Define the fight against stigma and discrimination as a priority area of intervention in the next PNISTVIH Action Plan and include a budget allocation for this area;
5. Promote the dissemination of Law 46/2006, of August 28, on the rights of PLHIV and mechanisms for defending these rights;
6. Monitor, follow up, and act in situations of stigma and discrimination in the context of HIV infection;
7. Ensure the right to sexual and reproductive health without discrimination;
8. Reactivate the Labour Platform against AIDS;
9. Define a periodicity for the replication of the PLHIV *Stigma Index* or other studies in the area of stigma and discrimination of PLHIV;
10. Review and amend the Armed Forces disability tables.

Recommendations to Civil Society Organizations

11. Disseminate information to its users and beneficiaries about the rights of PLHIV, enabling them to act in situations of discrimination;
12. Train all employees in the area of stigma, discrimination, and rights of PLHIV;
13. Collect information and report incidents of discrimination that they are aware of to a central structure (CAD, PNISTVIH, or INR);
14. Work on internal stigma and self-discrimination with its users and beneficiaries.

Recommendations for Health Services

15. Train health professionals in the area of stigma, discrimination, and rights of PLHIV;
16. Ensure the confidentiality and protection of users' personal data.

1. Introduction

It is estimated that there are currently approximately 38 million people living with HIV worldwide (UNAIDS, 2022), with the estimated number in Portugal being 41 889 as of December 31, 2019¹. Between 1983 and 2021, 64 257 cases of HIV infection were cumulatively diagnosed in Portugal, of those 23 399 were AIDS cases (DGS & INSA, 2022).

According to DGS & INSA (2022), during 2020 and 2021, 1 803 new HIV infection cases were diagnosed, corresponding to a rate of 8.7 new cases/10⁵ inhabitants, not adjusted for reporting delay. Those diagnoses were 2.5 times more frequent in men than in women. The median age of recently diagnosed individuals was 39.0 years, and 27,6% were aged 50 years or older. The lowest median age (31.0 years old) was found among men who have sex with men (MSM) that also account for 70.1% of cases diagnosed in individuals under the age of 30 years. The highest diagnosis rates occurred among the 25-29 years old age group (27.3 cases/10⁵ inhabitants), particularly amid men (45.1 cases/10⁵ inhabitants). Lisbon Metropolitan Area was the residence area for 48.9% of persons with a new diagnosis of HIV infection (15.3 cases/10⁵ inhabitants) and the second larger rate of diagnosis was identified in Algarve region (9.3 cases/10⁵ inhabitants). Most cases occurred in individuals born in Portugal (53.0%), which was also the country more frequently referred as probable country of infection (73.4%). Sexual transmission was reported in 92.0% of cases diagnosed in the 2 years period. Although cases of heterosexual transmission prevailed (51.8%), cases in MSM account for 56.0% of the new diagnoses between men. Clinical characteristics of newly diagnosed cases indicate that the majority was asymptomatic, however, a concurrent AIDS diagnosis occurred in 17.7% of cases and 55.4% of individuals were late diagnosis according to the new definition, the highest proportion observed among heterosexual men (70.8%).

Temporal trends show that between 2012 and 2021 both new HIV and AIDS diagnoses have declined, respectively by 48% and 66%, although 2021 diagnoses are not adjusted for reporting delay (DGS & INSA, 2022). Despite the downward trend, Portugal still exhibits one of the highest rates of new HIV and AIDS diagnosis among European Union countries thus keeping HIV as one of the priority health programs of the Directorate General of Health (DGS)².

The number of deaths from AIDS has also decreased, both in Portugal (298 deaths during 2020 and 2021) and worldwide, thanks to the high effectiveness of the current medication. However, not everyone has equal access to treatment as well as to prevention and support services, which led UNAIDS to establish a global strategy for 2021-2026, “*Ending Inequalities. Ending AIDS*” (UNAIDS, 2021) to reduce the gaps that prevent the elimination of this epidemic. The stigma and discrimination faced by people living with HIV (PLHIV) has been identified as a major obstacle to achieving this goal. It is therefore explained in *Outcome 5* of the Strategy as mentioned above (“*People living with HIV, populations, and people at risk enjoy human rights, equality, and dignity, being free from stigma and discrimination*”), and in one of the goals and commitments for 2025 (“*Less than 10% of*

¹Data provided by DGS/INSA

² <https://www.dgs.pt/programa-nacionaistvih.aspx>

people living with HIV and key populations experience stigma and discrimination”), continuing the vision of “Zero Discrimination” (UNAIDS, 2010).

Also, at a national level, focusing on the 2017-2020 national guidelines, Axis E, concerning Stigma and Discrimination, is established as one of the essential axes in the strategy to combat the epidemic in 2018, where it is foreseen to “Promote the realization of the second edition of the PLHIV Stigma Index, with the objective of measure the phenomena of stigma and discrimination experienced by people living with HIV in Portugal, seeking to assess trends that perpetuate these phenomena and accentuate barriers to access to prevention, diagnosis, treatment and care ” (DGS, 2018).

It should be noted that the priority in combating discrimination is also in line with the Sustainable Development Goals (SDGs) and its fundamental principle of “leaving no one behind.” However, PLHIV often live in fragile communities and are discriminated against, marginalized, and affected by inequality and instability. Until their needs and vulnerabilities are addressed, the HIV epidemic will not be eliminated, and the SDGs will not be achieved³.

1.1. PLHIV STIGMA INDEX: People Living with HIV Stigma Index

The People Living with HIV Stigma Index (PLHIV *Stigma Index*) is an international project developed by the Global Network of People Living with HIV (GNP+), the International Community of Women Living with HIV (ICW), the International Planned Parenthood Federation (IPPF), and the Joint United Nations Program on HIV/AIDS (UNAIDS).

It consists of a standardized tool launched for the first time in 2008 aiming to measure the stigma and discrimination experienced by PLHIV and to gather evidence on how these experiences affect their lives, allowing PLHIV, their networks, and local communities to advocate for the defence and promotion of their rights. In 2018 this tool was revised and in 2020 a standardized methodology was introduced, resulting in the creation of the *PLHIV Stigma Index 2.0*, used in the present study. The PLHIV Stigma Index 2.0 revision was informed by a combination of factors including shifts in the HIV epidemic; growth in available evidence on HIV related stigma especially amongst those key population groups experiencing it; and changes in the global response to HIV (test and treat strategy). The revision of the PLHIV Stigma Index methodology was informed by the need to ensure standardization of the sampling methods, ensure that all HIV populations are captured, expand the impact of health settings, and adopt the use of digital technology. The PLHIV Stigma Index 2.0 is an important instrument that has been adopted to measure the level of stigma and discrimination faced by people living with HIV, but importantly also to provide comparative data across countries and continents.

The *PLHIV Stigma Index* was created to be used by and for PLHIV, based on the GIPA principle (*Greater Involvement of People living with HIV and AIDS*)⁴ and with a focus on

³ https://www.unaids.org/en/AIDS_SDGs

⁴ https://data.unaids.org/pub/briefingnote/2007/jc1299_policy_brief_gipa.pdf

training networks and PLHIV. PLHIV Stigma Index has been implemented in over 100 countries and has reached over 100 000 PLHIV⁵.

Portugal developed the first edition of the *PLHIV Stigma Index* in 2013, where 1 062 questionnaires were collected. Respondents in this study reported 1 403 incidents of discrimination during the previous 12 months. More than 60% of these were for slander, insult or coercion (39% because of HIV status), 22% for aggravated assault (33% because of HIV status) and 17% for family, social or religious exclusion (74% because of HIV status). 26% of the situations of discrimination reported occurred within the family or community settings, and 12% took place in health care services (Ser+ & GAT, 2014).

This new version of *PLHIV Stigma Index 2.0* aims to:

- Document national experiences concerning the phenomena of stigma and discrimination currently experienced by people living with HIV in Portugal in different contexts of life;
- Evaluate trends to understand what changes have occurred since 2013 and what aspects perpetuate these phenomena;
- Create evidence to support the development of programs and projects in the field of stigma and discrimination, and highlight neglected areas that require future action, guiding policies, and programmatic interventions.

The *PLHIV Stigma Index* also helps to build the capacity of PLHIV to recognize and defend their rights, which is an important secondary gain in combating the stigma and discrimination associated with HIV/AIDS.

The Directorate General of Health funded this edition of the study in Portugal, and (as in 2013) it was developed by CAD – HIV Anti-Discrimination Centre⁶, a joint project of two civil society organizations (Ser+ - Portuguese Association for the Prevention and Challenge of AIDS, and GAT- Portuguese Treatment Activists Group). CAD is a national project that aims to ensure, promote, and implement the fundamental rights of people living with HIV, viral hepatitis, and more vulnerable populations, promoting the fight against stigma and discrimination.

The Executive Committee of this study was composed by:

- Ana Duarte, Ser+, Portuguese Association for the Prevention and Challenge of AIDS (Principal Researcher)
- Joana Bettencourt, Directorate General of Health, National Program for Sexually Transmitted Infections and HIV Infection
- João Brito, GAT, Portuguese Treatment Activists Group
- Sónia Dias, NOVA National School of Public Health, Public Health Research Centre, CHRC, NOVA University Lisbon

⁵ <https://www.stigmaindex.org/about-the-stigma-index/>

⁶ <https://cad.vih.pt/>

2. Methodology

The PLHIV *Stigma Index 2.0* is implemented through the application of a questionnaire directed by and for PLHIV on the impact of HIV infection on the different dimensions of the individual's life, assessing their perception regarding the number, type, and degree of situations of stigma and discrimination experienced.

Following the standard methodology, the questionnaire is applied through face-to-face interviews with other PLHIV. To this end, 19 people (living with HIV for more than one year in the regions covered by the project) were recruited to act as interviewers. There were 12 women and 7 men of different ages and belonging to different key populations. The interviewers participated in a two-day training program, which took place in September 2021 and included topics such as:

- Understanding the concepts of stigma and discrimination;
- Interview methods;
- Conducting the survey and completing in the forms;
- Confidentiality and ethics.

This methodology is in line with the GIPA principle, allowing the creation of an environment of trust between interviewer and interviewee, providing referral to support services for those interviewees who need them, fostering contacts and networks between PLHIV, breaking isolation and self-discrimination, and providing PLHIV who acted as interviewers with new skills, giving them a central role in the whole process of planning and implementing the study.

2.1. Geographic scope of the study

Following the PLHIV Stigma Index 2.0 study's standard methodology, the regions of the country (according to the NUTS III classification) that together account for more than 50% of the population of Portugal were selected (INE, 2020)⁷. The four chosen regions include rural and urban areas and correspond to the areas with the highest incidence of HIV infection in Portugal, together accounting for 78.4% of cases of HIV infection reported between 1983 and 2019 (DGS & INSA, 2020⁸ - most recent data available at the time of defining the sampling methodology), taking into account residence at the time of notification of the initial stage.

The regions selected for the implementation of the study were the following:

- Lisbon Metropolitan Area (27.7% of the national population; 52.0% of notified HIV cases);

⁷According to the INE classification, annual estimates of the resident population by place of residence (NUTS-2013); Information extracted from <http://www.ine.pt>, on 02/07/2020

⁸Accumulated cases between 1983 and 2019

- Porto Metropolitan Area (16.8% of the national population; 18.7% of notified HIV cases);
- Algarve (4.3% of the national population; 5.2% of notified HIV cases);
- Coimbra Region (4.2% of the national population; 2.5% of notified HIV cases).

The selection of these regions also allows the comparability of results with the 2013 study, which covered the districts of Lisbon, Porto, Setúbal, and Faro.

2.2. Participants and sampling strategy

Inclusion criteria for our participants were:

- PLHIV over 18 years old and residing in Portugal
- Are aware that they are living with HIV for at least 12 months
- Are able to give informed consent and understand all elements of the study
- Speak at least one of the languages in which the questionnaire is administered

Exclusion criteria for our participants were:

- Have already participated in the current study
- KP **not** living with HIV

Taking into account the number of HIV diagnoses at the national level and following the calculation formula required by standard methodology, a sample of **1 095** questionnaires was collected, assuming a margin of error of 4% and a confidence interval of 95% and applying data on the estimated prevalence of avoidance of healthcare by PLHIV due to anticipated stigma, which was 12 % as measured by 2013 Portugal PLHIV Stigma Index.

To ensure the sample's representativeness, quotas were established by region, according to the area of residence at the time of diagnosis of HIV cases reported in Portugal, to date (DGS & INSA, 2020) (see *Figure 2.1*).

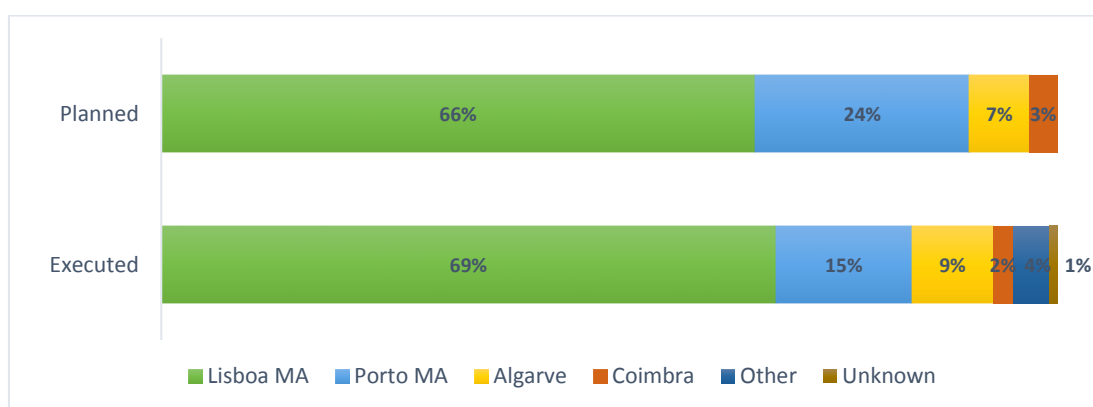


Fig. 2.1 Distribution of the sample across the various geographical areas considering the municipality of residence, %.

As may be observed in the graph (Figure 2.1), there is a slight over-representation of the Lisbon metropolitan area (69%; N=753) and Algarve (9%; N=99), to the detriment of the Porto metropolitan area (15%; N=167) and the region of Coimbra (2%; N=25), given the quotas defined based on HIV cases notified in Portugal. However, it should be noted that 45 respondents, despite being interviewed in hospitals or NGO settings in the selected areas, live outside of these areas, with 25 living in municipalities bordering Porto MA and 12 residing on the outskirts of the Coimbra region (the remaining 8 residing in Alentejo). Adding these to the respective sites, the number of the respondents living in the North region rises to 18% and those from the Centre region to 3%, figures already closer to the target.

Although quotas have not been established for people belonging to key populations (MSM - Men who have sex with men; SW - Sex workers; PWUD - People who use drugs; and Transgender people / who do not identify with the gender assigned at birth) there was an effort made to recruit them. 61% of participants (667) belong to at least one of the key populations. We also included vulnerable groups, like immigrants and ethnic minorities. People belonging to key and vulnerable populations constitute 73% of the total sample (i.e., 799 of the respondents belong to at least one of these populations).

The number of people participating in the study belonging to each key and vulnerable population is represented in Figure 2.2, with several people belonging to more than one population.

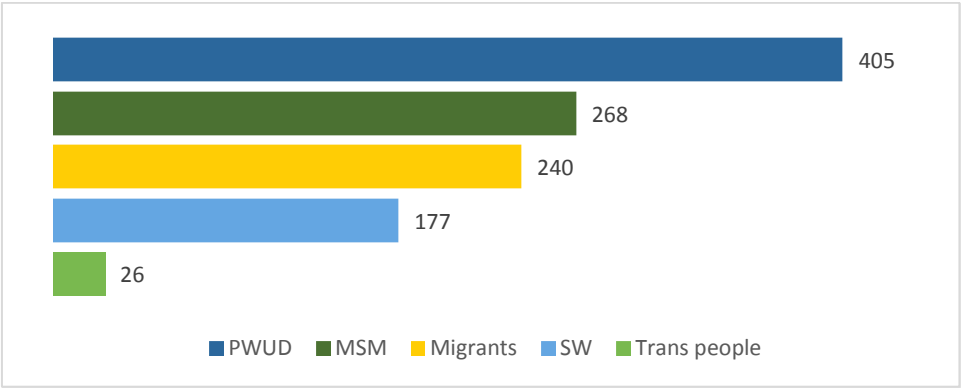


Fig. 2.2 Number of study participants belonging to each key and vulnerable populations⁹.

Regarding the sample recruitment process, two recruitment strategies were adopted, following the guidelines of the PLHIV Stigma Index 2.0 standard methodology:

- *Venue-based* sampling: recruitment of participants in hospitals with specialist HIV consultations and in civil society organizations (CSOs) with PLHIV support and monitoring services (intended sample by this route: 75%; sample collected by this route: 82%: 50% (N=548) in Hospitals and 32% (N=349) in CSOs);

⁹ MSM in this figure refers to all men who have sex with men, including gay men, bisexual men and other men who have sex with men.

- *Limited chain referral* sampling: All respondents were given 3 to 6 study leaflets to invite people they knew to participate (sample intended by this route: 25%; sample collected by this route: 18% (N=194)).

Figure 2.3 represents the number of participants recruited according to the recruitment strategies and locations mentioned above.

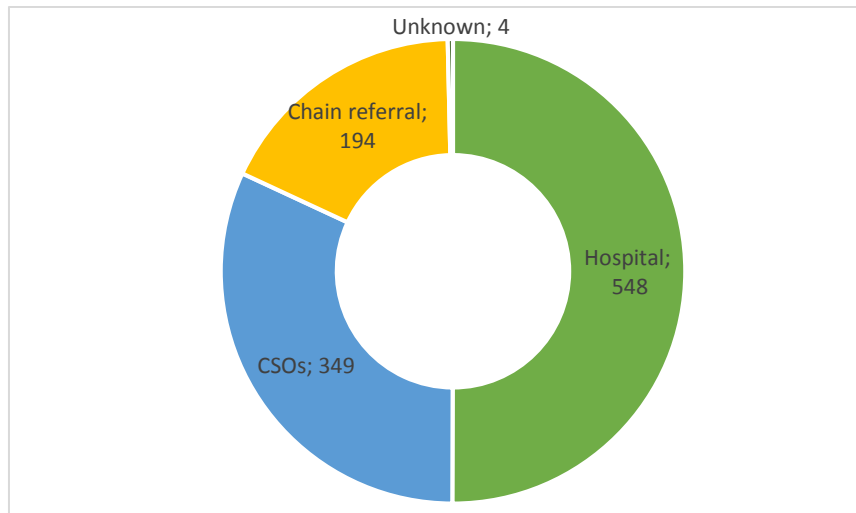


Fig. 2.3 Number of study participants recruited according to each recruitment strategy/site.

Identifying and selecting sites to consider for recruiting participants in each region was carried out with the assistance of *Key Informants*.

2.3. Study Instrument

The Questionnaire Notebook consisted of supporting documents (detachable) and the Questionnaire itself. Among the supporting documents were the following:

- Procedure sheet (for the interviewer);
- Information sheet for participants (with the most relevant information about the study);
- Free and Informed Consent Form (sample for the interviewee and the interviewer);
- Form for verification and quality control of completion (for the interviewer and coordinator);
- Form for support and referral (for cases where the need to refer the interviewee to a support service was detected);

The questionnaire itself consisted of 78 questions, divided into 8 sections:

- Information about yourself
- Disclosure of HIV status
- Your experience with stigma and discrimination

- Internal stigma and resilience
- Interaction with health services
- Human rights and effective change
- Stigma and discrimination experienced for reasons unrelated to HIV status
- Personal experience of stigma and/or discrimination (open question¹⁰)

A final question was added to these sections (included in the standardized international instrument) to know the reality of some discriminatory practices in Portugal, such as access to health or life insurance and to a career in the armed forces.

2.4. Ethical Approval of the study

In August 2020, the invitation to participate in the study was sent to the administrations and heads of service of hospital centres with HIV specialist consultation located in the selected geographic areas, followed by the submission of the study to the respective ethics committees. This process proved to be complex and time-consuming since each hospital centre has different procedures and forms for submitting studies, and information is often difficult to access. The pandemic situation, with the suspension of non-urgent hospital activity and doctors redirected to fight COVID-19, made this process even more difficult, lasting almost 1 year, with the last approval being received in June 2021. The study was approved in 10 hospital centres, comprising a total of 15 hospitals.

2.5. Implementation

The study was initially scheduled to be conducted during the year 2020. However, the impact of the COVID-19 pandemic, mainly in hospitals, made it impossible to comply with the planned schedule. As already mentioned, the approval of the study by the ethics committees of the hospitals was only concluded in mid-June 2021, when the CSOs were contacted to assess their interest and availability to collaborate in the study through the suggestion of people who could take over the role of interviewers, dissemination of the survey by its users/members, active recruitment of participants and/or provision of a place to carry out the interviews. In addition to the 15 hospitals, the study was conducted in 18 CSOs (divided into 24 application sites).

With each entity, the best time and methodology for conducting the study and inviting potential participants were defined, with the help of leaflets produced for this purpose. The best place for holding interviews was also decided, safeguarding the conditions of comfort, privacy, and confidentiality. All interviews were carried out in person, with the completion of the questionnaire on paper, starting with the presentation of the study aided by *the Information Sheet for participants*, followed by reading and filling out the *Free and Informed Consent Form*, where it was explicitly stated that participants could end the

¹⁰ Responses to this open question in the questionnaire are shown as quotes in this report.

interview or withdraw their consent at any time during the study. At the end of the interview (which lasted an average of 45m to 1h) and following the methodology used internationally, a symbolic compensation (€10 in shopping vouchers) was awarded to each interviewee for the time spent.

During the implementation of the interviews, which took place between October 2021 and March 2022, the coordination team remained in close articulation with the interviewers, supporting, monitoring, and ensuring quality control of the work carried out.

2.6. Data Analysis

The completed questionnaires were sent to the study team at ENSP-NOVA, responsible for its computerization and subsequent statistical treatment of the data.

Data processing was carried out using *IBM® SPSS® software*, which allowed analysis at different levels:

- Descriptive analysis of the various questions in the questionnaire, including analysis by gender or sex at birth, number of years living with HIV, age groups, and belonging to key and vulnerable populations;
- Comparative analysis of the most relevant questions with the equivalent questions from the 2013 PLHIV Stigma Index study, using hypothesis tests (Chi-square test and Fisher's exact test, considering a significance level of 5%).

3. Results

3.1. Section A: Sociodemographic Characteristics

The ratio between men and women (considering the sex assigned at birth) of the participants is 1.6 (61.8% of men vs. 38.2% of women), lower than what is observed in the notified cases of PLHIV in Portugal which is 2.6 (72.1% men vs. 27.9% women) (DGS & INSA, 2022)¹¹. Regarding gender identity, 60,1% (N=655) of respondents identify themselves as male, 38,3% (N=417) as female, and 0,7% (N=8) as transgender (*Figure 3.1*). Crossing the information between the sex assigned at birth and gender identity and considering Cis people (those who identify with the sex assigned at birth) and Trans people (those who do not identify with the sex assigned at birth), 59.8 % (N=648) of participants are Cis men, 37.8% (N=409) are Cis women, and 2.4% (N=26) are Transgender people.

¹¹Accumulated cases between 1983 and 2021

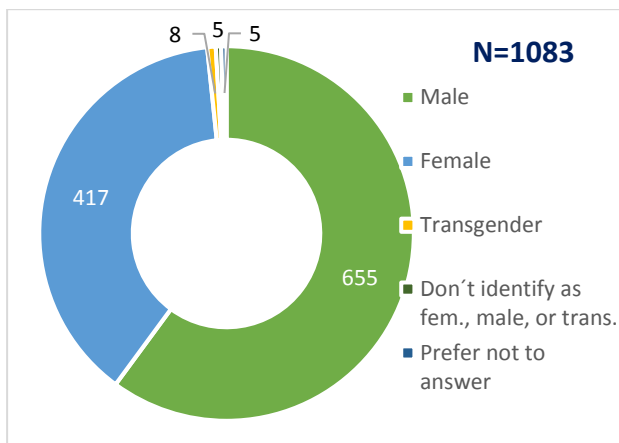


Fig. 3.1 Gender identity of the participants.

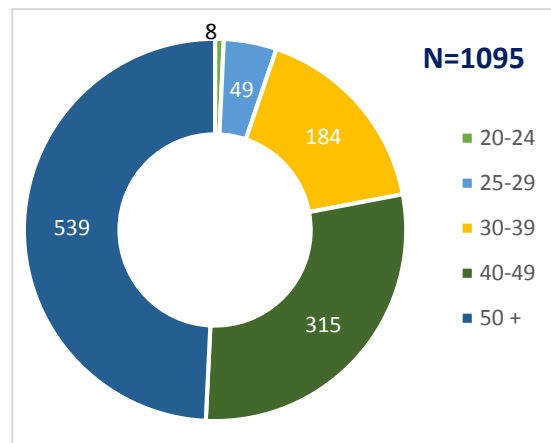


Fig. 3.2 Age of the participants.

Regarding age, approximately half of the participants (49.2%, N=539) were 50 years or more. If we consider those aged 40 years or more, they represent 78% of the sample (Figure 3.2), which may reflect the progressive ageing of people living with HIV in Portugal. Most participants know that they have been living with the infection for more than 10 years (60%) (Figure 3.3), and 52.8% do not currently have an intimate / sexual relationship with anyone. Of those who are in an intimate relationship (N=505), 56% state that their current partner is HIV-negative, while 37% have an HIV-positive partner (Figure 3.4).

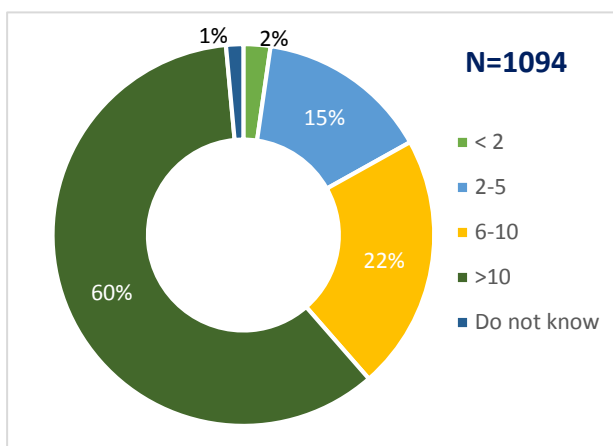


Fig. 3.3 Number of years living with HIV, %.

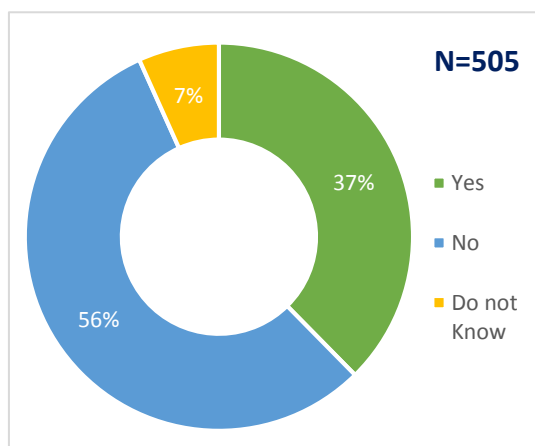


Fig. 3.4 Partners' HIV status, %.

80% of respondents do not have children under their care. Among those who have children, 47% have one dependent child, 32% have two, and 21% have three or more.

Regarding the level of education, the majority completed primary (40%) or secondary (36%) education, with only 13% having higher education (Figure 3.5), a much lower percentage than the general population (24%) (PORDATA, 2022a). It should be noted that at the time of the interview, 7.3% of the participants were attending some type of formal education.

One-third of the respondents reported being unemployed (Figure 3.6), which is also much higher than that of the general population (6.6%) (PORDATA, 2022b). This may be associated with the high rate of participants (47.9%) who reported not having been able to

meet basic needs (e.g., food, housing, clothing) in the last 12 months, either systematically (13.5%) or punctually (34.4%).

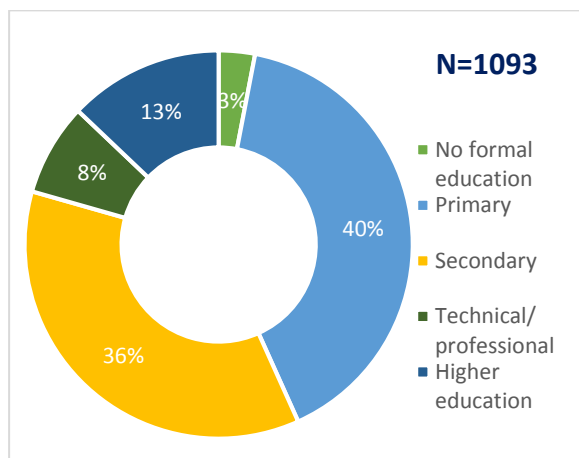


Fig. 3.5 Level of education completed, %.

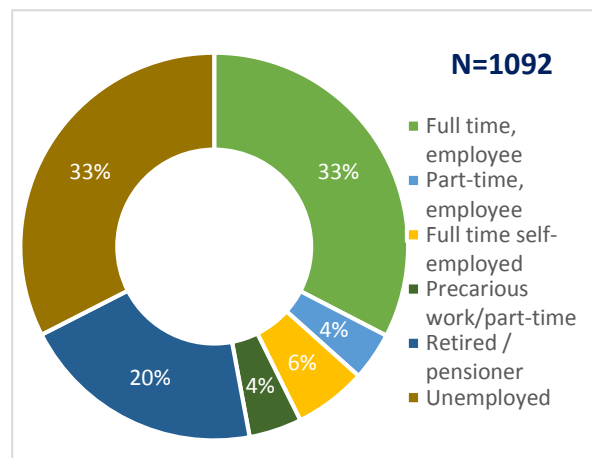


Fig. 3.6 Current employment situation, %.

As shown in *Figure 3.7*, 21% (N=229) of respondents are immigrants, of which, 17.5% (N=40) are undocumented. In addition, 12.9% (N=140) of the participants assume they have some disability (physical or intellectual), and 8.3% (N=90) have already been in prison. From the total of respondents, 40.2% belong or have belonged to at least one of the groups referred to in *Figure 3.7*, all of which may imply increase social vulnerabilities, namely concerning stigma and discrimination. Note that participants can belong to different groups at the same time.

Most respondents (86.6%) are not members of any network or support group for people living with HIV.

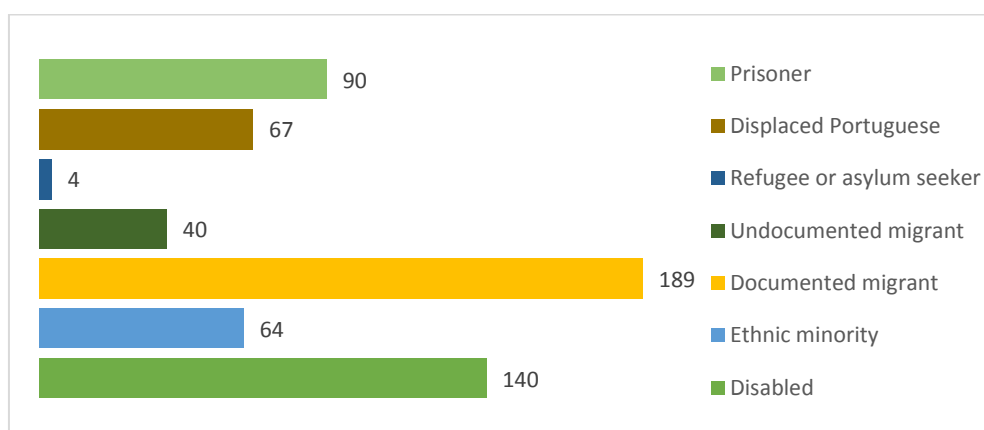


Fig. 3.7 Number of participants who identify themselves as belonging or having belonged to each group.

3.2. Section B: Disclosure of HIV Status

11.8% of respondents reveal that no one in their social network is aware of their HIV status, with the vast majority (88.2%) stating that at least someone knows about their status, namely their partner (67.7% of those with a partner; N=527), other family members (62.0%; N=660), friends (53.2%; N=573), and children (42.4% of those with children; N=288) (Figure 3.8). The difficulty of revealing one's serologic status to others is also shown in some comments provided in the open question of the questionnaire:

"I don't tell anyone I have HIV because I'm sure the discrimination is huge!"

"I never felt much discrimination because only my closest family and a few friends know about my status."

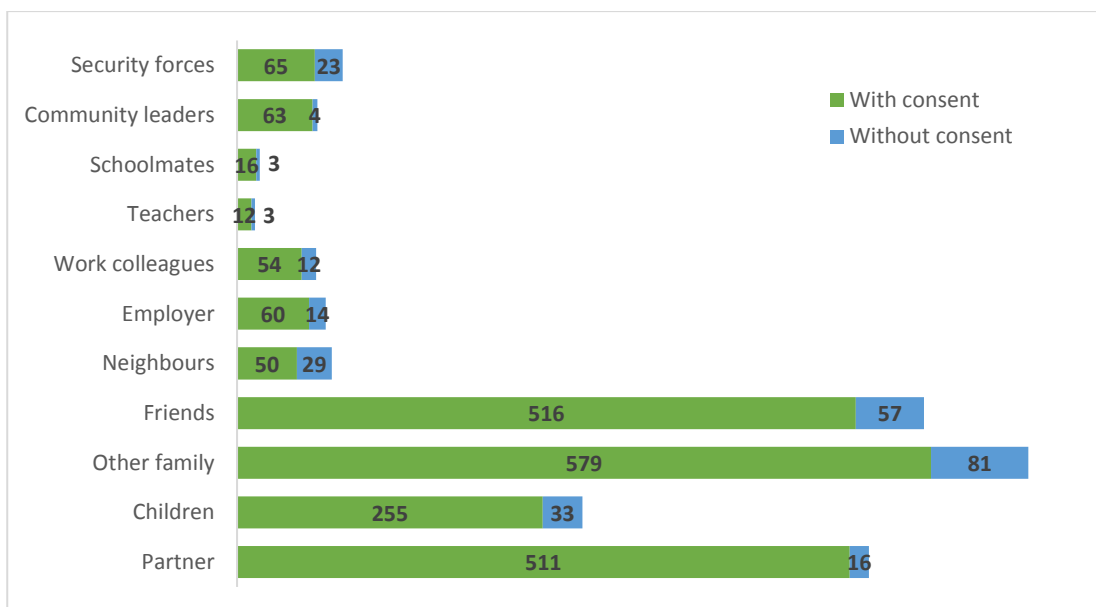


Fig. 3.8 Number of respondents whose HIV status is known to others (with and without consent).

Although this information was shared with the person's consent in most situations, 16.1% of respondents (N=176) have already encountered this information being shared without their permission. This happened mainly with family members (7.6%; N=81), friends (5.3%; N=57), and children (4.9% of those with children; N=33) (Figure 3.8), as exemplified in the following comment:

"At the hospital, a staff member told a friend of mine that I have HIV without my consent."

72.2% of respondents agree (totally or partially) that disclosing their HIV status to close people (e.g., partner, family, friends) was a positive experience, with 75.2% reporting having received support from close people, as exemplified by the quote from one of the respondents:

"I have people I can trust, making me feel better about myself."

With people respondents don't know well, the experience is the opposite, as only a third agree that it was a positive experience and that they received support in this way (Figure 3.9).

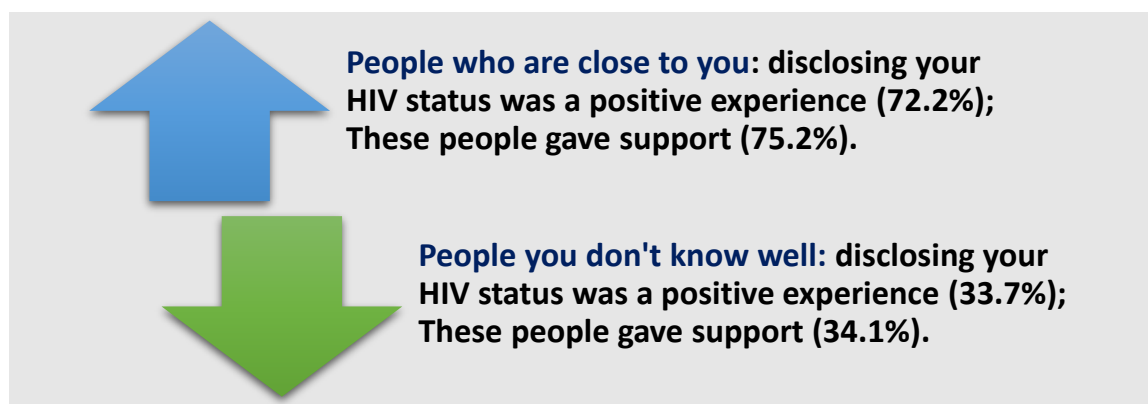


Fig. 3.9 Experience in disclosing one's HIV status to people close to and not known well.

Previous negative experiences and fear of discrimination are possibly associated with not disclosing one's serological status to people they don't know well, as revealed by some comments provided by respondents:

"Some people stop interacting with me after learning that I am HIV-positive or change their behaviour".

"I work in the social field and hear my colleagues, who don't know I have HIV, say that people with HIV shouldn't do certain jobs because of their infection."

It is important to note that for two-thirds of the study participants (66.6%) disclosing their HIV status has become easier over time.

3.3. Section C: Experiences of Stigma and Discrimination

When questioned about experiences of stigma and discrimination, 37.7% of respondents reported that they had already been the target of some discrimination because of having HIV. For 8.5%, this happened in the last 12 months. However, it should be noted that these data may be conditioned by the interview collection period, which took place between the end of October 2021 and March 2022, when the previous 12 months were spent in isolation due to COVID-19 pandemic, which naturally restricted contacts and possibilities of occurrence of discriminatory situations.

The most reported situations of discrimination (because of one's HIV status) refer to being the target of discriminatory comments, either by family members (18.3% [N=182] for more than 12 months ago; 3.1% [N=31] in the last 12 months) or by other people (19.0% [N=187] for more than 12 months ago; 4.2% [N=41] over the previous 12 months), being verbally

abused (11.4% [N=117] for more than 12 months ago; 2.7% [N=28] for the last 12 months) and being excluded from family activities (9.6 % [N=97] for more than 12 months ago; 2.2% [N=22] for the previous 12 months). It is also worth noting the high percentage of participants who reported having lost their job or having been denied a job offer due to HIV (8.4% [N=83] for more than 12 months ago; 0.9% [N=9] in the last 12 months), and those who have been physically assaulted (2.8% [N=29] more than 12 months ago; 0.8% [N=8] in the previous 12 months) (Figure 3.10).

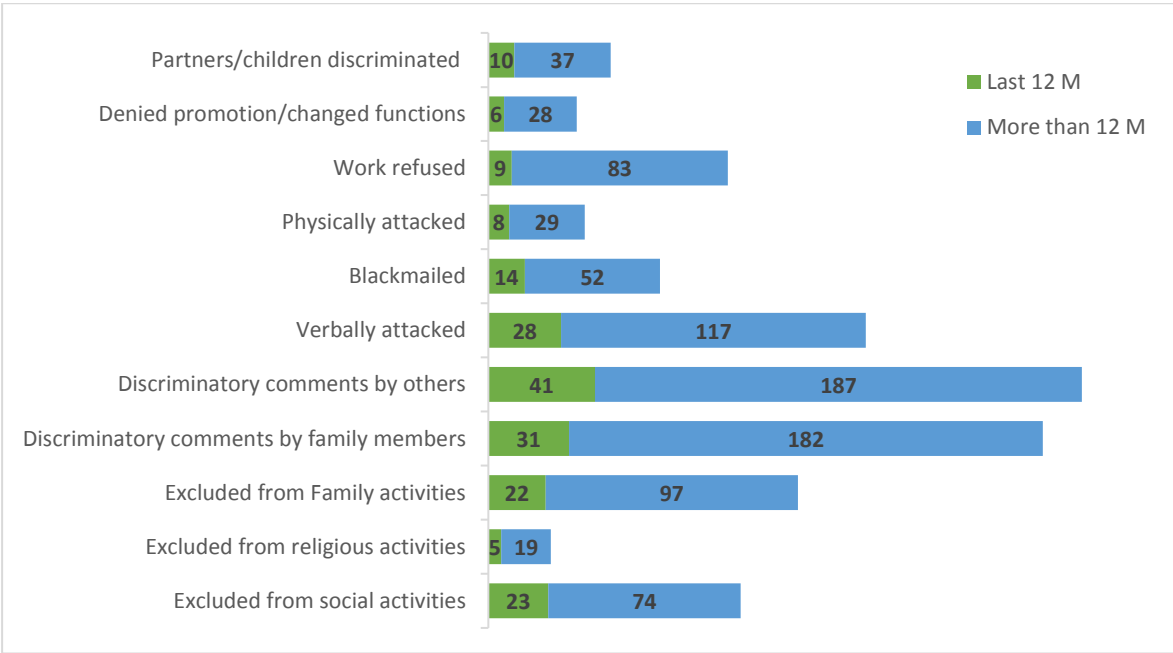


Fig. 3.10 Number of respondents reporting experiences of stigma and discrimination due to their positive HIV status, in the last 12 months and beyond the last 12 months.

Some of the comments provided by respondents in this regard are mentioned as examples:

“At family gatherings, they always put me aside. I also feel excluded by the inhabitants of the neighbourhood.”

“To this day, my relatives do not share plates, cutlery, or glasses with me, nor do they sit on the same bench, chair, etc.”

“I was discriminated against and verbally abused by my ex-partner. In addition, my former employer disclosed my HIV status to my co-workers without my consent.”

“I lost many jobs and was excluded from several applications when it was known that I was HIV positive. As a result, I stopped being able to practice my profession (cook).”

People belonging to key or vulnerable populations report discrimination for living with HIV more often (41.7%) than those not belonging to any of those populations (27%) (classified as general population). People who do or have done sex work, transgender people, and

those who use or have used drugs seem to be the most affected, with half or more of the respondents belonging to these populations reporting episodes of discrimination (Figure 3.11); this being illustrated by some comments provided by participants:

“Drug users are very discriminated against for using drugs and those with HIV even more so.”

“Especially when I was a drug user, when I had hepatitis C, and they found out I was HIV positive, I was very discriminated against and rejected.”

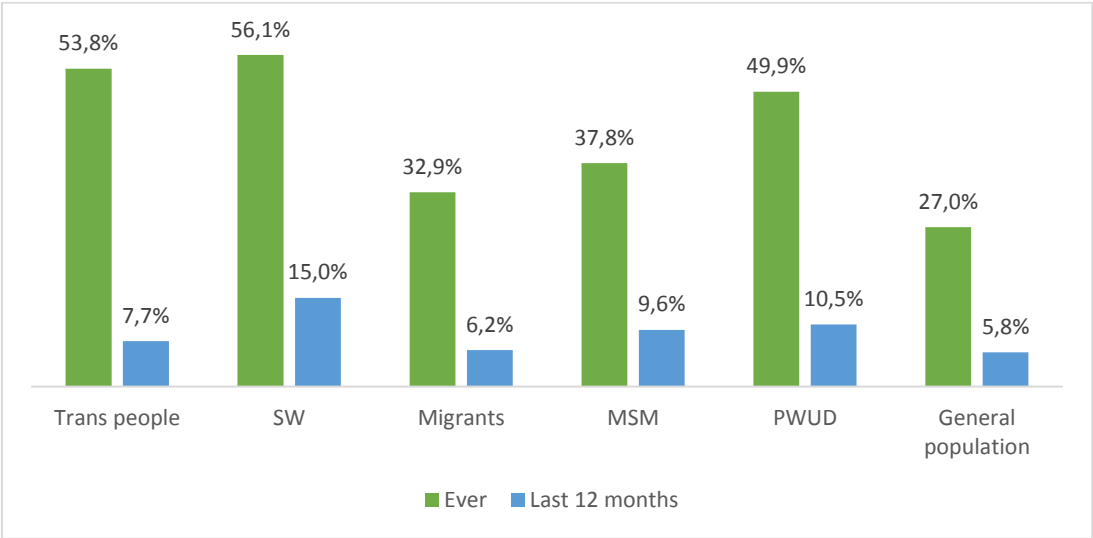


Fig. 3.11 Percentage of respondents from each key and vulnerable population who reported experiencing stigma and discrimination for living with HIV at any time and in the last 12 months.

Analysing the four most highlighted situations of stigma and discrimination and taking into account the situations that occurred more than 12 months ago (since the small number of cases that happened in the last 12 months does not allow for their disaggregation), it can be observed that transgender people are the ones who most frequently reported any of the situations of stigma and discrimination, with 44% reporting discriminatory comments by family members, 33.3% reporting discriminatory comments by other people, and 32% reporting situations of verbal aggression¹². The next most affected group is sex workers (with 29.3% reporting discriminatory comments by family members, 26.8% by other people, and 19.5% reporting exclusion from family activities) (Figure 3.12).

¹²Despite the high percentages, it is essential to mention that the absolute number of transgender people in the sample is low (N=26), and therefore there may be some bias in the results.

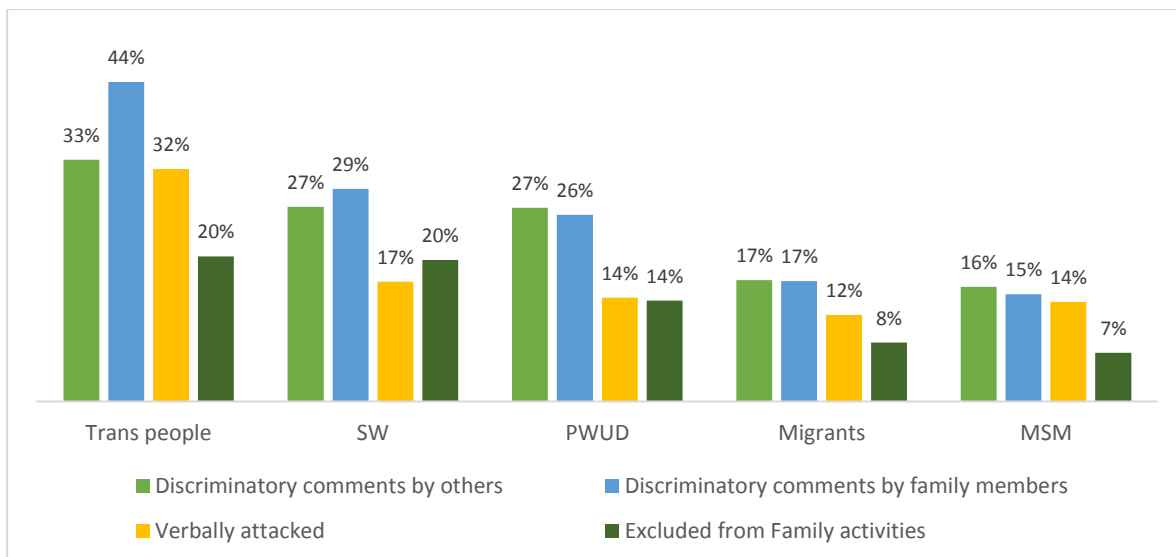


Fig. 3.12 Percentage of respondents from each key and vulnerable population who reported experiences of stigma and discrimination for living with HIV experienced more than 12 months ago, for the most frequent situations.

The percentage of Cis women who reported having suffered some form of discrimination (39.8%) is slightly higher than that of Cis men (35.1%); pattern is the same if we consider only the last 12 months (9.6% of women vs. 7.6% of men). However, these differences become more evident in the following three of the four most frequent situations of stigma and discrimination (considering situations that occurred more than 12 months ago): Cis women reported more frequently having been the target of discriminatory comments by family members (21% of women vs. 15.1% of men), having been verbally abused (13% of women vs. 8.9% of men), and being excluded from family activities (12.3% of women vs. 7.3% of men) due to their HIV status (*Figure 3.13*). This issue is mentioned by some respondents and may be aggravated in certain cultures:

“As a woman, I feel I have increased risk of stigma and discrimination. I have already trusted and revealed my status to a person I trusted who blackmailed me and threatened to expose me publicly. I felt helpless, terrified.”

“African women are doubly discriminated against for having HIV; HIV/AIDS is very poorly accepted within the community, especially when it is the woman who has it.”

“Since I’m a roman woman, I can’t tell anyone that I’m HIV positive, or I’ll be killed. I was kicked out of the Roma community for using drugs.”

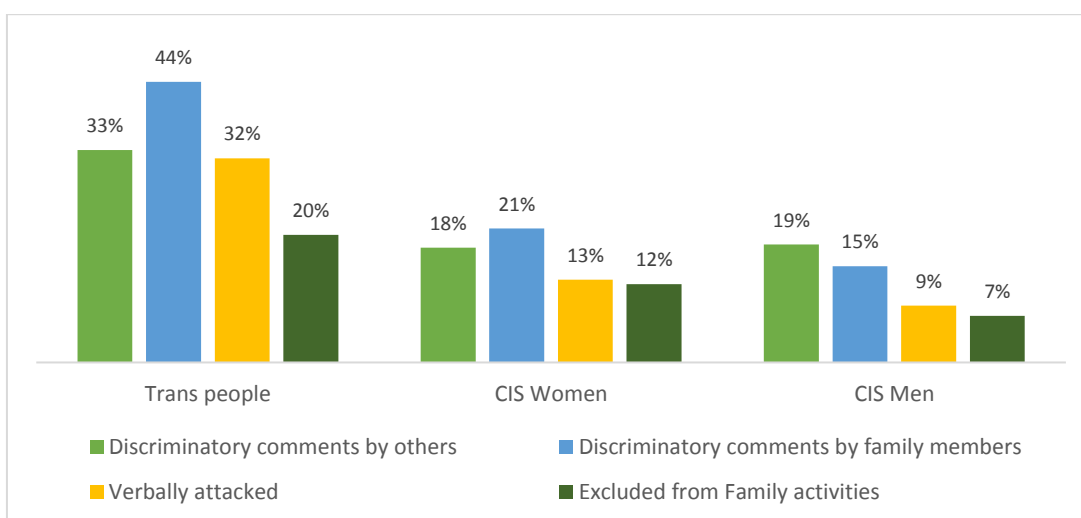


Fig. 3.13 Percentage of respondents reporting experiences of stigma and discrimination for living with HIV experienced more than 12 months ago for the most frequent situations, by gender.

Differences are also identified according to the number of years a person lives with HIV: people living with HIV longer report more situations where they have been the target of some form of discrimination (*Figure 3.14*).

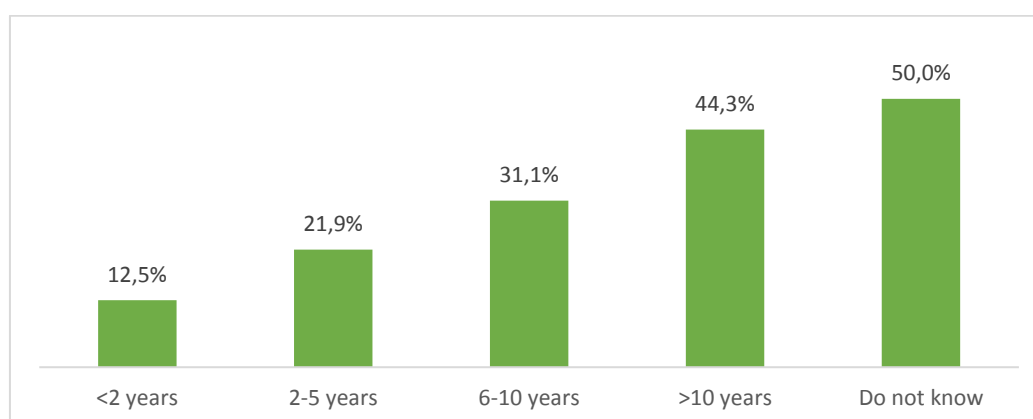


Fig. 3.14 Percentage of respondents reporting experiences of stigma and discrimination for living with HIV, by number of years of living with HIV infection.

In addition to the questions on experiences of stigma and discrimination included in the *PLHIV Stigma Index 2.0 questionnaire*, we added at the end of the questionnaire, 5 extra response options referring to situations of structural discrimination (i.e., situations of discrimination perpetuated by laws and regulations), namely in the access to life or health insurance, and access to or progression in the career of Armed Forces. Of the 837 respondents who answered these questions, 78 (9.3%) indicated at least one of the situations of stigma and discrimination.

Having been denied life or health insurance for having HIV is the most frequently mentioned situation (in the last 12 months and over a year ago) reported by 7% (N=56) of respondents who answered this question or to which it was applicable. 3.6% (N=28)

reported being denied health / life insurance because they refused an HIV test, and 1.3% (N=10) saw their premium increased due to HIV (Figure 3.15). It should be noted that many people living with HIV may choose to omit this information when purchasing insurance, so it is difficult to know the actual number of people affected by this issue.

Concerning the Armed Forces, 1.7% (N=10) of respondents who answered this question or to whom it was applicable reported having been prevented from joining this sector, and 1.4% (N=8) had been prevented from progressing in their careers (Figure 3.15).

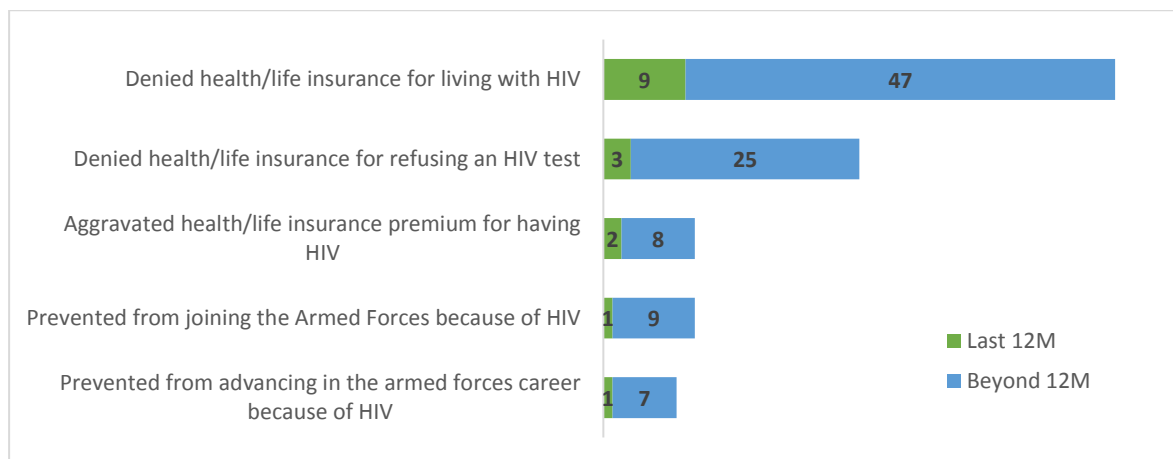


Fig. 3.15 Number of respondents reporting situations of discrimination in the context of insurance and armed forces for living with HIV in the last 12 months and beyond 12 months.

3.4. Section D: Internalized Stigma and Self-Discrimination

The impact that living with HIV can have on how people feel about themselves is well known. However, in this survey, most participants did not report changes in the last 12 months in the various aspects of life questioned due to living with HIV. Still, around a quarter (24.7%; N=269) said their ability to deal with stress has worsened, as well as their ability to fall in love (20.7%; N=213), to have close relationships (18.5%; N=201), and the desire to have children (16.6%; N=119), showing the implications of the HIV infection in establishing intimate relationships. On the other hand, several respondents identified improvements in the last year in various aspects of their lives due to living with HIV, the most frequent being the ability to contribute to the community (27.4%; N=290), respect for others (24.8%; N=270), self-confidence (24.4%; N=263), self-esteem (23.7%; N=258) and the ability to achieve personal or professional goals (23.7%; N=248) (Figure 3.16), as exemplified by some of the comments provided in the open question of the questionnaire:

“I feel I am an agent of transformation in the lives of the people I work with.”

“I try to keep my self-esteem high and get on with my life.”

“The 1st step was to accept the disease and stop feeling sorry for myself. Then I created goals and objectives for myself, which was very liberating, even to help other people living with HIV.”

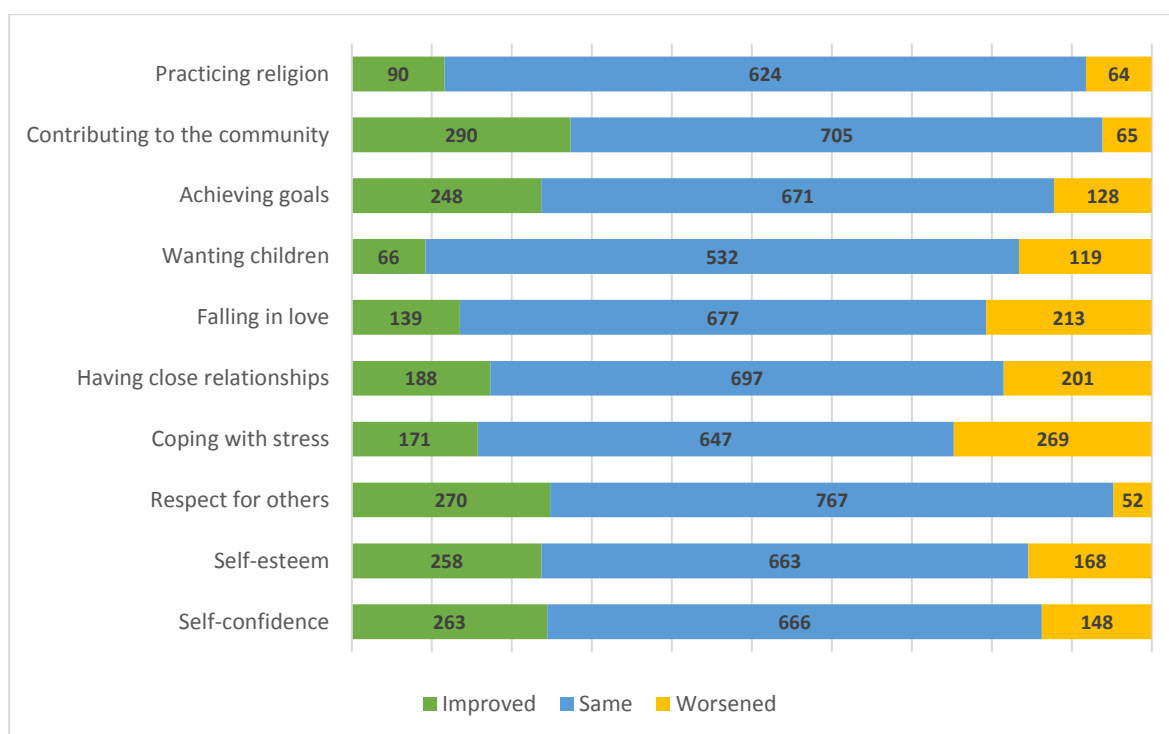


Fig. 3.16 Number of respondents reporting an improvement, worsening, or no change in different aspects of their lives due to living with HIV in the last 12 months.

Considering the impact of HIV infection on these same aspects of life, but in the period before the last 12 months, the majority of respondents continues to report no change (65.6%), 22.8% state that, in general, the various aspects of life mentioned have improved, and 11.6% reported that they have worsened.

The social stigma that exists about HIV (negative perception of the infection and of the people living with it) is often internalized by PLHIV, generating negative feelings towards themselves (internalized stigma) and leading people to isolate themselves or exclude themselves from certain activities (self-discrimination). In this survey, 90.5% of the participants reported at least one manifestation of internalized stigma and 30% at least one self-discriminating behaviour in the last 12 months, showing that these issues are far from being overcome.

Migrants are the ones who report the most some manifestation of internal stigma (95.4%), followed by sex workers (92%). The former is also one of the populations that reports more self-discriminatory behaviours in the last 12 months (40.1%), together with transgender people (40.0%)¹³ (Figure 3.17).

¹³Despite the high percentages, it is important to mention that the absolute number of transgender people in the sample is low (N=26), and therefore, there may be some bias in the results.

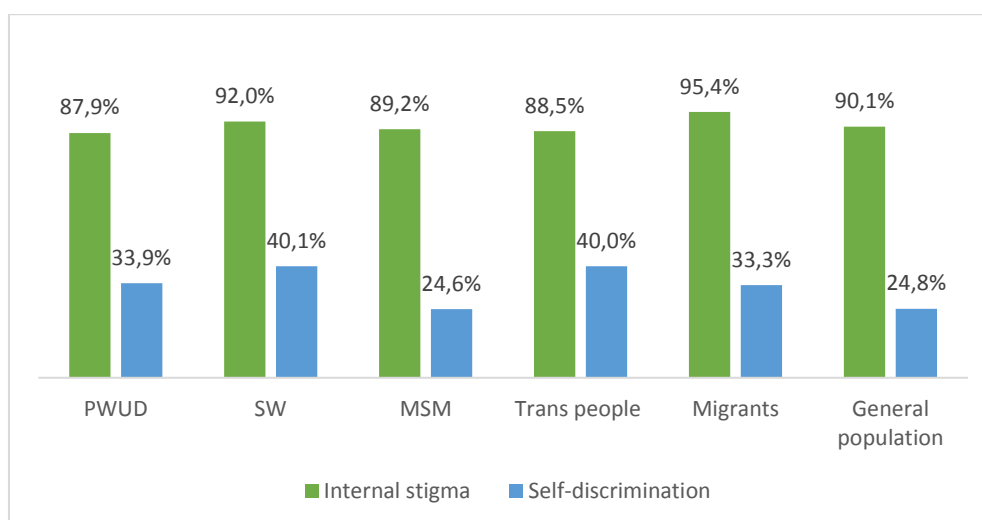


Fig. 3.17 Percentage of respondents reporting some manifestation of internal stigma or self-discriminating behaviour in the last 12 months for living with HIV, by each key and vulnerable population.

Internalized stigma manifests itself mainly in the decision not to have sexual intercourse (reported by 16.8% of respondents) and isolation from family and friends (14.8%) (referring to the last 12 months) (Figure 3.18), as exemplified by the comment of one of the respondents:

“I feel very lonely and isolated since I have known my HIV status. I have withdrawn from my friends for fear they would find out.”

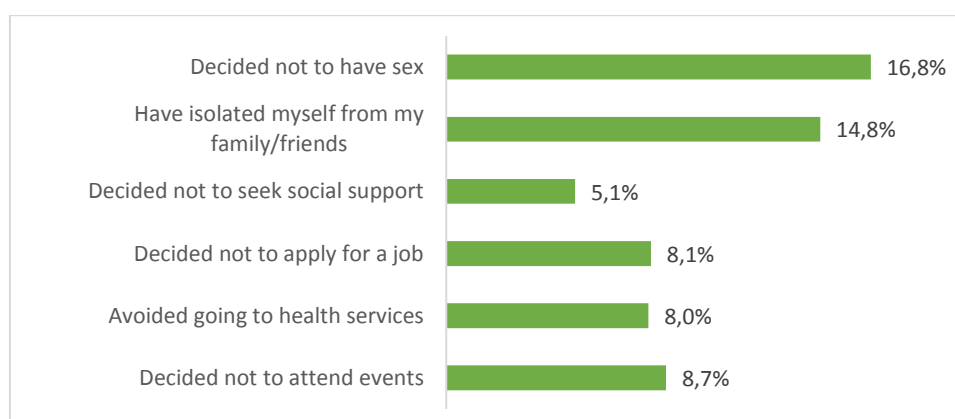


Fig. 3.18 Percentage of respondents who had the referred behaviours (of self-discrimination) for living with HIV in the last 12 months.

Analysing by gender, after trans people (40%), these are Cis women who most frequently report having had at least one self-discriminating behaviour in the last 12 months (33.7% of women vs. 26.7% of men), with the difference being more noticeable in the decision not to have sexual intercourse (19% of women vs. 14.8% of men).

The percentage of participants who reported having isolated themselves from family or friends in the last 12 months due to HIV decreases with age (37.5% in participants aged 20 to 24 years vs. 12.8% in participants over 50 years old). However, the opposite happens

concerning the decision not to have sexual intercourse (0% in participants aged 20 to 24 vs. 22.1% in participants over 50 years old).

Regarding internalized stigma, it can be seen from the answers given that disclosing the serological status to others continues to be perceived as difficult by the vast majority (82.1%), with 81.4% choosing to hide their status from others. Furthermore, negative feelings associated with the HIV infection continue to persist, namely guilt (reported by 30.5% of respondents) and shame (reported by 27.2%) (Figure 3.19). Some comments provided by respondents reinforce these numbers:

"I've known about the diagnosis for 2 years, and I still haven't been able to reveal it to anyone. I think that's why I didn't go through many discriminatory situations. The biggest stigma I still suffer is my own."

"I hide my status. I don't tell anyone, so I don't think I've ever experienced discrimination."



Fig. 3.19 Percentage of respondents mentioning some manifestations (associated with internalised stigma).

Migrants show the most difficulty in disclosing their HIV status to others (88.3% find it difficult, and 87.9% hide it). Feelings of guilt and shame are reported more often by transgender people (46.2%). Sex workers are the next group to feel guilt (42.9%), and migrants to report feelings of shame (37.7%).

Analysing by gender, Cis women present higher percentages than Cis men in all response options associated with internalised stigma, both in the difficulty in disclosing their HIV status (85.5% of women vs. 80.1% of men) and in feelings of shame (36.1% of women vs. 20.9% of men), guilt (33.7% of women vs. 28.1% of men) and worthlessness (19.2% of women vs. 13.5% of men).

The number of years living with HIV also seems to influence the disclosure of HIV status, with disclosure happening less often in people living with HIV for more years (92% of disclosure among those living with HIV for less than 2 years vs. 79% for respondents that live with HIV for more than 10 years). Age category also influences disclosure, with older individuals having slightly less difficulty disclosing their HIV status (87.5% of disclosure among participants between 20 and 24 years old vs. 81.2% among participants over 50 years old). Even so, the percentages remain high, even with increasing age and years of

living with HIV. In terms of negative feelings (guilt, shame, uselessness) associated with HIV infection, no downward trend was observed when data was analysed per categories: of the years of living with infection or of age.

3.5. Section E: Interaction with Health Services

3.5.1. HIV testing, Care, and Treatment

Most respondents (54%) tested for HIV voluntarily. Still, a very significant percentage of participants refer that the test was done without their knowledge (30%) (Figure 3.20) in different situations, one of them being the situation of imprisonment, as mentioned by one of the respondents:

“I don't understand why they would test for HIV when entering prison and, on top of that, without saying anything.”

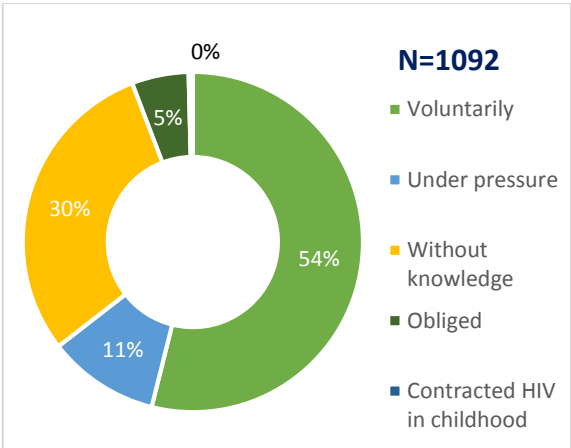


Fig. 3.20 Decision to get tested for HIV, %.

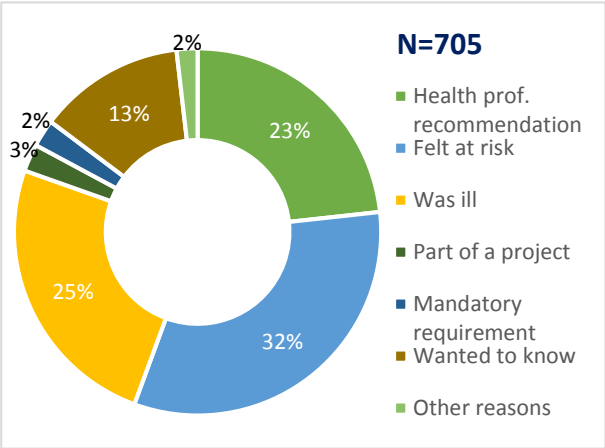


Fig. 3.21 Reason for taking HIV test, %.

The main reasons given for taking the HIV test were perception of being at risk for HIV (32%), followed by being ill (25%), and HIV test having been recommended by a health professional (23%) (Figure 3.21).

For most participants (84.5%), less than 6 months had elapsed between the moment they first thought they should take the test and the moment they took it, with 12.2% reporting having avoided the test due to fear of other people's reaction to a positive test.

Almost all respondents (97.8%) reported taking or having already taken antiretroviral treatment, with 33.1% having postponed or avoided receiving care or treatment for HIV. The most frequently mentioned reason for hesitating, delaying or preventing initiation of HIV treatment was not being prepared to deal with being HIV positive (25.8%), followed by the fear that others (people not close to them) would discover their HIV status (12.9%) and that health professionals would mistreat them or disclose their HIV status without their

consent (12.6%) (Figure 3.22). It should be noted that 15% of respondents admit to having missed some dose of their antiretroviral treatment in the last 12 months for fear that someone would discover their HIV status.

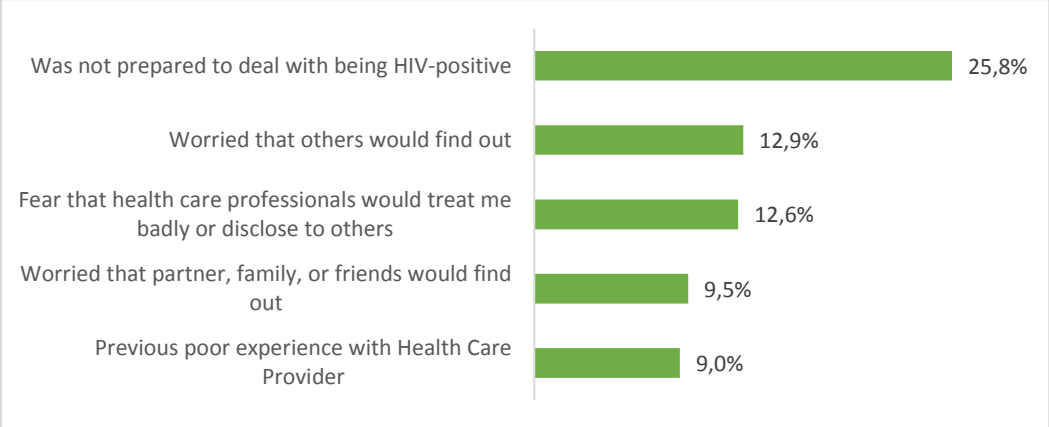


Fig. 3.22 Respondents who answered “yes” to each listed reasons for postponing or avoiding receiving care or treatment for HIV, %.

Most participants (89.1%) reported having decided to start treatment as soon as it was available, as they were aware of its benefits, with 5.4% saying they decided to wait and start later, and 5.2% mentioning to have been pressured/forced by a healthcare professional to start treatment.

About 30% of respondents started antiretroviral treatment on the same day they were diagnosed, 22.4% within 30 days, and 21.3% between 1 and 6 months after diagnosis (Figure 3.23).

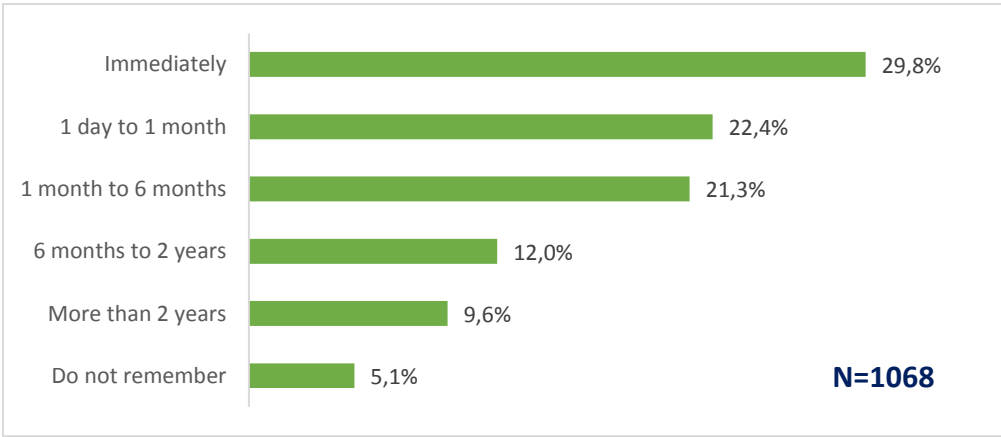


Fig. 3.23 Time between diagnosis and initiation of antiretroviral treatment, %.

Currently, the vast majority (90.3%) reports having an undetectable viral load, with 5.7% mentioning that the virus was detectable in the last analyses they performed (referring to the previous 12 months).

27.8% of the respondents had already interrupted or stopped their antiretroviral treatment. Of these, almost half (47%) had done so in the last 12 months, with most referring that the reason for the interruption was not related to stigma (56%). Even so, 17.3% admit to having stopped treatment in the last 12 months for fear of someone discovering their HIV status, and 11.5% for not feeling prepared to deal with the diagnosis (Figure 3.24).

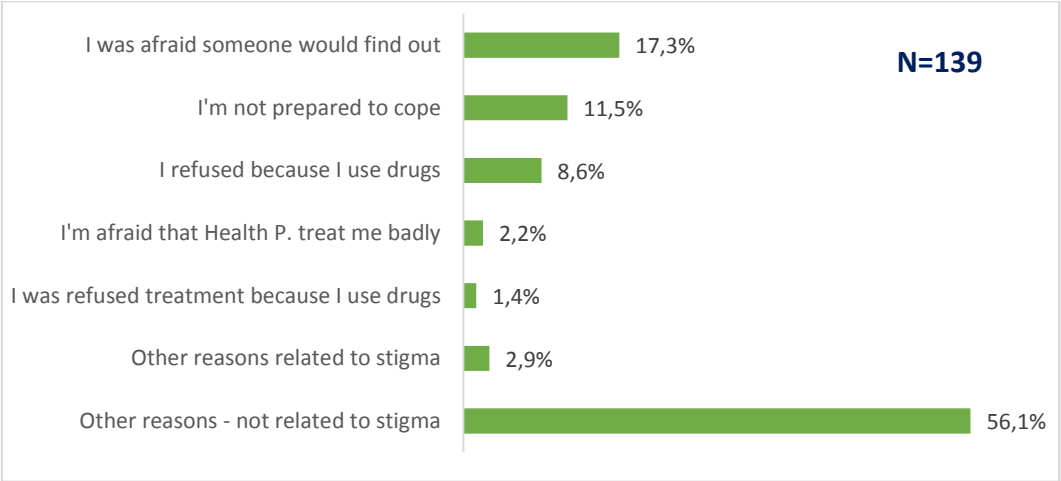


Fig. 3.24 Stigma-related reasons for having interrupted or stopped antiretroviral treatment in the last 12 months, %.

The most frequently mentioned reason for avoiding returning to treatment after having interrupted it is not being prepared to cope with the disease (32.5%), followed by having had a previous bad experience with a health professional (13.8%) (Figure 3.25). This situation is illustrated by the comment provided by one of the respondents:

“I've already been disrespected in a public hospital when at a counter, I was told, 'The appointment of the infected is not here!' So, after that, for a long time, I didn't want to know about any more appointments because I was afraid of being humiliated.”

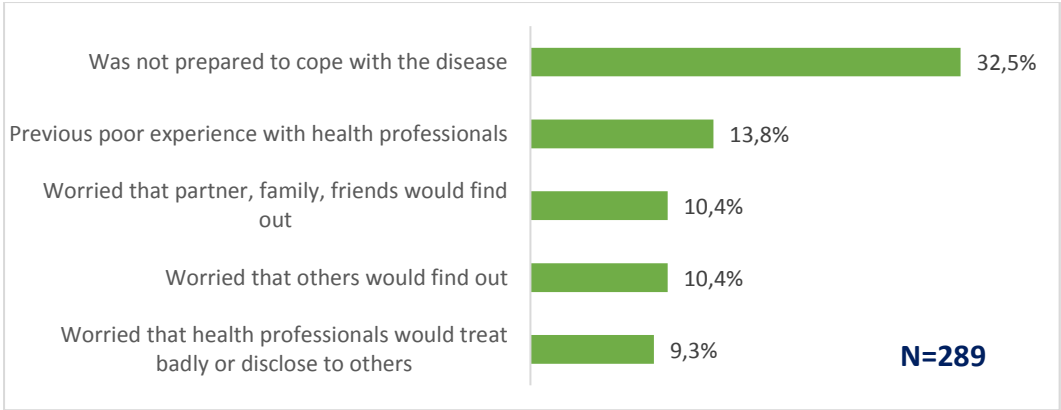


Fig. 3.25 Reasons for avoiding returning to treatment after having interrupted it, %.

Regarding (not related to stigma) reasons for stopping or interrupting treatment in the last 12 months (situation covering 152 respondents), the most frequently mentioned reasons are: not being able to tolerate the side effects of medication and reasons related to alcohol or drug use (15.1% for both), followed by difficulty in collecting the medication (11.2%) (Figure 3.26).

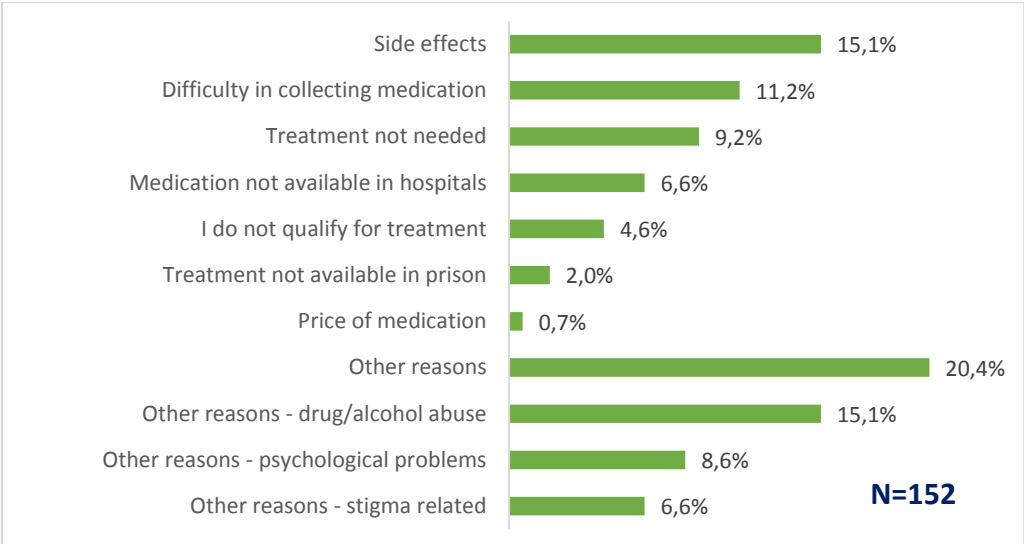


Fig. 3.26 Reasons not related to stigma for having interrupted or stopped antiretroviral treatment in the last 12 months, %.

3.5.2. General Health Status

Most participants describe their current health as good (53.9%) or fair (39.9%), with 6.2% classifying it as poor. The most frequently reported health problems diagnosed in the last 12 months are mental health problems (28.9%), non-transmissible diseases (14.9%), and addiction syndrome related to alcohol or drug consumption (12.8%). % (Figure 3.27).

28% had not received treatment for these health problems in the last 12 months.

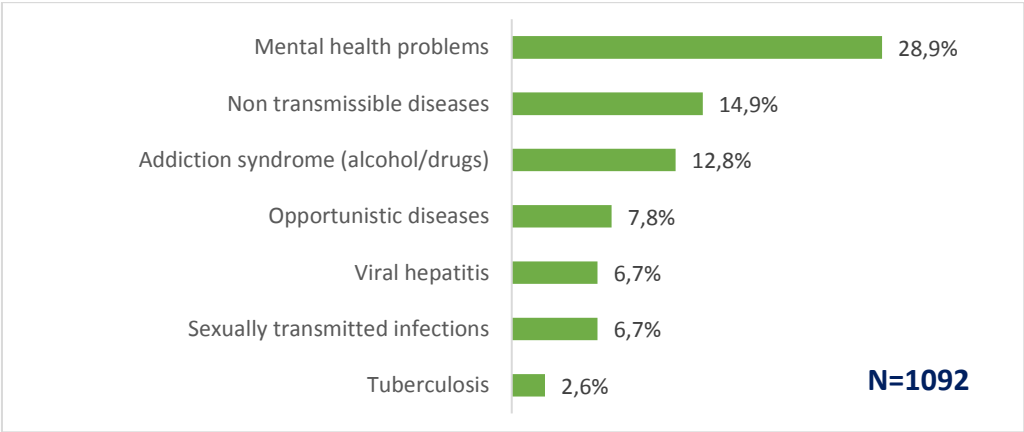


Fig. 3.27 Health problems diagnosed in the last 12 months, %.

3.5.3. Experiences with Health Services

96.6% of respondents receive HIV-related healthcare and treatment in public hospitals, with 10 people receiving it in private hospitals, 9 people at NGOs or community-based organizations, and 8 participants claiming to receive treatment in various locations. Only 1% (10 participants) say they are not currently receiving healthcare or HIV treatment.

52.1% of respondents are aware of community-based centres that provide HIV-related services where they can resort to, but only 3.8% receive HIV-related health care in one of these centres. The services that are most known as being provided by those centres are: the provision of information about HIV (95.9%), prevention services and materials (86.7%), screening (85.9%), and psychosocial support (84.1%) (Figure 3.28). It is important to note that these centres are found essentially in large cities, being scarce in the rest of the country, as mentioned in this comment:

"I would like to suggest that support associations for people with HIV should be established also outside Lisbon. I live in an area of the country where there are no HIV-related services."

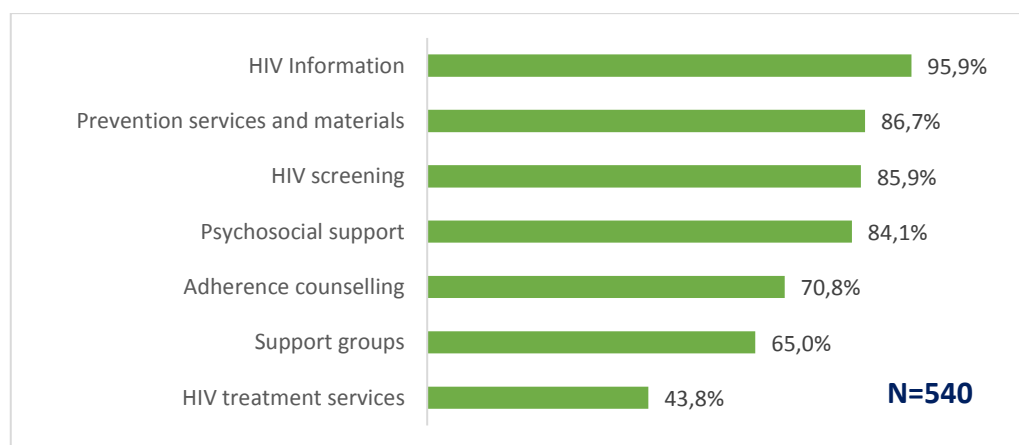


Fig. 3.28 Knowledge of HIV-related services provided in community-based centres, %.

We observe that 22% of respondents report some discrimination situation in the last 12 months by healthcare professionals, either in specific HIV services, in sexual and reproductive health services, or in other health services (the response categories evaluated in each area are specified further below).

Similar to what was observed at the level of social discrimination, people who do or have done sex work seem to be the most affected by discrimination in healthcare, with 41% of respondents belonging to this population reporting at least one episode of discrimination in health services in the last 12 months. They are followed by people who use or have used drugs (27.5%) and migrants or people who belong to an ethnic minority (20.4%) (Figure 3.29).

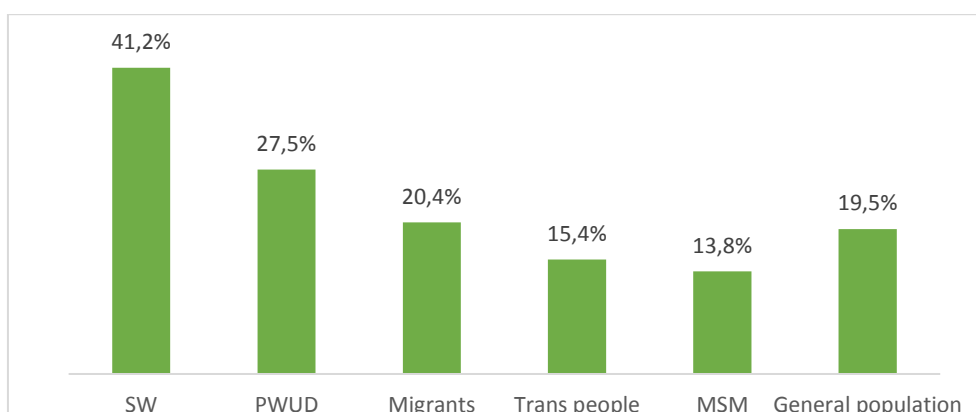


Fig. 3.29 Percentage of respondents who report discrimination for living with HIV in health services (general, HIV services, sexual and reproductive health services) in the last 12 months according to each key and vulnerable population.

Analysing data by gender, 33.7% of Cis women report discrimination in health services in the last 12 months, a much higher percentage than that of Cis men (14.2%) and trans people (15.4%). This discrepancy may be related to the fact that several questions asked related to sexual and reproductive health services, which are usually addressed to women.

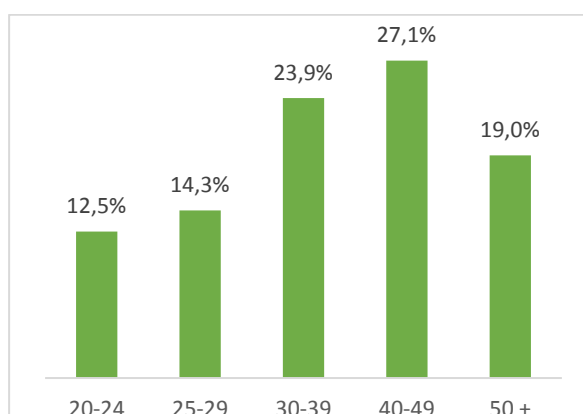


Fig. 3.30 Respondents reporting discrimination due to living with HIV in health services in the past 12 months, by age group, %.

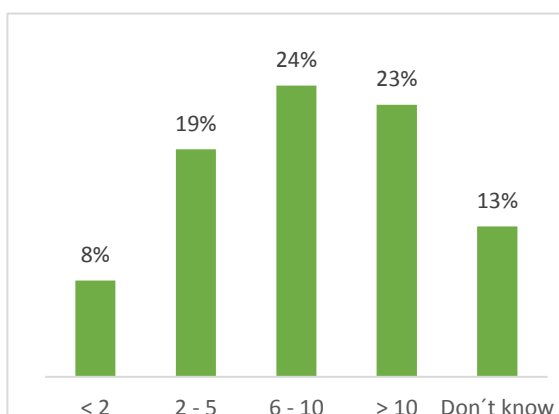


Fig. 3.31 Respondents reporting discrimination for living with HIV in health services in the past 12 months, by number of years living with HIV, %.

There is a tendency for older people and those with more years of living with HIV to report more frequently situations of discrimination in health services (except for respondents over 50 years of age, where the percentage decreases) (*Figures 3.30 and 3.31*). This may indicate that some respondents listed stigmatising situations experienced more years ago and not necessarily in the last 12 months, as was asked.

In the context of HIV-related appointments and tests, 11% of participants reported some form of discrimination in the last 12 months, the most frequent being health workers avoiding physical contact or taking extreme precautions (such as wearing two pairs of gloves) (5.9%), followed by being advised not to have sex (4.2%), and disclosing their HIV

status to others without their consent (3.8%) (Figure 3.32). Study participants mentioned moral and value judgments in their responses to the open question:

“The HIV doctor did not believe that I would stop using and that any medication would work for me. Nurses and assistants looked at me sideways as if I were an animal. Always judging me. I always felt rejected.”

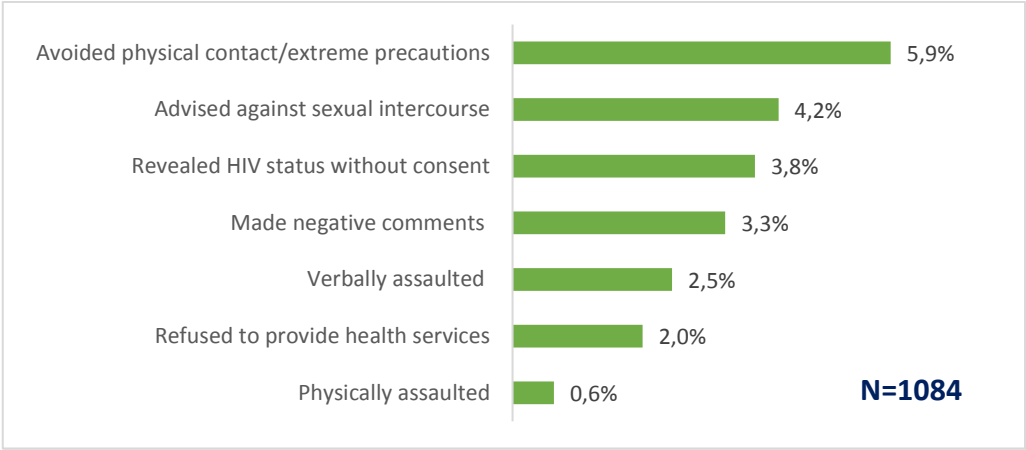


Fig. 3.32 Situations of discrimination in HIV-related health services in the last 12 months, %.

More than half of the total respondents (N=564) have sought non-HIV-related health services in the last 12 months, of these, 560 answered next question regarding types of discriminatory practices when seeking non-HIV-related care. Among 560, 16% reported some kind of discrimination by the healthcare professionals, again the most frequent being the adoption of extreme precautions (10.9%), followed by having made negative comments about them (5.0%) and disclosing their HIV status to others without their consent (4.1%) (Figure 3.33).

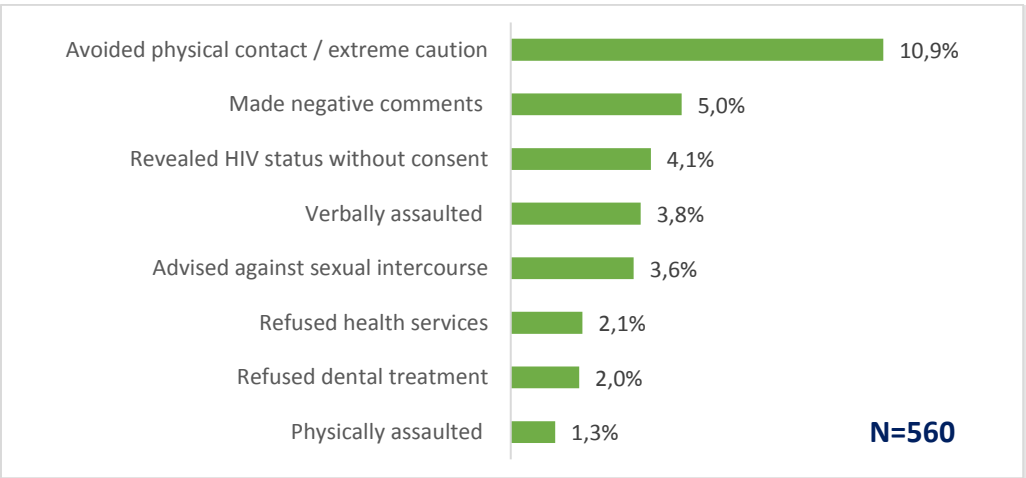


Fig. 3.33 Situations of discrimination in health services not related to HIV in the last 12 months, %.

The following are some comments provided by respondents to the open question, many referring to recent situations:

“In a foot surgery, the nurse said I could not be operated there because it was not the AIDS treatment ward.”

“In 2017, when cleaning a catheter at the oncology day hospital, the nurse who treated me was wearing a full protective suit, saying that all precautions were not enough.”

“A few months ago, I went to a dental clinic and was informed that I could only be seen after all the clients due to my HIV status.”

“Yesterday at the oncologist appointment, the doctor mistreated me verbally and did not provide care, sending me to the infectious disease specialist.”

It should be noted that 49% of participants reported that they usually do not reveal their HIV status in health services not related to HIV, so the number of situations of discrimination that could occur in this context may be underestimated. On the other hand, of all life contexts, it is probably in the health services that individuals most often disclose their HIV status, being, therefore, more exposed to situations of discrimination, as mentioned by one of the respondents:

“Health services, as they are the places where people expose their status most frequently, are the ones where I feel more discrimination, whether at the level of treatments or persuasion to certain medical acts, sterilization of material, issues related to maternity, among others.”

Confidentiality remains a concern identified by many participants, with 46.7% reporting they are not sure their medical records are kept confidential and not disclosed without their consent and 9.5% saying their confidentiality is not assured. This issue is also referred to in several comments:

“At an appointment, my family doctor asked me to inform the nurse that I had HIV. I felt bad. If I had a hole, I would have hidden myself.”

“In a report of post-urgent appointment, they wrote that I had HIV without my consent.”

“A specialist doctor who signed me up for surgery wrote the information about my serology in the surgical proposal with a red pen.”

Concerning family planning, 7% of respondents reported situations of discrimination in the last 12 months. The most reported situations were subjecting the prescription of antiretroviral treatment to a specific contraceptive method (4.4%; N=40) and advising not to have children (4.2%, N=37) (Table 3.1). One of the respondents shares the experience of discrimination:

"When I was pregnant with my son, the doctor told me that I shouldn't have children because I have HIV. Asked me several times how it was possible."

The municipalities where these situations occurred most frequently were Lisbon (16) and Almada (12). It is important to note that only in 6 situations (out of the 94 reported) the person shared what happened with someone, which may indicate the isolation and feeling of powerlessness in which situations of discrimination are often experienced.

Table 3.1. Situations of discrimination experienced in terms of sexual and reproductive health.

HCP attitudes concerning family planning in the last 12 months (all participants)		HCP attitudes concerning pregnancy, childbirth, and breastfeeding (women only)		
		Last 12 months	+ 12 months	
Advised you against having children	37	3	30	Advised you to end the pregnancy
Pressured you to get sterilized	9	7	41	Pressured you to use a type of contraceptive method
Sterilized you without consent	6	0	46	Pressured you to do a specific type of childbirth
Refused you contraceptives or family planning	2	1	52	Pressured to do antiretroviral treatment during pregnancy
Told you that to get HIV treatment, you would have to use a specific contraceptive method.	40	1	49	Pressured you to use a particular breastfeeding practice

Regarding pregnancy, childbirth, and breastfeeding, 27% of the women who answered this question (N=364) reported some discriminatory practice, most of which occurred more than 12 months ago. Of these, the most frequent was the pressure to uptake antiretroviral treatment during pregnancy (16.5%; N=52) and to use a specific breastfeeding practice (15.7%; N=49). It is also essential to highlight the 7 cases in the last 12 months involving pressure to use a particular type of contraceptive method and the 3 situations where women were advised to end their pregnancies. It should be noted that 10% (N=33) of women reported having already been recommended to end their pregnancy due to their HIV status, which is challenging to justify clinically (Table 3.1).

3.6. Section F: Human Rights and Effective Change

15% of respondents reported having suffered at least one situation of violation of their rights (Figure 3.34), with 3.5% (N=38) reporting that this situation occurred in the last 12 months.

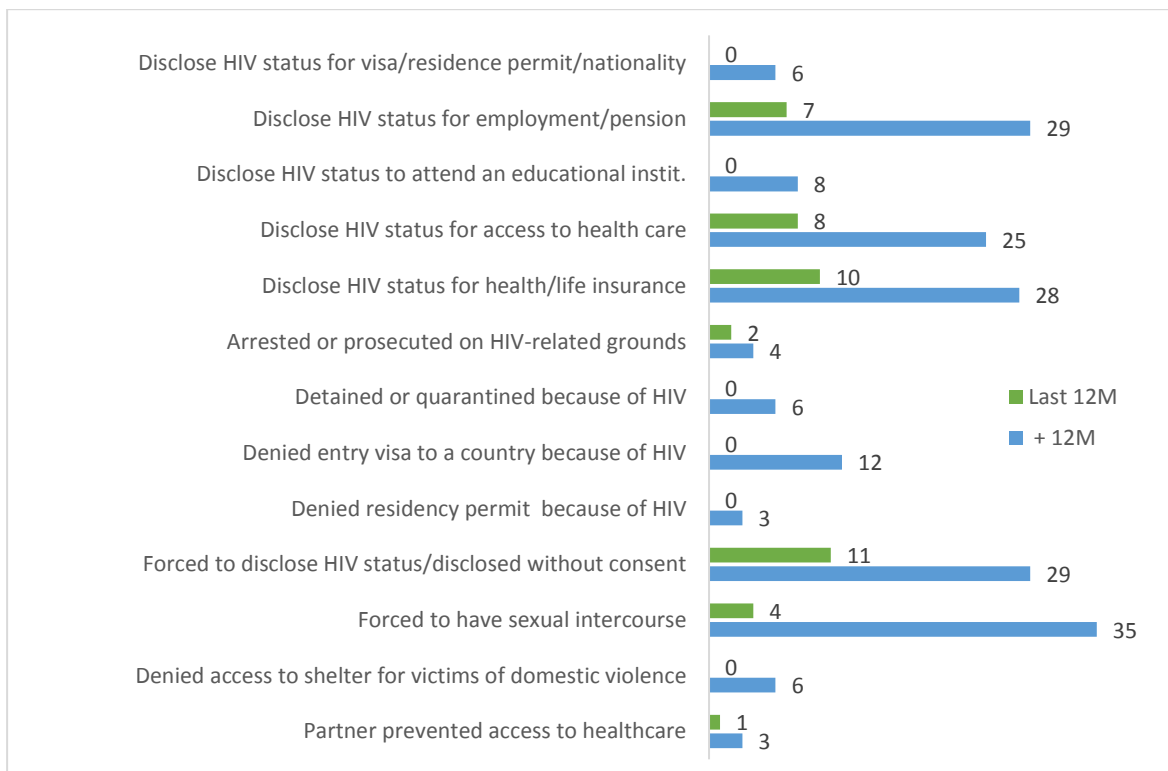


Fig. 3.34 Number of respondents reporting situations of disrespect for their rights experienced in the last 12 months and in the previous period.

The most reported situation, that happened more than 12 months ago, was being forced to have sexual intercourse (3.2%; N=35). This issue is also mentioned in a comment:

“I have already been forced to have sex without my consent. I’ve been raped on the street and in jail. I feel very unprotected.”

The remaining situations refer to issues related to non-voluntary disclosure of HIV status, namely being forced to take HIV test or reveal HIV status to apply for a job or obtain a pension (2.7%; N=29), to get health/life insurance (2.6%; N=28) or to access healthcare (2.3%; N=25) and having been forced to disclose HIV status publicly or having it disclosed without consent (2.7%; N=29). These are also the situations most frequently identified in the last 12 months (*Figure 3.34*).

In people belonging to (at least) one key or vulnerable population, situations of violation of rights seem to be more frequent compared to those who do not belong to any of these populations, with particular relevance for those who do or have done sex work (30% of SW report at least one situation of disrespect for their rights), followed by people who use or have used drugs (19%) and men who have sex with men (19%) (*Figure 3.35*).

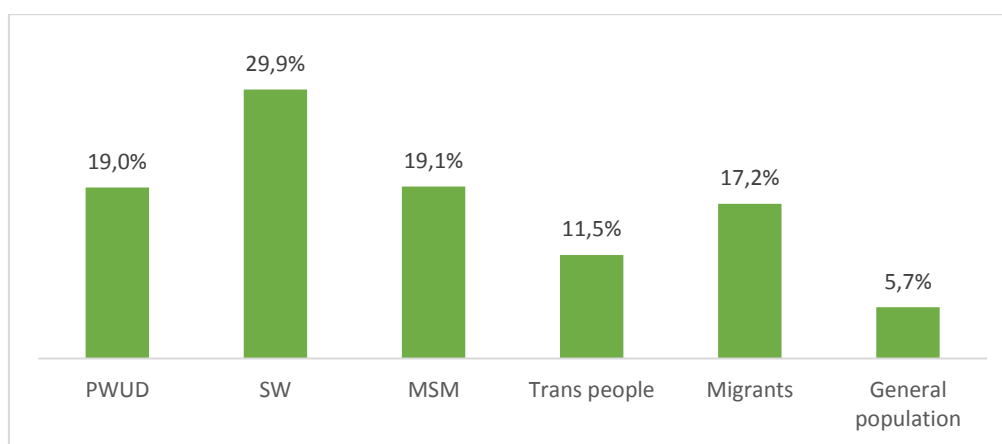


Fig. 3.35 Respondents who report situations of disrespect for their rights, according to each key and vulnerable population, %.

Concerning gender, women seem to be more likely to experience these situations of disrespect for their rights than men (17% of women vs. 13% of men refer to at least one of these situations).

Analysing data by age groups and the number of years living with HIV, situations of violation of rights are more reported by respondents between 30 and 49 years of age and by those living with HIV for a longer period of time (*Figures 3.36 and 3.37*).

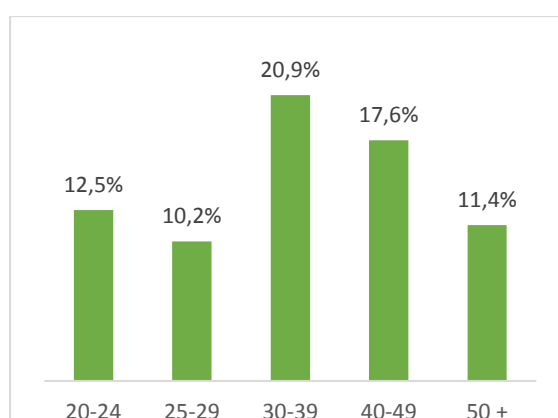


Fig. 3.36 Respondents reporting at least one situation where their rights were not respected, by age group, %.

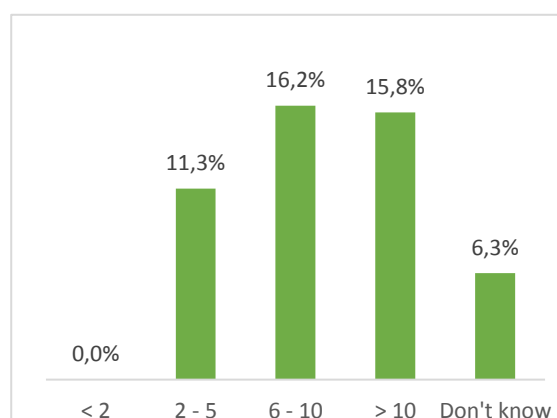


Fig. 3.37 Respondents reporting at least one situation where their rights were not respected, by number of years living with HIV, %.

Only 7 of the 38 people, who reported some situations of violation of rights in the last 12 months, had adopted some procedures in response to what had happened; namely, two had filed a complaint, two had publicized the situation, one had contacted a governmental entity, and one contacted a support organization for people living with HIV. In only one case, the respondent mentioned that the issue was resolved after the procedure he had taken, with 5 stating that nothing happened or that the problem was not resolved.

81% (N=26) of the people who experienced situations of violation of rights in the last 12 months did not adopt any action. The main reasons given were not knowing where to turn or what to do (9 out of 26), followed by having little conviction that the process would have

a positive outcome (4 out of 26), feeling intimidated or afraid to act (3 out of 26), and not wanting to risk having their HIV status revealed (3 out of 26).

Most respondents seem not only to be unaware of where they can turn to in the event of a violation of their rights but are even unaware of the existence of national laws to protect people living with HIV from discrimination (57%), with only 43% saying that they know of the existence of such laws.

To combat stigma and discrimination, the actions taken the most mentioned by respondents are supporting other PLHIV, either by giving them emotional, financial, or other support to help them deal with a situation of stigma and discrimination (8.3% [N=89] in the last 12 months and 19% [N=205] beyond last 12 months) or confronting or informing those who discriminated against them (8.2% [N=88] in the previous 12 months and 19.1% [N=206] more than 12 months ago). Interestingly, the number of actions taken decreases when discrimination is done against oneself (4.7% [N=51] confronted or informed someone who discriminated against them in the last 12 months and 11.4% [N=123] more than 12 months ago). The other actions, which imply greater and more public exposure, are less mentioned (*Figure 3.38*).

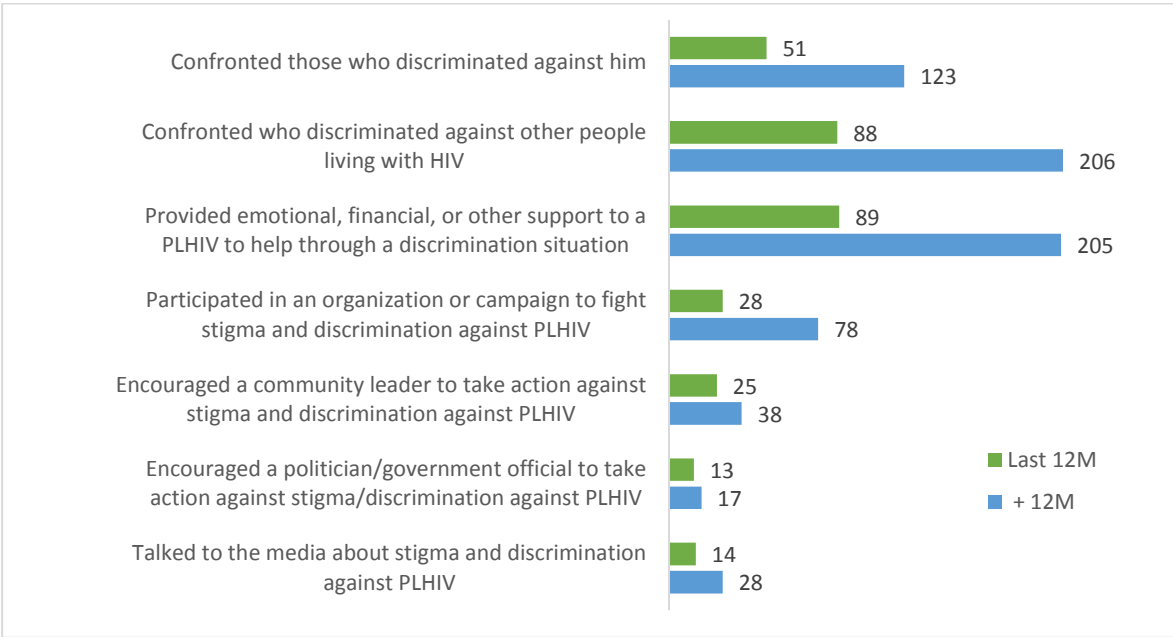


Fig. 3.38 Number of respondents who report having carried out actions to combat stigma and discrimination in the last 12 months and in the previous period.

3.7. Section G: Stigma and Discrimination for non-HIV reasons

Many people living with HIV belong to vulnerable populations which are also stigmatized. The accumulation of vulnerability factors may, therefore, expose them to further discrimination, which is why it is essential to explore the stigma and discrimination experienced not because of HIV infection but by belonging to a specific key population. The key populations considered in this section are:

- **Transgender people:** Despite 26 people identifying themselves as transgender or having a sex assigned at birth different than their gender identity, only 8 respondents answered this sub-section. Of these, 7 reported at least one situation of discrimination due to their gender identity, with 2 reporting some discrimination in the last 12 months.
- **MSM/Gay:** 53 respondents (male) identify themselves as MSM (men who have sex with men) and 162 as gay/homosexual, in addition, 22 do not identify themselves as MSM or gay/homosexual (nor bisexual) but have had sex with other men. Thus, in total 237 respondents responded to this sub-section. Of these, 64.6% report at least one situation of discrimination for being gay/MSM, with 12.7% reporting some discrimination in the last 12 months.
- **WSW/Lesbian:** 6 participants (female) identify themselves as WSW (women who have sex with women) and 3 as lesbians, with, in addition to these, 18 who despite not identifying themselves with the categories described above (nor bisexual), have had sex with other women. Thus, 27 respondents were eligible to respond to this sub-section, however only 25 responded to questions about discriminatory situations. Of these, 6 (24%) reported at least one case of discrimination for being lesbian/WSW, with one participant reporting some situations of discrimination in the last 12 months.
- **Bisexual:** 31 male and 18 female participants identify themselves as bisexual. Of these, 28.6% reported at least one situation of discrimination for being bisexual, with 2 participants (4.1%) reporting some situation of discrimination in the last 12 months.
- **Sex workers (SW):** 177 respondents reported having had sex in exchange for money or other goods, and of these, 43 identify themselves as sex workers. However, only 129 people answered the questions regarding situations of discrimination. Of these, 45.7% report at least one case of discrimination for being/having been a sex worker, and 9.3% reported some situation of discrimination in the last 12 months.
- **People who use drugs (PWUD):** 405 respondents reported having injected or consumed drugs such as heroin, cocaine, or methamphetamines regularly, of which 356 identified themselves as drug users. However, only 391 people answered the questions regarding situations of discrimination. Of these, 76.7% reported at least one experience of discrimination for using/having used drugs, with 10% reporting some situation of discrimination in the last 12 months.

Considering the above, Transgender people, PWUD, MSM, followed by SW, are the respondents who most frequently reported having been the target of some discriminatory situations, both in general and in the last 12 months, for belonging to a key population¹⁴.

Analysing the various situations of discrimination questioned, the most frequently mentioned by respondents belonging to all populations (except transgender people) was being the target of negative or discriminatory comments by members of their family (considering the period before the last year, *Table 3.2*). It should be noted that 60% of PWUD, 42% of MSM, and 31% of SW who answered this question mentioned this situation. In addition, being verbally abused and being excluded from family activities were also frequently mentioned. 71% of Transgender people and 36% of MSM who answered this question claimed to have been verbally abused (more than a year ago), with 51% of PWUD feeling excluded from family activities (*Table 3.2*).

Table 3.2. Discrimination situations experienced more than 12 months ago due to belonging to each key and vulnerable populations¹⁵

More than 12 months ago...	Trans	MSM/ Gay	WSW/ Lesbian	Bisex.	SW	PWUD
Felt excluded from family activities because of being...	3 (38%)	39 (17%)	0 (0%)	3 (6%)	31 (24%)	197 (51%)
Family members made negative comments about being ...	2 (25%)	100 (42%)	4 (16%)	8 (16%)	39 (31%)	232 (60%)
Were afraid to go to the health services because it was...	2 (29%)	15 (6%)	1 (4%)	1 (2%)	9 (7%)	80 (21%)
Avoided looking for health services for fear someone would find out ...	1 (14%)	9 (4%)	0 (0%)	0 (0%)	9 (7%)	80 (21%)
Was verbally assaulted for being...	5 (71%)	85 (36%)	4 (16%)	4 (8%)	30 (23%)	147 (38%)
Was blackmailed for being...	2 (29%)	20 (8%)	2 (8%)	1 (2%)	12 (9%)	47 (12%)
Was physically assaulted for being...	2 (29%)	40 (17%)	1 (4%)	1 (2%)	24 (19%)	67 (17%)

The same trend appears when considering the last 12 months, with 25% of Transgender people and 6% of PWUD reporting having been the target of negative or discriminatory comments by members of their family. Also, 8% of MSM and 7% of SW claimed to have been the target of verbal aggression (*table 3.3*).

¹⁴ It should be noted that the number of trans people who responded to this section was very low, so the percentages should be interpreted with caution, as well as possible inferences. The same goes for WSW/Lesbians and Bisexuals.

¹⁵ Only the individuals who responded to each option were counted to calculate the percentages.

Table 3.3. Situations of discrimination experienced in the last 12 months for belonging to each key and vulnerable populations¹⁶

In the past 12 months...	Trans	MSM/ Gay	WSW/ Lesbian	Bisex.	SW	PWUD
Felt excluded from family activities because of being...	1 (13%)	10 (4%)	0 (0%)	0 (0%)	2 (2%)	21 (5%)
Family members made negative comments about being ...	2 (25%)	11 (5%)	0 (0%)	2 (4%)	1 (1%)	23 (6%)
Were afraid to go to the health services because it was...	0 (0%)	2 (1%)	0 (0%)	0 (0%)	1 (1%)	12 (3%)
Avoided looking for health service for fear that they would find out ...	0 (0%)	3 (1%)	0 (0%)	0 (0%)	1 (1%)	7 (2%)
Was verbally assaulted for being...	1 (14%)	18 (8%)	1 (4%)	1 (2%)	9 (7%)	21 (5%)
Was blackmailed for being...	1 (14%)	2 (1%)	0 (0%)	1 (2%)	2 (2%)	6 (2%)
Was physically assaulted for being...	1 (14%)	2 (1%)	0 (0%)	1 (2%)	5 (4%)	8 (2%)

Transgender people, MSM, Bisexual, and PWUD respondents reported that, in general, other people from the same vulnerable population and family members or friends know that they belong to that vulnerable population (with percentages ranging between 74% and 92%, see *Table 3.4*). These percentages are lower for SW and WSW. Knowledge by other people in the community, on the other hand, is higher in the case of transgender people and PWUD (where 75% of the former and 72% of the latter state that other people in their community know that they belong to this vulnerable population, *Table 3.4*).

Table 3.4. People who know that the respondent belongs to each key and vulnerable populations¹⁶

The following people know who are/was...	Trans	MSM/gay	WSW/ Lesbian	Bisex.	SW	PWUD
Other people of this vulnerable pop.	6 (75%)	208 (89%)	12 (46%)	37 (77%)	79 (59%)	362 (92%)
Family or friends	7 (88%)	204 (87%)	11 (42%)	36 (74%)	58 (43%)	352 (90%)
Other people in the community	6 (75%)	132 (57%)	5 (19%)	23 (49%)	37 (28%)	283 (72%)

PWUD are the respondents who most often report belonging to a network or support group for the respective vulnerable population, in this case, people who use drugs (32% of PWUD belong to a PWUD support group). WSW is the only population in which no participant reported belonging to a network or support group for WSW (*Table 3.5*).

Table 3.5. Respondents who belong to a network or support group, for each key and vulnerable populations¹⁶

	Trans	MSM/gay	WSW/ Lesbian	Bisex.	SW	PWUD
Belongs to network/ support group	1 (11%)	30 (13%)	0 (0%)	4 (8%)	13 (10%)	131 (32%)

¹⁶ Only the individuals who responded to each option were counted to calculate the percentages.

4. Comparative analysis between the study results of 2013 and 2021

As mentioned in the introduction, one of the objectives of the current replication of the *PLHIV Stigma Index* study in Portugal is to assess the evolutionary trends of stigma and discrimination in our country. To this end, a comparison will be made of some results obtained in the *PLHIV Stigma Index* developed in 2013 with the one implemented in 2021/22. However, it should be noted that, as mentioned earlier, between 2018 and 2020, several changes were introduced to the study by the International Partnership, both in the questionnaire itself and in the data collection methodology, limiting the comparative analysis of results between the two studies carried out.

4.1. Sample Comparability

The number of valid surveys in the two periods is relatively similar, with 1 062 in 2013 and 1 095 in 2021.

The geographical areas covered were also roughly the same, despite the selection criteria being different, with more than 90% of respondents in both studies residing in the metropolitan areas of Lisbon, Porto, and Algarve. The main differences noted are the non-coverage of the Coimbra region in 2013 and the over-representation of the Porto metropolitan area (41% [N=435] in 2013 vs. 15% [N=167] in 2021), compared to coverage of Lisbon (52% [N=550] in 2013 vs. 69% [N=753] in 2021) and Algarve (2% [N=17] in 2013 vs. 9% [N=99] in 2021) (see *Figure 4.1*).

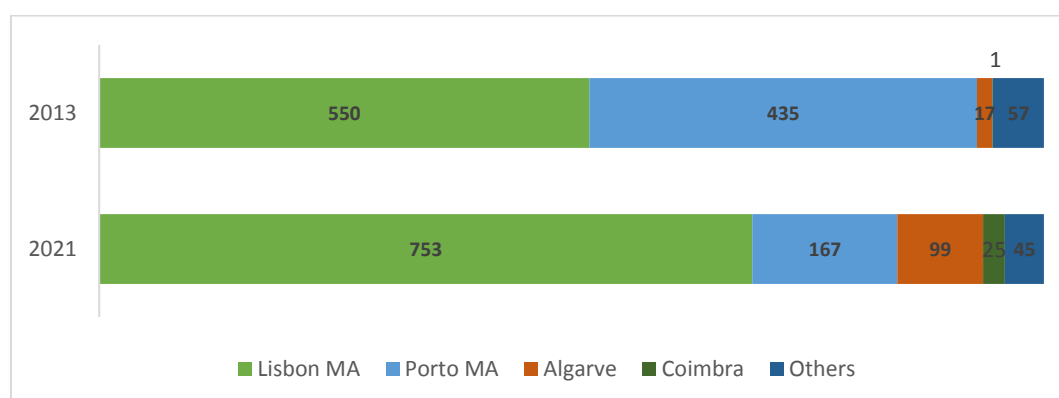


Fig. 4.1 Geographical distribution from the *PLHIV Stigma Index 2013* and *Stigma Index 2.0 2021* studies, according to the respondent's municipality of residence.

Concerning gender, it must be noted that this question was asked differently in the two studies, thus compromising their comparability. While in 2013, there was only one question corresponding to sex/gender, with three possible answers (*Male*, *Female*, and *Transgender*), in the 2021 questionnaire, there was a question regarding the sex assigned at birth and another regarding gender identity (where in addition to *Male*, *Female*, and *Transgender*, there were also 2 other response categories: *I do not identify as*

male, female or transgender and Prefer not to answer). According to the indications of the International Partnership of the *PLHIV Stigma Index*, in the 2021 edition, not only individuals who identified themselves as such were considered transgender, but all those whose gender identity differed from the sex assigned at birth, which may be the basis of the difference that can be observed between 2013 (with 7 respondents - 0.7% - who identified themselves as transgender) and 2021 (with 26 respondents - 2.4% - in this category, but in which only 8 - 0.7% - identify as such) (see *Figure 4.2*).

As for the ratio between men and women, it differs little between both samples, being slightly higher in 2013 (1.9, with 65% [N=695] men and 34% [N=360] women) than in 2021 (1.6, with 60% [N=648] men and 38% [N=409] women) (see *Figure 4.2*).

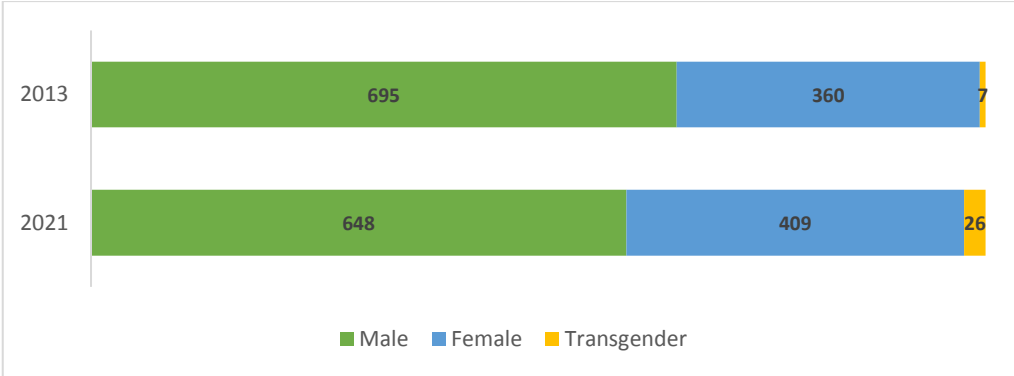


Fig. 4.2 Distribution of samples from the *PLHIV Stigma Index 2013* and *PLHIV Stigma Index 2.0 2021* studies, according to the gender of the respondents.

Regarding the age of the respondents, age groups are generally lower in the 2013 study compared to the 2021 study, in which about half of the respondents are aged 50 or over (compared to 26% in the 2013 study) (*Figure 4.3*). This fact may be related to the progressive ageing of people living with HIV in Portugal.

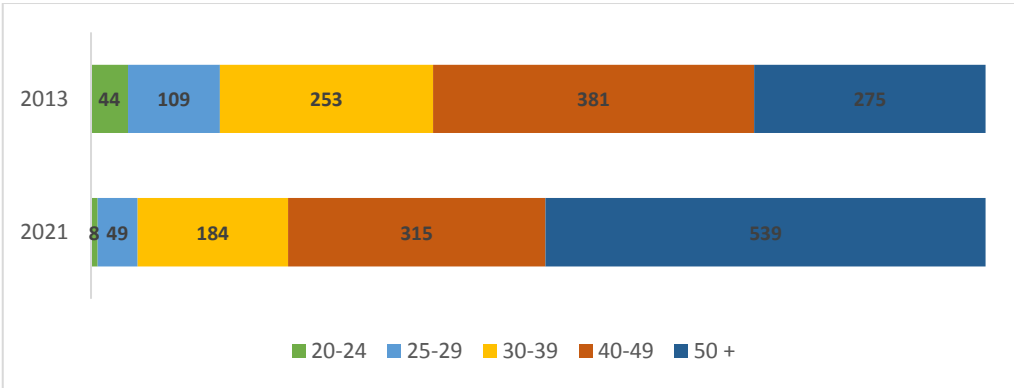


Fig. 4.3 Distribution from the *PLHIV Stigma Index 2013* and *PLHIV Stigma Index 2.0 2021* studies, according to the age of the respondents.

The older age of respondents in 2021 also seems to be reflected in the number of years they have been living with HIV, with 45% (N=491) acquiring the infection 15 or more years

ago in the most recent study (vs. 23% [N=239] in 2013 study), and 13% living with HIV for less than 4 years (vs. 29% in 2013) (see Figure 4.4).

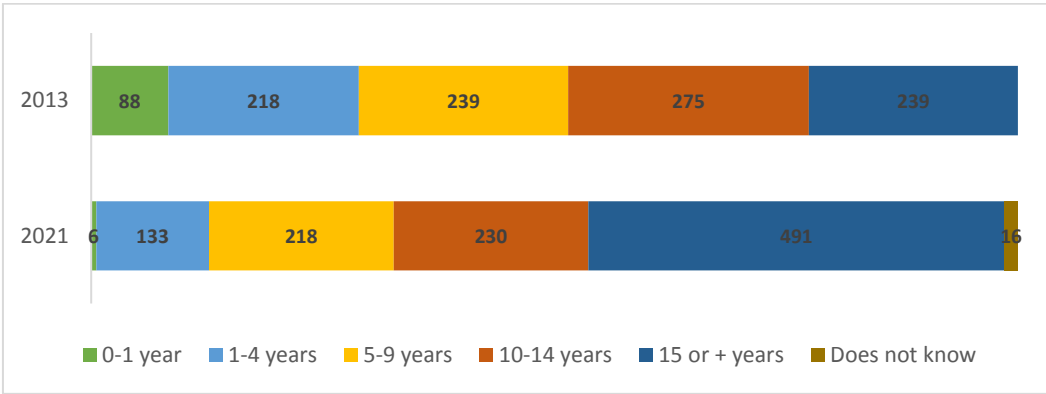


Fig. 4.4 Distribution from the PLHIV *Stigma Index 2013* and PLHIV *Stigma Index 2.0 2021* studies, according to the number of years that respondents have lived with HIV.

Analysing the level of education, it is not possible to identify a pattern between the 2013 and 2021 samples, since in the most recent study, despite the higher percentage of respondents with higher education (8% [N=85] in 2013 vs. 13% [N=141] in 2021), there are also more participants who only have primary/basic education (33% [N=352] in 2013 vs. 40% [N=440] in 2021) (see Figure 4.5). However, it is essential to note that in this question, there were some differences in the response categories, where in 2013 “primary education” was replaced in 2021 by “basic education or equivalent,” and where “technical education” in 2013 became “technical or professional education” in 2021 – those categories may not be considered equivalent by the participants, resulting in differences in the answers.

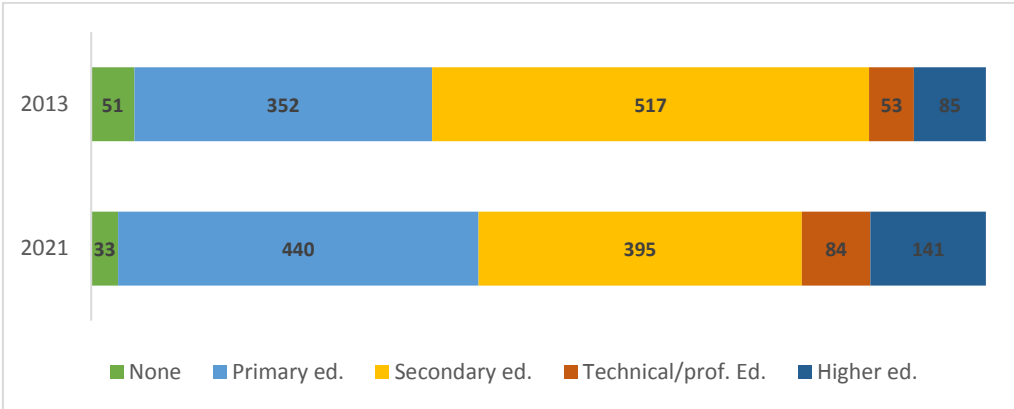


Fig. 4.5 Distribution from the PLHIV *Stigma Index 2013* and PLHIV *Stigma Index 2.0 2021* studies, according to the respondents' level of education.

Finally, it is important to note that the 2021 sample included more people belonging to (at least one) key and vulnerable population (73.0%) compared to the 2013 sample (60.5%). Such is reflected in the various vulnerable populations (with less expression in people who use drugs), all of them being more represented in the 2021 sample (see Figure 4.6).

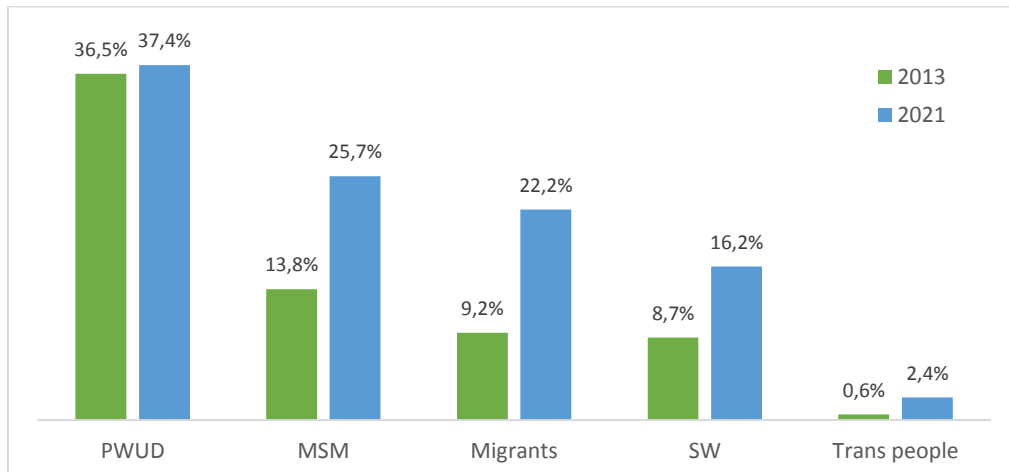


Fig. 4.6 Percentage of individuals belonging to each key and vulnerable population, in the 2013 and 2021 studies.

4.2. Experiences of Stigma and Discrimination

As already mentioned, the differences between the questionnaire applied in 2013 and 2021 are substantial, with some response categories in this section being different (and therefore not comparable). Moreover, even those that are similar and will be compared, still have some differences, both in the format of the questions and possible answers, as in the wording used. Hence, their comparability is relative and should be interpreted with caution.

Between 2013 and 2021 there was a significant decrease in the experiences of discrimination experienced in the last 12 months related to work (from 7% to 0.9% for denial of work or dismissal, and from 21.3% to 0.6% for changes in functions) (see *Figure 4.7*). Another response category that shows a significant decrease is related to discrimination against (respondent's) close family members, which drops from 7.9% to 1.1%.

The remaining differences are very low and not statistically significant. It should be noted, however, that in some cases, a slight increase in the percentage of respondents who report having experienced discriminatory situation in the last 12 months is observable, namely having been spoken badly about or made discriminatory comments for having HIV (up from 4.5% in 2013 to 5.7% in 2021) and being verbally abused (rises from 2.2% to 2.7%) (see *Figure 4.7*).

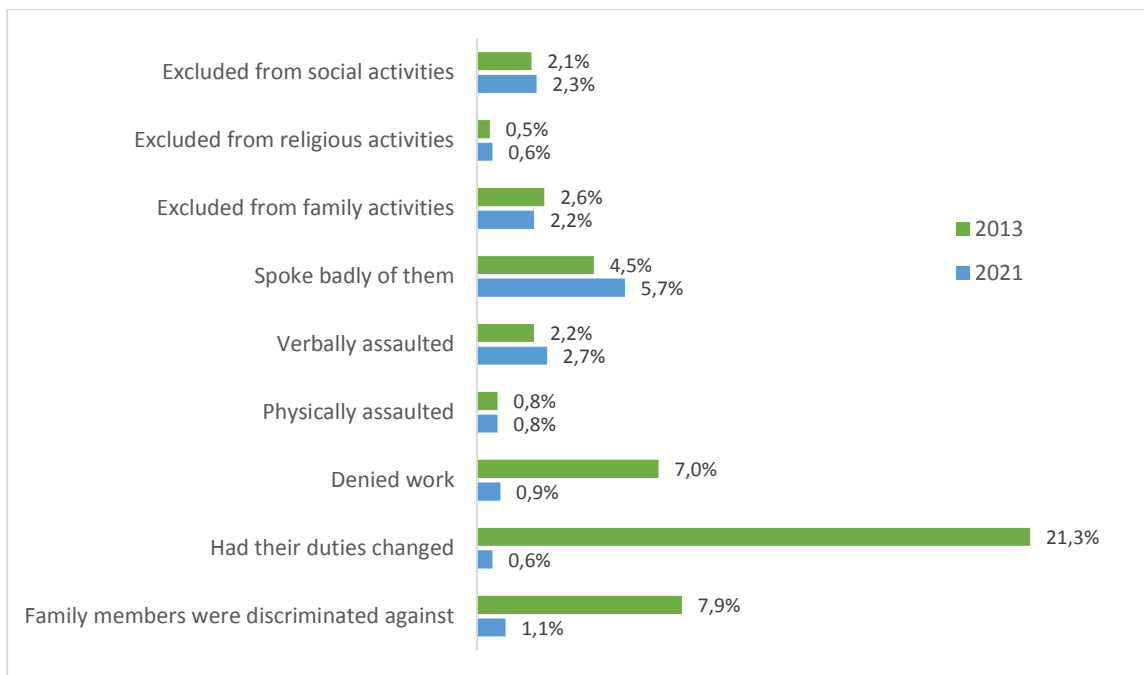


Fig. 4.7 Respondents reporting experiences of stigma and discrimination in the last 12 months, in the 2013 and 2021 studies, %.

Considering the percentage of respondents who report having been the target of at least one of these situations of discrimination in the last 12 months, a large and statistically significant decrease from 29.1% (in 2013) to 8.5 % (in 2021) is noted.

4.3. Internalized Stigma and Self-Discrimination

In the questions regarding internal stigma and self-discrimination, the differences between the 2013 and 2021 questionnaires are also accentuated, mainly concerning feelings associated with internalized stigma, in which only two response categories are comparable.

Regarding self-discrimination, there is a substantial and statistically significant decrease in almost all (comparable) response options, highlighting the decision not to participate in social events (decreased from 19.3% in 2013 to 8.7 % in 2021), avoiding going to health services (decreased from 16.5% in 2013 to 8.0% in 2021) and isolating from family and friends (down from 25.0% to 14.8%). The response option in which the difference was smaller (just over 1%, without significant differences) concerns the decision not to have sexual intercourse, becoming the main self-discrimination behaviour noted in 2021 (in 2013 appeared in 3rd place) (see *Figure 4.8*).

It should be noted that the percentage of respondents who indicated at least one of these self-discriminating behaviours also decreased significantly, from 48.7% in 2013 to 29.4% in 2021.

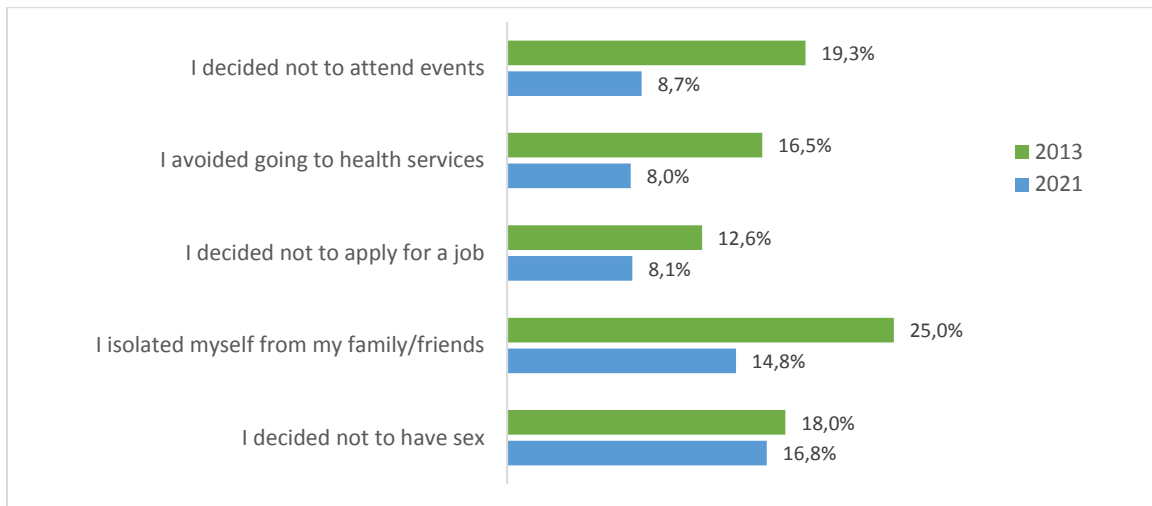


Fig. 4.8 Respondents who report some of the self-discrimination behaviours mentioned, in the last 12 months, in the 2013 and 2021 studies, %.

In terms of the two response options related to internalized stigma, where it is possible to make a comparison between the 2013 and 2021 studies, the same downward trend can be seen: from 55.5% to 30.5% for participants who reported feeling guilty for having HIV, and from 40.4% to 27.2% for those who mention shame for having HIV (statistically significant differences) (see *Figure 4.9*).

There is also a significant decrease in the percentage of respondents who experienced at least one of these negative feelings related to internalized stigma, from 67.5% (2013) to 40.4% (2021).

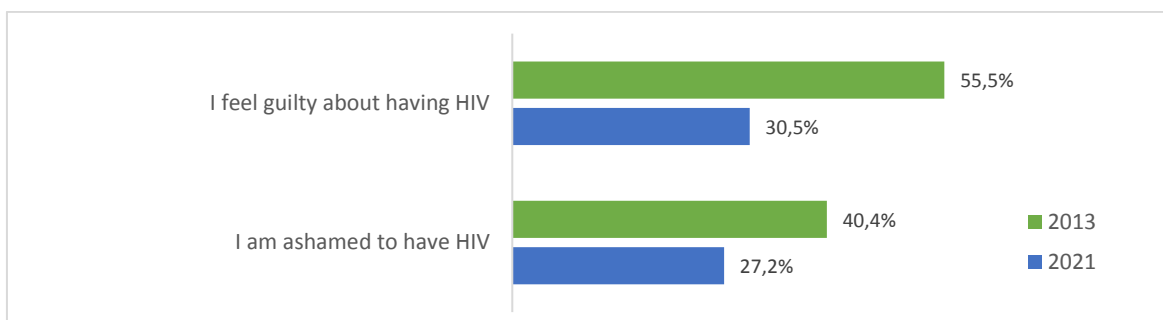


Fig. 4.9 Respondents reporting feelings of guilt or shame (internalized stigma), in the 2013 and 2021 studies, %.

4.4. Interaction with Health Services

Concerning the decision to take HIV test, a slight increase can be observed in the percentage of respondents who did it voluntarily, without any pressure from others (from 51.3% in 2013 to 53.9% in 2021). However, the increase in those who report that they were tested without their knowledge is even more substantial (rising from 21.9% in 2013 to 29.7% in 2021) (see *Figure 4.10*).

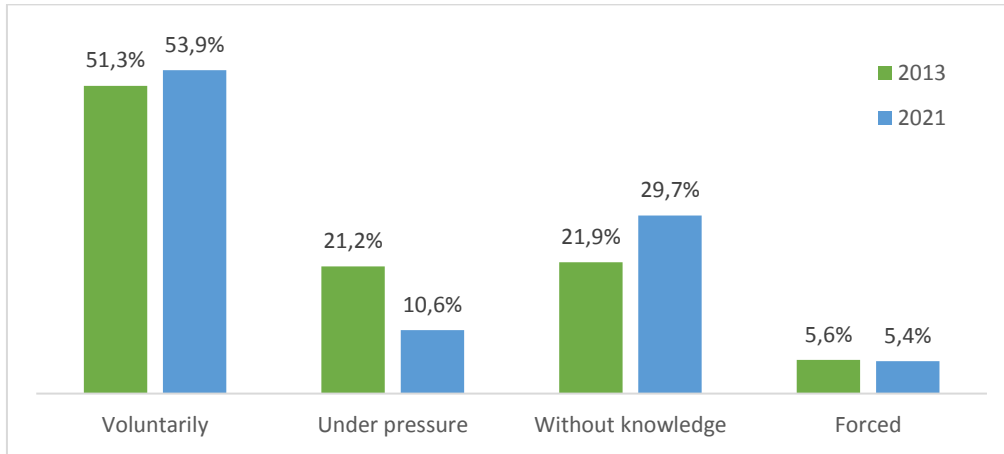


Fig. 4.10 Decision to take HIV test, in the 2013 and 2021 studies, %.

Regarding situations of discrimination experienced in the health services in the last 12 months (including sexual and reproductive health), there has been a decrease in all (comparable) options, with emphasis on issues related to pregnancy, childbirth, and breastfeeding that assume, in 2021, values below 1%. Denial of healthcare also dropped from 8.6% (in 2013) to 3.4% (in 2021). The exception is the conditioning of antiretroviral treatment to the use of a specific form of contraception, which increases from 2.9% to 4.4%, although this difference is not considered statistically significant (see *Figure 4.11*).

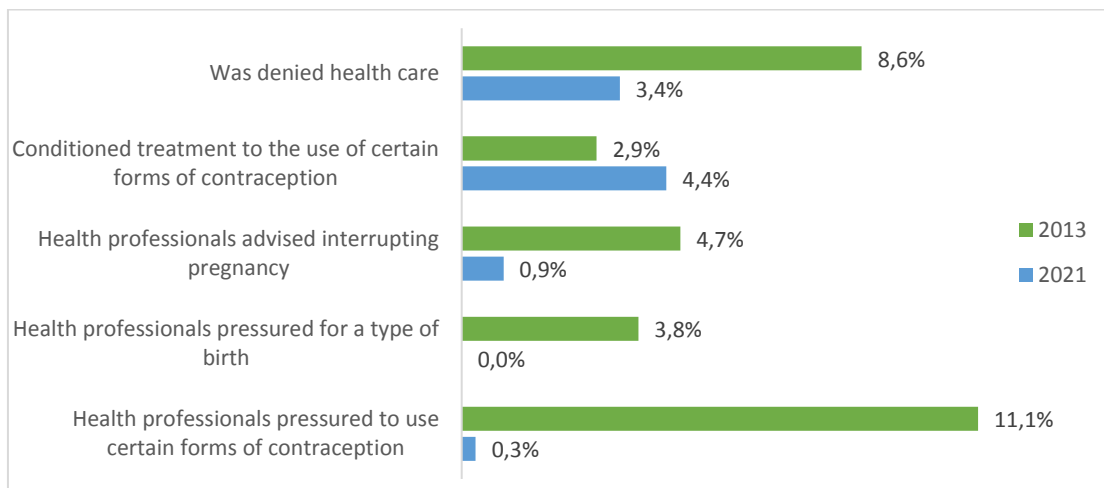


Fig. 4.11 Situations of discrimination experienced in health services in the last 12 months, in 2013 and 2021 studies, %.

Analysing the 5 situations together, the percentage of people who have been the target of at least one of the mentioned situations also shows a decrease, 11.3% in 2013 and 7% in 2021. Regarding the level of confidentiality, there is an increase in respondents who state that their medical records were not kept confidential (from 5.3% in 2013 to 9.5% in 2021), and a decrease in those who say that confidentiality of their medical records was ensured (from 64.1% in 2013 to 43.8% in 2021).

4.5. Human Rights and Effective Change

As in the previous sections, in terms of situations of rights violation that are comparable between the 2013 and 2021 studies, there was a decrease in cases of rights violations (due to HIV) experienced in the last 12 months. Although these questions in 2013 present relatively low percentages, in 2021, the value of all response options is equal to or less than 1% (see *Figure 4.12*). Even so, it is essential to mention that the most marked option, both in 2013 and in 2021, is the denial of health or life insurance due to the HIV status.

Analysing globally, the percentage of people who identified at least one of these situations of violation of their rights in the last 12 months decreased from 6.2% (N=66) in 2013 to 1% (N=11) in 2021.

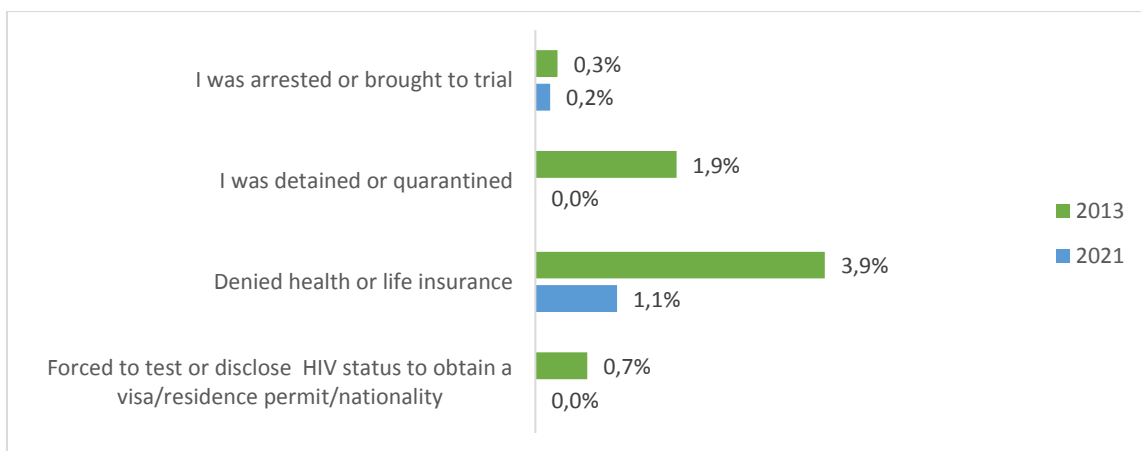


Fig. 4.12 Situations of violation of rights in the last 12 months, in the 2013 and 2021 studies, %.

On the other hand, of the people who experienced situations of disrespect for their rights in the last 12 months, the percentage of those who took some action decreased (from 32.1% [N=18] in 2013 to 19.4% [N= 7] in 2021), having also decreased for those who stated that the issue has been resolved (17.6% [N=3] in 2013 to 14.3% [N=1] in 2021), and increased for those who claimed that nothing happened (17.6% [N=3] in 2013 to 71.4% [N=5] in 2021).

Regarding actions taken to deal with situations of stigma and discrimination, three response options are comparable between the 2013 and 2021 studies, and all of them were mentioned less often in the current 2021 study, as can be observed in *Figure 4.13*.

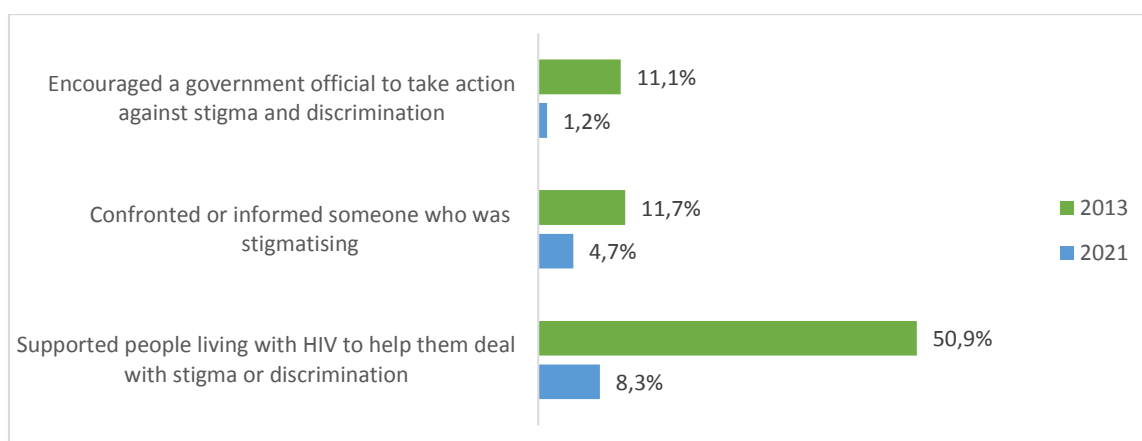


Fig. 4.13 Actions taken regarding stigma and discrimination in the last 12 months, in the 2013 and 2021 studies, %.

5. Discussion

Conducting the *PLHIV Stigma Index 2.0* in 2021/22 in Portugal made it possible to measure the stigma and discrimination experienced by PLHIV in this country and assess the evolutionary trend of these phenomena, with the goal of advocating for the defence and promotion of their rights.

The **sample** collected from 1 095 questionnaires approximates the distribution of HIV cases notified in Portugal in terms of geographic distribution and gender (despite some underrepresentation of the metropolitan area of Porto and males), seeking to ensure representativeness concerning PLHIV over 18 years old and residing in this country. The key populations (MSM; SW; PWUD; Transgender people) and vulnerable groups (immigrants/ethnic minorities) which are often subject to higher levels of discrimination, are represented in the sample, making up 73% of respondents, many of them accumulating several vulnerability factors. This vulnerability is also reflected in some indicators that seem to show a lower socioeconomic level than the average of the Portuguese population, with more unfavourable levels of education, unemployment, and financial difficulties. Also of note is the advanced age level of the respondents (half aged 50 years or more, and 60% living with HIV for more than 10 years), which may reflect the progressive ageing of people living with HIV in Portugal.

The **disclosure of HIV status** remains a sensitive issue (12% did not tell anyone), usually only shared with people in the closest circle, with the reaction of people less close rarely perceived as positive (34%). However, situations in which information was shared without the person's consent persist, being reported by 16% of respondents.

From 2013 to 2021 there seems to have been a decrease of **experiences of social stigma and discrimination**, with a significant reduction (from 29% to 8.5%) in the number of people reporting having been the target of any of the situations described (and comparable between both studies) in the last 12 months. However, it must be considered that the

decrease may have been influenced by the decline in social interactions in the previous 2 years due to the COVID-19 pandemic. Nevertheless, it cannot be denied that social discrimination continues to be a relevant issue, having already been felt by 38% of the respondents, manifesting mainly in discriminatory comments and verbal aggression. It disproportionately affects people belonging to key populations (especially SW, transgender, and PWUD) and women. Regarding additional questions, 7% of respondents have already been denied life or health insurance due to their HIV status and many may have never faced this situation because they chose not to reveal this information when applying for life or health insurance. It should be noted that in 2021, Law No. 75/2021, of November 18 was approved¹⁷, which prohibits discriminatory practices in accessing credit and insurance contracts by people who have overcome or mitigated situations of aggravated health risk, so it is expected that this discriminatory practice will cease in the coming years. Nevertheless, it is important to continue to monitor this issue.

Despite respondents living with HIV for many years, the impact of HIV continues to be felt, both positively (namely in the ability to contribute to the community [27.4%]) and negatively (essentially in the ability to deal with stress [25%] and falling in love [20.7%]). Some aspects of **internalized stigma** show a downward trend (comparing to 2013 study), but globally it is still very high (90.5% of participants identified at least one manifestation of internalized stigma, namely the difficulty in disclosing their serological status to others, and/or feelings of guilt and shame), often leading to **self-discriminatory behaviours** (30% reported some self-discriminatory behaviour in the last 12 months, namely not having sex and/or isolating themselves from family and friends). These feelings are more present in some key and vulnerable populations (immigrants, SW, and transgender people) and women. It should be highlighted that internalized stigma and self-discrimination may have important consequences, not only in terms of the suffering they cause to the individual (note that 29% of respondents report having been diagnosed with a mental health problem in the last 12 months, a situation that may be related to the stigma and discrimination to which they are subjected and the internalization of these feelings), but also in relation to the prevention-treatment continuum, which is an important aspect in the fight against the epidemic.

Considering the impact these issues have on **HIV testing and treatment**, for almost half of the respondents (46%), the test was not entirely voluntary (those who were tested without their knowledge increased from 22% to 30%, from 2013 to 2021), and 12% reported having avoided doing so for fear of other people's reactions, which could be one of the underlying causes of the high number of late diagnoses that exist in Portugal (DGS & INSA, 2022)¹⁸. Also, in terms of treatment, 33% postponed or avoided receiving it for reasons related to stigma and discrimination, and 15% missed a dose of ART in the last 12 months for fear that someone would find out about their serological status.

Discrimination **in health services** seems to have decreased since 2013, with a drop from 11% to 7% of respondents who report having been the target of one of the mentioned situations (and comparable between the two studies) in the last 12 months. However, analysing all the response options in the 2021 study referring to discrimination in health

¹⁷ Available at https://www.pgdlisboa.pt/leis/lei_mostra_articulado.php?nid=3478&tabela=leis&so_miolo=

¹⁸ 55.4% of late diagnoses in 2020/21

settings (and not just the comparable ones), 22% of respondents report some situation of discrimination in the last 12 months by healthcare professionals, whether in specific HIV services, in sexual and reproductive health services, or in other health services, which is a very expressive value. As with social discrimination, discrimination in healthcare settings disproportionately affects some key populations (SW and PWUD) and women. Discrimination situations are more frequently reported in non-HIV-related health services (16%) than in the context of HIV-related appointments and tests (11%). However, this number may be underestimated since 49% of participants say they usually do not disclose their HIV status in non-HIV health services. The most mentioned situation is of healthcare professionals avoiding physical contact or taking extreme precautions (6% in HIV-related services and 11% in non-HIV-related services), with 4% of respondents reporting that their serological status was revealed to others without their consent. The issue of **confidentiality** seems to have worsened from 2013 to 2021, with an increase in respondents who report that their medical records were not kept confidential (from 5.3% in 2013 to 9.5% in 2021). Concerning **sexual and reproductive health**, 7% of respondents identify some situations of discrimination in the context of family planning in the last 12 months, and 27% of women claim to have already suffered pressure concerning pregnancy, childbirth, and breastfeeding. In this regard, it should be noted that, in the last 12 months, 4% of respondents reported having been advised (by healthcare professionals in the area of HIV) not to have sexual intercourse, 4% not to have children, and 3 women were advised to interrupt pregnancy, which may indicate that the U=U message¹⁹ and the current state of art in monitoring pregnancy are not yet sufficiently disseminated and internalized by healthcare professionals, even those working in HIV.

Situations of **violation of rights** seem to be rarer than those of discrimination, being reported by 15% of respondents, and being more frequent in key populations (namely SW, PWUD, and MSM) and women, with the most reported situation being that of having been forced to have sex (3.2%). Considering the last 12 months, the percentage of respondents who claim that their rights have not been respected is 3.5%, essentially referring to the obligation to disclose the HIV status in various contexts, with a visible decrease for the response options comparable between 2013 and 2021 (from 6.2% to 1%). The assertiveness of people in defending their rights is low (having decreased between 2013 and 2021), with the vast majority of respondents who experienced situations of violation of rights in the last 12 months not taking any action (81%), essentially because they don't know where to turn for help or what to do. As this could be one of the primary vehicles for change in terms of stigma and discrimination, it is urgent to empower people living with HIV to defend their rights, as well as to publicize and facilitate the forms of filing a complaint and increase the efficiency of mechanisms for controlling the application of the law and sanctions in cases where the law is not respected.

This questionnaire also made it possible to assess intersectionality since many people living with HIV also belong to one or more key populations, thus accumulating vulnerability factors, and may therefore be exposed to increased situations of discrimination. This issue,

¹⁹ Undetectable=Untransmittable; a message reflecting scientific evidence that someone with HIV with an undetectable viral load for at least 6 months does not transmit the infection through sexual contact. For more information, see <https://unaids.org.br/2018/07/indetectavel-intransmissivel/>

which is visible in the analysis of some categories of the questionnaire, becomes clearer in the last section, which aims to assess the **stigma and discrimination suffered for reasons unrelated to HIV status**. Here we can see that Transgender people, PWUD, and MSM are the ones who most report being discriminated against, as they belong to key populations. It should be noted, however, that these are also the populations that most frequently report that people (from the same vulnerable population, family members or friends, and other people in the community) know that they belong to that key population. In other words, people who do sex work may not be so discriminated against because most people in their social network don't know it.

It should be noted that this section did not have questions for migrants or people belonging to an ethnic minority, so there is no information on this specific vulnerability factor. On the other hand, the small number of transgender people covered in the study makes it difficult to disaggregate the data and generalize the results, so investing in future studies specific to these two sub-populations could be interesting. People living with HIV who are not on treatment are also scarce in the sample, which may be related to the fact that the vast majority were recruited in hospitals and CSOs (where one of the main objectives is to link people to health care). It would therefore be interesting for future studies to focus on this sub-population and try to understand the role of stigma and discrimination in withdrawing from healthcare.

On the other hand, the strengths of this study include: the use of an international standard methodology and instrument, which have therefore already been tested and validated, as well as the high number of people in the sample and the good representativeness of most vulnerable populations.

6. Recommendations

As previously mentioned, one of the objectives of developing the *PLHIV Stigma Index 2.0* is to create evidence to support the development of programs and projects in the field of discrimination, guiding policies, and programmatic interventions. Therefore, we provide some recommendations to key actors whose actions can have a significant influence on eliminating the HIV-related stigma and discrimination that still exists. It should be noted that many of these recommendations were already made when the first edition of the *PLHIV Stigma Index* was carried out in 2013 but were never put into practice.

Recommendations to the Parliament

1. **Review Law 46/2006, of August 28, on rights and discrimination, replacing "aggravated health risk" with "health condition" and including discrimination suffered in the family and social environment.**

The terminology used in the current law of "aggravated health risk" gives rise to the interpretation that PLHIV have an increased risk of death and health problems, which legitimizes situations of discrimination in some contexts, namely within the scope of life and health insurance. Thus, it would be more correct to change this terminology, expressly prohibiting discrimination based on the person's "health condition," this term being comprehensive and including any pathology. On the other hand, situations of discrimination that occur in the family and social sphere, which are among the most frequent, as can be seen from the results of this study, are not identified in the law as discriminatory practices, which end up legitimizing and perpetuating them. Therefore, its inclusion in this law would constitute an important instrument for protecting the rights of people living with HIV in these situations.

2. Reinforce the mandate of the INR – National Institute for Rehabilitation, for monitoring and acting in situations of discrimination based on health conditions.

Law 46/2006, of August 28, was created to punish discrimination based on disability and its application is monitored by INR. However, this body is essentially dedicated to issues related to disability, with discrimination occurring on other health grounds being neglected. Therefore, it would be important to reinforce the mandate of INR for these cases, including the fight against discrimination in its main objectives (and even in its name) and defining in its competencies the opening of investigations and the issuing of opinions in situations of discrimination. In this sense, it would be helpful to reinforce the obligation to inform the INR in case of discrimination, including in Law 34/2007 of February 15, and sanction those who do not do so. On the other hand, for better surveillance and monitoring of the situation, it is suggested that the INR's Annual Report disaggregates the discrimination complaints, according to the cause and type of discrimination suffered.

Recommendations to the Government, DGS, and PNISTVIH

3. Regulate Law No. 75/2021, of November 18, which prohibits discriminatory practices when accessing credit and insurance contracts.

In November 2021, Law n. º 75/2021 was approved, prohibiting discriminatory practices in accessing credit and insurance contracts by people who have overcome or mitigated situations of aggravated health risk, which may include many people living with HIV. However, despite the law's approval, these situations persist, with insurers claiming that, as this is a differentiated clinical situation, the refusal or increase of insurance is not considered a discriminatory practice, since the person has HIV infection. The regulation of this law and the drafting of the National Agreement on Access to Credit and Insurance provided for therein may clarify the situations covered by the law through a reference grid that defines the terms and deadlines for each pathology or disability, in line with therapeutic progress and existing scientific data.

4. Define the fight against stigma and discrimination as a priority intervention in the next PNISTVIH Action Plan and include a budget allocation for this area.

The creation of the Priority Program for Sexually Transmitted Infections and HIV Infection (PNISTVIH), which replaced the previous National Program for HIV Infection and AIDS, implied the definition of the attributions of the new Program, which states (point j) *“Defending the rights of people living with HIV infection and eliminate barriers and discrimination in public institutions and services.”* Combating stigma and discrimination is also foreseen in the vision, goals, and priority actions of the new PNISTVIH Action Plan²⁰, which indicates that these issues will be given more relevance in the near future. Therefore, it is crucial to ensure that concrete actions are defined to combat stigma and discrimination, which prioritize the contexts in which situations of discrimination or violation of the rights of PLHIV occur more frequently (namely health services) and are mainly targeting the people most affected by these issues (people from vulnerable populations, and women). On the other hand, in addition to acknowledging the importance of this area, the budget allocation should be provided so that projects can effectively be developed and funded, in partnership with CSOs, in the fight against stigma and discrimination against people living with HIV.

5. Promote the dissemination of Law 46/2006, of August 28, on the rights of PLHIV and mechanisms for defending these rights.

As noted in this study, most people who experience discrimination end up not taking any steps to defend their rights, mainly because they do not know the law and do not know what to do or where to turn for help. It is of great importance to create mechanisms that allow the wide-scale dissemination of existing legislation on stigma and discrimination, the rights of PLHIV, and the resources available to support them in defending their rights.

6. Monitor, follow up, and act in situations of stigma and discrimination in the context of HIV infection.

PNISTVIH monitors and includes in its annual report the main data regarding the activities and results achieved at the national level in HIV area (e.g., screenings carried out, preventive materials distributed, etc.). It would also be essential to monitor (and include in the mentioned report) information regarding situations of stigma and discrimination that occurred at the national level each year. In addition to monitoring these situations, it would also be helpful particularly in more extreme cases involving structural issues (laws, regulations, etc.) to have direct intervention in issuing guidelines for each situation.

7. Ensure the right to sexual and reproductive health without discrimination.

As seen in this report, the situations experienced and reported in sexual and reproductive health demonstrate a need for training healthcare professionals to ensure compliance with the deontological code for the right to sexual and reproductive health without

²⁰Described in the Report “Infection by HIV in Portugal – 2022” (DGS & INSA, 2022)

discrimination, as it is an essential component of the universal right to the highest physical and mental health standard, enshrined in the Universal Declaration of Human Rights and other international conventions, declarations, and agreements. Note that sexual and reproductive health concerns both men and women.

8. Reactivate the Labour Platform against AIDS.

The initiative of the Labour Platform against AIDS²¹ mobilized, for the first time in Portugal, important actors in the field of HIV work who assumed commitments in terms of prevention, information, treatment, and non-discrimination of workers (or candidates) with HIV infection (expressed in the Code of Conduct "Companies and HIV"²²), having developed several training actions for its members and workers. However, despite this study showing some improvement in stigma and discrimination in the work context, these situations continue to exist and can significantly impact the lives of PLHIV. Thus, it would be of great importance to reactivate the Labour Platform against AIDS encouraging the reaffirmation of the commitment of former members and subscribers to the Code of Conduct and seeking the involvement of new members.

9. Define a periodicity for the replication of PLHIV *Stigma Index*, or other studies in the area of stigma and discrimination of PLHIV.

Since most situations of discrimination or violation of rights are not self-reported, the only way to understand the evolution of stigma and discrimination against people living with HIV is through the implementation of nationwide studies that assess this issue. Having already conducted the *PLHIV Stigma Index* in 2013 and 2021/22, it would be of great interest to define a periodicity (around 5 years is suggested) for it to be implemented again to analyse the evolution of stigma and discrimination in Portugal, allowing the redirection of policies and practices and the design of interventions aimed at areas where change is less favourable.

10. Review and amend the Armed Forces disability tables.

The regulations to access the Armed Forces and Maritime Police (subject to the Ministry of National Defence) continue to require HIV and viral hepatitis screening tests, tacitly excluding those with these infections. The Ombudsman has repeatedly pronounced the discriminatory nature of these regulations, calling for the adoption of solutions based on a case-by-case assessment of situations²³. Tables of unfitness and incapacity for service in the Armed Forces²⁴, drawn up in 1999, are the basis of this discriminatory provision. It is urgent to review and update those according to medical advances and current scientific knowledge in terms of treatment.

²¹More information at https://www.ilo.org/lisbon/publica%C3%A7%C3%B5es/WCMS_723256/lang--pt/index.htm

²²More information at https://www.ilo.org/lisbon/oit-e-portugal/WCMS_651171/lang--pt/index.htm

²³ Recommendation No. 32/B/1999 and Recommendation No. 7/B/2012 of the Ombudsman's Office

²⁴Constant in Ordinance no. 790/99 of September 7, available at <https://dre.pt/dre/detalhe/portaria/790-1999-581048>

Recommendations to Civil Society Organizations

11. Disseminate information to its users and beneficiaries about the rights of PLHIV, enabling them to act in situations of discrimination.

Due to their proximity to PLHIV, namely to more disadvantaged populations and those with less literacy and ability to defend their rights, CSOs are in a privileged position to provide these people with clear and accessible information on stigma and discrimination, supporting them, encouraging them, and enabling them to defend their rights.

12. Train all employees in stigma, discrimination, and rights of PLHIV.

Training CSO employees in the rights of PLHIV, stigma, and discrimination is essential for them to guide their professional conduct following the best ethical and deontological practices and know how to recognize and act in situations of discrimination.

13. Collect information and report incidents of discrimination that they are aware of to a central structure (CAD, PNISTVIH, or INR).

In addition to acting against discriminatory situations that they are aware of, it would be important that CSOs report these situations to a central structure (CAD, PNISTVIH, or INR). Only with a generalized reporting system it will be possible to monitor the frequency and scope of situations of discrimination annually.

14. Work on internalized stigma and self-discrimination with its users and beneficiaries

As can be seen from the study results, internalized stigma is still very present, being the cause of great suffering and isolation of PLHIV and constituting an important obstacle in the fight against this epidemic. Thus, it is recommended that CSOs develop mechanisms and strategies to reduce the internalized stigma and self-discrimination of their beneficiaries, whether through psychological support, self-help groups, peer support, or other programs.

Recommendations for Health Services

15. Train healthcare professionals in stigma, discrimination, and rights of PLHIV.

As health contexts are those where PLHIV most disclose their HIV status, and considering that it was the context in which most respondents reported having suffered discrimination in the last 12 months (22%), it is essential to invest in training of healthcare professionals (from all areas, services, and levels of care) so that they guide their professional conduct following the best ethical and deontological practices and according to current scientific evidence. This training should be an integral part of their initial training, and it should also be made available throughout their professional career.

16. Ensure the confidentiality and protection of users' personal data.

Despite the ethical principle of confidentiality appearing in all deontological codes of healthcare professionals and the protection of personal data being explicit in the legislation, this issue is still not respected. It is essential to make healthcare professionals aware of the fulfilment of these obligations and to create mechanisms that facilitate and supervise their application.

7. Conclusion

Although the results of this 2021 study seem to indicate a favourable evolution in terms of stigma and discrimination suffered by PLHIV in various contexts of their lives (comparing with 2013 results), stigma and discrimination remain very relevant issues in Portugal, especially in health services, disproportionately affecting people belonging to key populations (MSM; SW; PWUD and Transgender people) and vulnerable groups (immigrants/ethnic minorities and women). Still, some aspects like respecting the confidentiality of medical records and dealing with situations of discrimination, are worse, comparing with 2013 results. To change this reality is crucial that the recommendations made to parliament, government, CBOs and health services are followed.

Bibliography

- DGS & INSA. (2020). Infeção VIH e SIDA em Portugal – 2020. INSA. <http://repositorio.insa.pt/handle/10400.18/7243>
- DGS & INSA. (2022). Relatório Infeção por VIH em Portugal – 2022. INSA. <https://www.insa.min-saude.pt/relatorio-infecao-por-vih-em-portugal-2022/>
- DGS-Direção Geral da Saúde. (2018). INFEÇÃO VIH E SIDA: Desafios e Estratégias. In ARS Norte. DGS. https://www.arsnorte.min-saude.pt/wp-content/uploads/sites/3/2019/05/4.-RelatorioVIH_SIDA2018.pdf
- INE. (2020). Statistics Portugal - Web Portal. Retrieved July 2, 2020, from <http://www.ine.pt/>
- PORDATA. (2022a). População residente com idade entre 16 e 89 anos: total e por nível de escolaridade completo mais elevado. <https://www.pordata.pt/Portugal/Popula%C3%A7%C3%A3o+residente+with+age+between+16+and+89+years+total+e+por+n%20%C3%ADvel+of+education+complete+most+high-2101-169770>
- PORDATA. (2022b). Taxa de desemprego: total e por sexo (%). [https://www.pordata.pt/Portugal/Taxa+de+desemprego+total+e+por+sex+\(percentage\)-550](https://www.pordata.pt/Portugal/Taxa+de+desemprego+total+e+por+sex+(percentage)-550)
- Ser+ & GAT. (2014). The People living with HIV Stigma Index: Portugal 2013. In CAD-Centro Anti-Discriminação VIH. SER+, Associação Portuguesa para a Prevenção e Desafio à Sida. https://cad.vih.pt/wp-content/uploads/2019/12/stigma-index_portugal-final-report-1.pdf
- UNAIDS. (2010). UNAIDS 2011–2015 Strategy: Getting to zero. https://www.unaids.org/en/resources/documents/2010/20101221_JC2034_UNAIDS_Strategy
- UNAIDS. (2021). Global AIDS Strategy 2021-2026. <https://www.unaids.org/en/Global-AIDS-Strategy-2021-2026>
- UNAIDS. (2022). Global HIV & AIDS statistics — Fact sheet. <https://www.unaids.org/en/resources/fact-sheet>



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