



Associação Portuguesa para a Prevenção e Desafio à Sida  
Learning and Growing With All People Who Lives With HIV and AIDS

# GAT

Grupo Português de Activistas  
sobre Tratamentos de VIH/SIDA  
Pedro Santos



# PORTUGAL

# THE PEOPLE LIVING WITH HIV STIGMA INDEX

## 2013



# Portugal



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Website: [www.sermais.pt](http://www.sermais.pt)

Email: [sermais.org@sermais.pt](mailto:sermais.org@sermais.pt)

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# Acronyms

<b>ACM</b>	High Commission for Migration (formerly ACIDI, High Commission for Immigration and Intercultural Dialogue)
<b>ADIS/SIDA</b>	Support and Development for Intervention in AIDS Fund of PNIVS
<b>ART</b>	Antiretroviral therapy
<b>CAD</b>	Counselling and Early Detection Centre for HIV
<b>CIG</b>	Commission for Citizenship and Gender Equality
<b>CSO</b>	Civil Society Organisation
<b>DDI-URVE</b>	Department of Infectious Disease/Epidemiological Reference and Vigilance Unit
<b>FNSC</b>	National Civil Society Forum
<b>GAT</b>	Portuguese Group of Treatment Activists
<b>GIPA</b>	Greater Involvement of People Living with HIV
<b>GNP+</b>	Global Network of People Living with HIV
<b>ICW</b>	International Community of Women Living with HIV/AIDS
<b>INE</b>	National Statistical Institute
<b>INR</b>	National Institute for Rehabilitation
<b>INSA</b>	National health Institute (Doctor Ricardo Jorge)
<b>IPPF</b>	International Planned Parenthood Federation
<b>MIPA</b>	Meaningful Involvement of People Living with HIV and AIDS
<b>MSM</b>	Men who have sex with men
<b>NGO</b>	Non-Governmental Organisation
<b>PLHIV</b>	People living with HIV
<b>PNVIH/SIDA</b>	National Programme for HIV/AIDS
<b>PVT</b>	Prevention of Vertical Transmission (sometimes referred to as Mother-To-Child Transmission)
<b>SER+</b>	Portuguese Association for the Prevention and Challenge of HIV/AIDS
<b>UNAIDS</b>	Joint United Nations Programme on HIV/AIDS
<b>UNGASS</b>	United Nations General Assembly Special Session on HIV/AIDS

## Hospitals

<b>HC - CHLC</b>	Hospital dos Capuchos – Hospital Centre of Lisboa Centro
<b>HEM - CHLO</b>	Hospital Egas Moniz – Hospital Centre of Lisboa Ocidental
<b>HF</b>	Hospital of Faro EPE
<b>HGO</b>	Hospital Garcia da Orta
<b>HJU - CHP</b>	Hospital Joaquim Urbano – Hospital centre of Porto
<b>HPH - ULSM</b>	Hospital Pedro Hispano – Local Health Unit of Matosinhos
<b>HPP - HC</b>	HPP Hospital of Cascais, Dr. José de Almeida
<b>HPV - CHLN</b>	Hospital Pulido Valente – Hospital Centre of Lisboa Norte
<b>HSB - CHS</b>	Hospital de São Bernardo – Hospital Centre of Setúbal
<b>HSJ - CHSJ</b>	Hospital de São João – Hospital Centre of São João
<b>HSM - CHLN</b>	Hospital Santa Maria – Hospital Centre of Lisboa Norte
<b>HUC</b>	Hospital of University of Coimbra



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- ViiV Healthcare
- Gilead
- AbbVie

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# Contents

Acronyms .....	3
Acknowledgements .....	4
Contents .....	6
List of Charts and Tables .....	8
Executive Summary.....	9
Chapter 01 - Introduction .....	13
<b>The Stigma Index.....</b>	<b>13</b>
<b>Country Background.....</b>	<b>14</b>
<b>New Infections .....</b>	<b>14</b>
<b>AIDS related deaths.....</b>	<b>15</b>
<b>Discrimination cases.....</b>	<b>15</b>
<b>Legal Framework.....</b>	<b>16</b>
<b>Objectives of this study .....</b>	<b>17</b>
<b>Methodology .....</b>	<b>18</b>
GIPA & MIPA principles.....	18
Selection and training of the interviewers .....	18
Goals of the training program .....	18
<b>Site selection.....</b>	<b>19</b>
Hospitals and Hospitals Centres .....	19
Non-Governmental Organizations and Civil Society Organizations .....	20
Sample size.....	21
Statistical Analysis and Processing of Data.....	21
<b>Study limitations and challenges .....</b>	<b>22</b>
Hospital approvals .....	22
Variability of approval process and criteria .....	23
Retention of the interviewers.....	23
Sample bias .....	23
Chapter 2 – Background characteristics and household composition .....	25
<b>Gender.....</b>	<b>25</b>
<b>Age .....</b>	<b>26</b>
<b>Education level.....</b>	<b>26</b>
<b>Relationship status.....</b>	<b>27</b>
<b>Sexual activity .....</b>	<b>27</b>
<b>Employment situation .....</b>	<b>28</b>
Chapter 3 – Experience of stigma and discrimination.....	29
<b>Internalised Stigma and self-discrimination .....</b>	<b>29</b>
Self-evaluation of health status and communication with health professionals	30
<b>Access to ART and other treatments .....</b>	<b>30</b>

Discrimination complaints .....	30
Discrimination in education.....	30
Discrimination in the work place .....	31
Confidentiality in the work place .....	31
Reactions in the work place.....	31
Chapter 4 - Experience of testing, disclosure, treatment & having children .....	32
Reasons and decisions for HIV testing.....	32
Discrimination in health care services.....	32
Conclusions.....	34
Recommendations .....	37
Recommendations to Parliament .....	37
Recommendations to the Government.....	38
Recommendations to the National Program for HIV/AIDS Infection (PNIVS) ....	39
Recommendations to Civil Society Organizations (CSO) .....	39



# List of Charts and Tables

## Charts

Chart 1 – Notifications and diagnosis per year* .....	14
Chart 2 – AIDS related deaths* .....	15
Chart 3 –HIV-related discrimination complaints per year – INR and CAD .....	16
Chart 4 – Distribution of notified cases accordingly to region, infection stage, gender & age .....	24
Chart 5 – Gender distribution .....	25
Chart 6 – Age distribution of sample .....	26
Chart 7 – Education level by gender .....	26
Chart 8 – Relationship status by gender.....	27
Chart 9 – Years of relationship, by gender .....	27
Chart 10 – Sexually active by gender .....	28
Chart 11 – Employment situation .....	28
Chart 12 – Internalised stigma and self-discrimination.....	29
Chart 13 – Denial of health care due to HIV status .....	33
Chart 14 - Incidents of discrimination reported.....	34

## Tables

Table 1 – Selected Hospital Centres and Hospitals .....	20
Table 2 – Margin of error and sample size .....	21





## Executive Summary

HIV-related stigma and discrimination are widely recognized as major barriers to accessing HIV prevention, care, treatment, and support services. The purpose of this study is to collect information on stigma and discrimination experienced by People Living with HIV (PLHIV) in Portugal, and contribute to an evidence base for advocacy, change and programmatic intervention to address HIV-related stigma and discrimination.

The report quantifies the number, type and degree of stigma and discrimination situations experienced by PLHIV in Portugal in the various environments in which they live - family, social, employment, education, health care and social support, and access to public and private services - as well as the level of knowledge about their rights and ways to defend them.

## Methodology

This study uses the *People Living with HIV Stigma Index Questionnaire* developed by GNP+, ICW, IPPF and UNAIDS to conduct interviews, following the accompanying standard methodology. Interviewees were recruited through various civil society organizations (CSO), non-governmental organizations (NGO), and at HIV hospital clinics. Interviewers were themselves PLHIV. The study was conducted in 2013, beginning in mid-March. Approximately 1,060 in-depth interviews were conducted in various locations around the country.

## Major Findings

### Internal Stigma and self-discrimination

The large majority of respondents are self-accusing or feel responsible for their HIV status. Women are twice as likely as men to express a tendency to suicide (31% females to 16% males). As a result of HIV status, the majority of respondents have decided not to have children. Combined with social and familial isolation, these factors impact negatively on work and health outcomes.

### Self-evaluation of health status and communication with health professionals

Almost two-thirds of respondents report a positive state of health (33% very good and 30% good). Over one third (36%) of those who did not experience internal stigma rated their health as excellent or very good, compared to just 27% of those who did experience internal stigma.

# Stigma Index



Good communication with health professionals also correlates with positive outcomes, as shown by an increasing number of years of infection and a decrease of contacts.

## Access to ART and other treatments

There is a direct relationship between access to antiretroviral therapy (ART) and increasing age level, indicating an almost unanimous ease of access to ART (99%), however 16% report lack of access to medication for opportunistic infections. Most women who wished to have children (82%) had access to ART as prevention of vertical transmission (PVT), and almost all (95%) had access to information about healthy pregnancy and motherhood.

## Discrimination complaints

Most PLHIV are unaware of their rights, legislation and defense mechanisms. Very few CSOs collect data in a systematic and comparable manner. They lack standard and efficient procedures to defend the rights of their clients. The INR merely registers discrimination complaints, with no proactive action taken on the evaluation of the complaint or the investigative procedures.

## Discrimination in education

While there were relatively few instances of discrimination in education reported, these are still worrisome due to the universal and protective nature that the educational context should provide. It should also be noted that in most cases teachers and/or institutions were unaware of the interviewee's health status (this was known in only 38 cases). Nonetheless during the previous year, 16 respondents reported having been forbidden to attend an educational institution, due to their HIV status. Two cases were also reported of respondents' children being denied access to an educational institution.

## Discrimination in the work place

Of the 97 respondents who were dismissed from their jobs, one third considered it due to their HIV status. An additional 56 respondents believed they were refused a job and 197 respondents had their job functions changed for the same reason.

## Confidentiality in the work place

More than 93% of respondents state that neither work colleagues, employers nor customers know their HIV status. However, 36% of respondents believe that a company may require employees to take an HIV test, and 12% believe that a company can administer an HIV test to employees without their knowledge.



## Reactions in the work place

Of those whose HIV status became known at their workplace, the majority felt supported by their colleagues, employers and customers. However 20% of these respondents report discriminatory or very discriminatory attitudes from their employers, 18% percent from clients and 13% from coworkers.

## Reasons and decisions for HIV testing

Slightly more than one quarter of the respondents (26%) stated that desire to know was their reason for obtaining an HIV test, while more than one fifth (22%) were tested due to suspicion of disease-related symptoms.

Slightly more than half of respondents (51%) were tested voluntarily, but almost 4 out of 10 (39%) did not receive pre- or post-counseling. There appeared to be a direct relationship between increasing age and mandatory testing or testing without knowledge. Over 70% of men who have sex with men (MSM) report voluntarily deciding to be tested. On the other hand, inmates report being tested without their knowledge about one third (35%) of the time, or undergoing mandatory testing another third (31%) of the time.

## Discrimination in health care services

79 respondents report being denied health care due to their HIV status. Intravenous drug users (IDU) report the highest rate of refusal of health services (13%), followed by men who have sex with men (MSM), transgender and sex workers. 147 respondents reported being advised not to have children (25% of women and 28% of sex workers), and 59 reported being pressured to undergo sterilization. Unlike in the workplace or school context, HIV status is known by professionals in 98% of healthcare interactions. Oftentimes, this is at the initiative and/or with consent of the PLHIV. Still, however respondents report discrimination in 3% of cases. Furthermore, 11% of respondents report that confidentiality regarding health information was violated without their consent, with 30% report not being sure if this happened. This situation is especially prevalent amongst inmates (18%) reporting this.

## Recommendations

This study culminates in a detailed list of recommendations to Parliament, Government, the National Program for HIV/AIDS Infection (PNVIHS) and Civil Society Organizations (CSO). Please refer to the full list in the body of this report for specific and concrete recommendations to these stakeholders and key players.

Summary of recommendations to Parliament and Government

# Stigma Index



- broaden the scope of existing antidiscrimination legislation
- increase transparency, equity and publicity of discrimination inquiries
- improve disaggregation and quality of data on discrimination complaints
- improve enforcement mechanism and impose penalties for non-compliance with investigation and reporting requirements of anti-discrimination legislation and regulations
- promote the wide dissemination of the law, rights of PLHIV, types of discrimination and ways to challenge discrimination
- increase effectiveness, efficiency and supervision of the inspection and/or regulatory entities
- address the obstacles and barriers to conducting multicenter studies involving social health units

## Summary of recommendations to the National Program for HIV/AIDS Infection (PNIVS)

- implement anti-discrimination training
- promote the wide dissemination of the law, rights of PLHIV, types of discrimination and ways to challenge discrimination
- initiate regular research studies of HIV and AIDS stigma and discrimination

## Summary of recommendations to Civil Society Organizations (CSO)

- collect data on discrimination in a systemized and uniform manner to facilitate the consolidation of this information and enable consistent monitoring of discrimination cases
- advocate with decision makers and public administration for more effective and efficient anti-discrimination programs and policies for PLHIV.



## Chapter 01 - Introduction

### The Stigma Index

The People living with HIV (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/AIDS (ICW), the International Planned Parenthood Federation (IPPF), and the Joint United Nations Programme on HIV/AIDS (UNAIDS).

Those organizations have been working together since 2005 developing a methodology and the content of a survey that can be applied globally to measure, evaluate and compare the levels of stigma and discrimination towards People Living with HIV (PLHIV) in different countries or regions.

The Index allows for the systematic study of stigma, discrimination and rights of PLHIV—what forms and to what degree they exist in different countries. The Index contributes to promoting those rights and fighting discrimination and should be used as an advocacy tool for better legislation and regulation protecting rights and challenging discrimination.

The Anti-Discrimination Centre, a joint initiative of SER+ and GAT, supported by the ADIS/SIDA funding program of the National Program for HIV/AIDS Infection (PNIVS), addresses the issues of HIV/AIDS related stigma and discrimination in Portugal, and supports PLHIV subject to discrimination. Given the lack of accurate quantified data on this subject in Portugal, the Centre applied to use the stigma index, organizing the survey and data treatment in accordance with all study specifications. This Report reflects the process and results of the study.

This study was conducted by PLHIV using a participative methodology. Interviewers collected data to measure the level, number, type and degree of HIV/AIDS related stigma and discrimination in Portugal; to fill the gaps and deficiencies in official reports; as well as document the social and personal impact; and the level of knowledge and trust about rights and means of protection of those rights.

The study was coordinated by an Executive Committee that included Dr. António Diniz, the head of the National HIV/AIDS Program; Dr. Diana Vicente, researcher at the Law School of Lisbon New University; and Dr. Pedro Silvério Marques, coordinator of Anti-Discrimination Centre

# Stigma Index



Scientific and methodological guidance was provided by an Advisory Board that included Andreia Pinto Ferreira, General Coordinator of SER+, Luís Mendão, Chair of the Board of GAT, Ricardo Baptista Leite, MP, member of the Parliament Health Commission and Coordinator of the All-Party Working Group on HIV-AIDS, and Maria do Céu Rueff, from the Centre of Biomedical Law of the Coimbra University and member of the Ethics Commission of the Medical School from the Lisbon University.

## Country Background

The UNAIDS 2010/2014 Program states that for effective control of the HIV epidemic we need to attain 3 ZEROS:

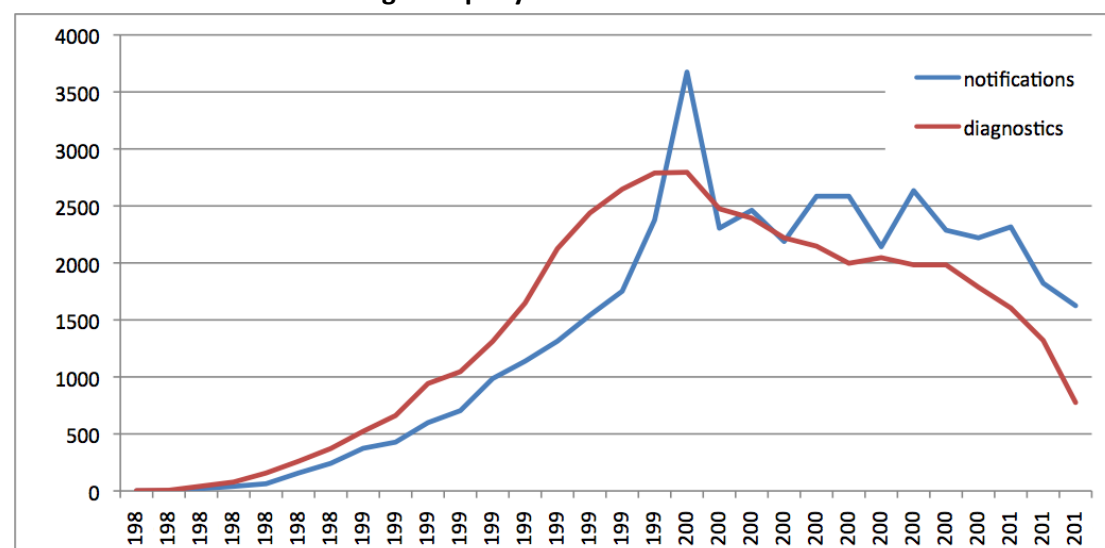
- ZERO new infections
- ZERO AIDS related deaths and
- ZERO discrimination cases.

The well-known limitations and deficiencies of the epidemiologic monitoring system and delays in notification and sub-notification create some difficulties in measuring the evolution of HIV/AIDS incidence and prevalence rates. However, broad patterns can be detected.

## New Infections

Accordingly to the figures published by the National Health Institute's (INSA) Department of Infectious Diseases—Reference and Epidemiological Vigilance Unit (DDI-URVE), the number of cases notified and diagnosed per year is shown in the following chart. It shows a levelling of new diagnosis in the last decade, around 2.000 per year and also a levelling of notifications at around 2.400 per year.

**Chart 1 – Notifications and diagnosis per year\***



\* Last two years figures must be taken very cautiously given the delays in notifications.

# Portugal



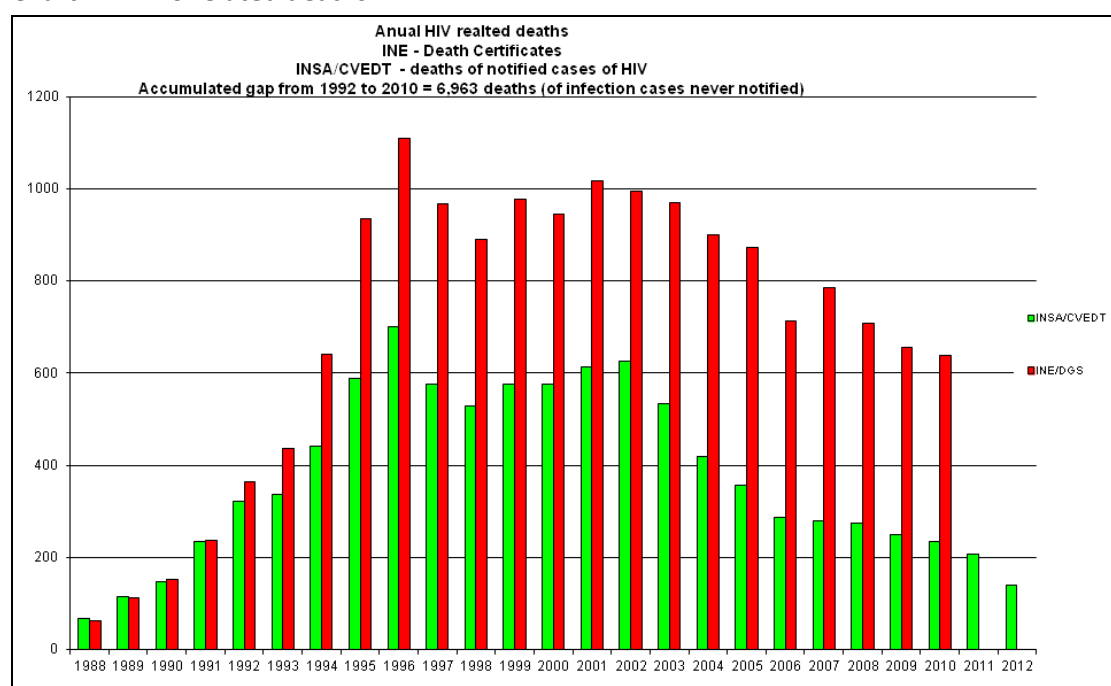
## AIDS related deaths

Two series of data concerning AIDS related deaths are available in Portugal: the National Statistical Institute (INE) figures based on death certificates, and the INSA/DDI-URVE figures that record deaths of previously notified cases.

For the years where both series exists, 1994 to 2010, differences between them are very suggestive and has increased to a ratio of 1 to 3 (one death of notified cases against three certified deaths).

The two series are represented in the following chart.

**Chart 2 – AIDS related deaths\***



\*(According to INE death certificates and INSA recorded deaths of notified cases of HIV)

## Discrimination cases

Although existing anti-discrimination legislation mandates that the National Statistical Institute (INE) report annually on types of discrimination—including by physical or mental disability, origin of the complaint, area of discrimination and legal framework--in the five reports published to date, the INR cites the lack of cooperation by the different government organizations and agencies that should report the cases and the very low number of cases reported.

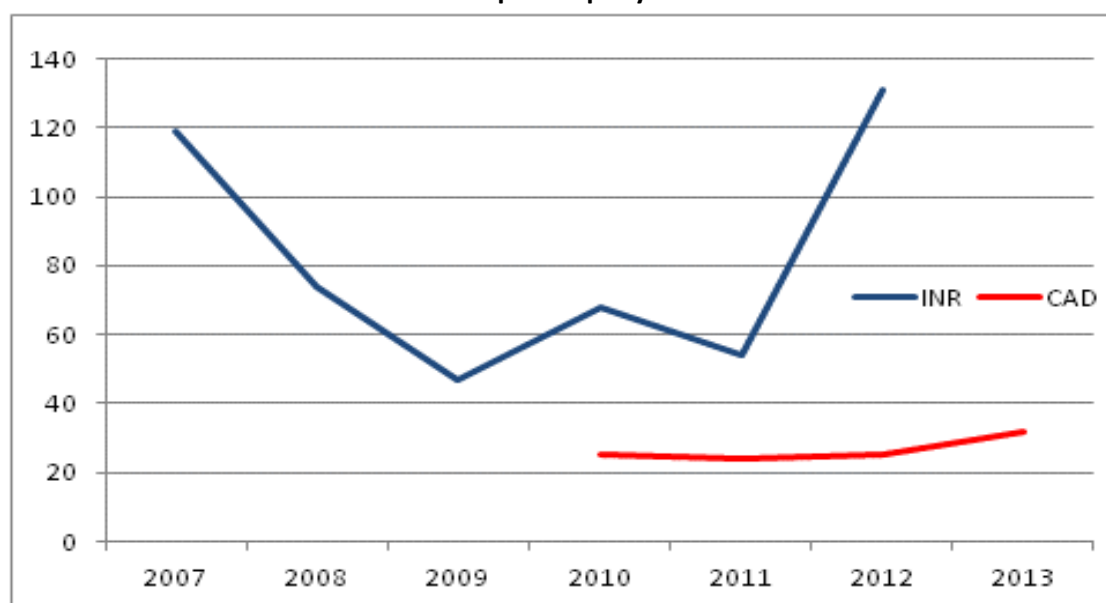
Since its beginnings in 2010 the Anti discrimination Centre for HIV (CAD) has received an average of 25 complains per year concerning HIV related discrimination. In addition to the

# Stigma Index



lack of trust of the general population in the system, until a consistent and reliable methodology is used it will be difficult to accurately measure the level of stigma and discrimination.

**Chart 3 –HIV-related discrimination complaints per year – INR and CAD**



With this study we are able to identify the areas where more cases are identified and to quantify the incidence and prevalence of those cases, to evaluate the effects of anti-discrimination policies and laws and regulations and to advocate for reforms and changes.

## Legal Framework

Discrimination is forbidden in Portugal accordingly to International and European Treaties, Conventions, Declarations and Commitments that the country has ratified, as well as Article 13 of the Constitution of the Republic of Portugal. However specific and operational legislation identifying what should be considered discriminatory actions and classifying those acts as offences, not crimes, was only approved in 2006, during the European year of disabilities (Law 46/2006, August 28<sup>th</sup>).

The initial drafts of this law restricted its ambit or scope essentially to discrimination for reasons of physical or mental disability. PLHIV efforts and action resulted in the inclusion of discrimination of people with an “aggravated health risk”.

Seven years after its approval by Parliament, its main deficiencies and limitations and the main reasons for these may be enumerated:

- At the time, the use of the expression “aggravated health risk” was considered acceptable and its inclusion in the law was seen as a major advancement in the





recognition and protection of the rights of PLHIV. This however resulted in unwanted, negative and perverse consequences.

- Non-consideration of family and social discrimination in the discriminatory actions (articles 4 and 5) and lack of analysis of the causes of discrimination.
- Legal absence of controlling bodies or mechanisms independent of the entities where the discrimination cases are reported. It is not surprising that 90% of complaints are dismissed when investigator and judge belong to the organization cited.
- Absence of any sanction for government and other public services when not complying with their legal reporting obligations.

In the application and use of the competences given by the law, other deficiencies may be listed:

- The National Institute for Rehabilitation (INR) never made use of its legal powers to issue a mandatory, though not binding, statement on each and every inquest, inquiry or disciplinary actions or process in the public administration for actions taken by a public servant, agent or holder of a public job.
- INR annual reports analyse the data only according to the narrow legal typified cases of discrimination and area where complaints originated – i.e. labour, health, school systems, etc. Such analysis that does not allow for the identification of causes – aggravate risk of health, physical or mental disability.
- Lack of information, education and communication policies and strategies to publicize and implement the law. Only the minimum of materials were produced, and were not replenished due to lack of funds when copies ran out.
- PLHIV are not aware of their rights and do not trust the existing legal means to protect and defend them. Most times they not even present a formal complaint.

## Objectives of this study

Data and information collected will:

- Document and record the national situation and real life experiences of stigma and discrimination.
- Establish the quantitative evidence to support:
  - the proposal of measures and programs targeting discrimination
  - the recommendations for political and policy changes
  - the design of specific and targeted interventions
- Measure and evaluate future changes and the evolution of discriminatory situations. The results of this study will become the base line for future studies related to stigma and discrimination in Portugal.

Additionally the almost exclusive participation in the study of PLHIV as interviewers and



interviewees, trainers, volunteers and coordinators fulfilled the objective of their empowerment by:

- Increasing their level of general knowledge and their social and professional skills.
- Increasing their knowledge of their rights and means to defend and protect those rights.
- Increasing their ability to recognise and deal with discrimination cases and situations.
- Increasing their intervention and mobilization capacity through the establishment of new informal networks of PLHIV, either among interviewers or between interviewer and interviewee.

## Methodology

### GIPA & MIPA principles

(Greater Involvement of People Living with HIV (GIPA) and Meaningful Involvement of People Living with HIV (MIPA) principles)

With the exception of the data processing and of two of the four trainers, all of the other 25 persons actively involved in the study were PLHIV. For most of the interviewers this was the very first time were they a) were considered as peer experts developing a professional work related to their expertise and experience on HIV; b) were able to develop a new and more balanced and equalitarian relationship with doctors and nurses; c) received a financial compensation for their involvement in AIDS work; d) broke isolation and self-discrimination and developed contacts and networks with other PLHIV.

### Selection and training of the interviewers

Call for applications were made in SER+ and GAT sites, in HIV Hospital Clinics, and participant Non-governmental Organizations (NGO) and Civil Society Organizations (CSO) by flyers and posters announcing this study and recruitment conditions. From the 25 applicants 17 trainees were selected.

These 17 trainees were geographically distributed as following: Lisbon metropolitan area (10) Oporto Metropolitan area (4), Setubal (2) and Faro (1).

Based on the Project User Guide, interviewer training aimed to create a safe and trusting environment to allow trainees to reflect on their own discrimination experiences and learn from their peers through an interactive and participative methodology.

### Goals of the training program

- To achieve a fair knowledge of the structure and development of the STIGMA INDEX



- To reflect on trainees own stigma and discrimination experiences in order to get a clear and accurate notion of those concepts.
- To obtain full and detailed understanding of the content, objectives and procedures of the questionnaire.
- To develop their capacities to conduct and register the interviews.
- To raise their awareness to the usefulness of the data and information collected, both in the present and for future use.

The three and a half day training course (5 – 8 February 2013) – focused on analysis and discussion of the concepts and tools of the study (GIPA and MIPA, stigma vs. discrimination, confidentiality and informed consent); and in the building up and training of the technical and practical capacities needed to conduct the interviews.

On the last half day of the course the initial draft questionnaire was applied amongst the trainees in the real conditions they would find in the field. This also served as the questionnaire pre-test and was useful to correct some flaws and errors and to make the questionnaire more user friendly.

From the 17 PLHIV trained to be *Stigma Index* interviewers, 16 demonstrated the will, availability and capacity to conduct the study.

## Site selection

### Hospitals and Hospitals Centres

Parallel to the selection and training of the interviewers, and based on the most recent available data on geographic distribution of notified cases (December 2011), districts with a prevalence higher than 5% were chosen – Lisbon, 38%, Porto, 19,7%, Setubal, 12,7% and Faro with 5,4%.

Within those districts, Hospitals or Hospitals Centres seeing more than 5% of total outpatients were selected based on a survey made in 2009. Additional hospitals that did not fit this criteria due to incomplete or non-available figures (HPV, HC, HEM and HSB) were included due to public knowledge of the high number of patients followed. Two other hospitals (HUC and HF) were also included due to the social and demographic characteristics of the populations served even though they did not reach the 5% threshold.

The fifteen selected hospitals are shown in the following table.

# Stigma Index



**Table 1 – Selected Hospital Centres and Hospitals**

District	Hospital Center	Hospital	# HIV out-patient consultations	% HIV out-patient consultations	# PLHIV followed as out-patients	% PLHIV followed as out-patients
<b>Lisboa</b>	Amadora/Sintra	HFF	4,620	5.7%	1,833	8.1%
	Cascais	HPP - HC	3,565	4.4%	1,124	4.9%
	CHLN	HSM	5,826	7.2%	1,362	6.0%
		HPV	n.a.		n.a.	
	CHLC	HCC	6,947	8.6%	3,000	13.2%
		HSJ	5,024	6.2%	2,155	9.5%
		HC	n.a.		n.a.	
	CHLO	HEM	8,080	10.0%	n.a.	
<b>Porto</b>	CHP	HJU	10,657	13.2%	2,058	9.0%
	ULSM	HPH	3,301	4.1%	1,200	5.3%
	CHSJ	HSJ	9,000	11.1%	1,814	8.0%
<b>Coimbra</b>	HUC	HUC	3,725	4.6%	1,088	4.8%
<b>Setúbal</b>	CHS	HSB	n.a.		n.a.	
	HGO	HGO	n.a.		n.a.	
<b>Faro</b>	Faro	HF	3,827	4.7%	1,242	5.5%

From the fifteen selected hospitals only eight completed the authorization process. The average length of time to get the authorizations was of 91 days, ranging from 38 to 134 days. The forecasted period for approval as per the initial project proposal was 100 days.

## Non-Governmental Organizations and Civil Society Organizations

The study was introduced to all NGOs and CSOs with facilities in the districts selected either personally or through the National Civil Society Forum (FNCS) of the National Programme for HIV/AIDS. CSOs were asked to disseminate information, flyers and posters of the study, announce the call for interviewers, promote adherence to the study and, when possible to lend space in their facilities to conduct the interviews.

Ten CSOs responded positively – some with more than one location – but due to lack of users or lack of interest of the users and poor dissemination of the information, only 6



effectively participated. In those 6 CSOs the project was conducted in 10 different locations, 7 in Lisbon and 1 each in Porto, Setubal and Faro.

The responses obtained in the CSOs in Lisbon compensate for the poor participation of local hospitals.

## Sample size

The size of the sample was based on the most recent epidemiologic figures available at the time of the development of the study (INR December 2010). Given 39,347 cases diagnosed and aiming at a confidence level of 95% (+- 5% confidence interval), the impossibility of randomization and of knowing, in advance, the interviewed distribution – geographical, age, socio and economic status, gender, way of transmission – compared with the same parameters for the total number of cases, the size of the sample was determined by the acceptable range of sample error.

The best estimative for the sample size according to variable sample errors are shown in **Table 2**.

**Table 2 – Margin of error and sample size**

margin of error	sample size
±1%	7,700
±2.5%	1,500
±3.0 %	1,000
±5%	400

Time and financial constraints were considered when defining the acceptable margin of error and sample size of the study. The project proposal specified a margin of error of between 2.5% to 3%, thus a sample size of 1,000 to 1,500 interviews. Even with time constraints and long approval processes in several hospitals, more than 1,060 interviews were conducted, exceeding the minimum acceptable sample size.

## Statistical Analysis and Processing of Data

The Stigma Project Manual for data entry and processing defines the statistical analysis and all variables and correlations to be analyzed, allowing for international and country to country comparisons. The data entry and analysis was processed, using SPSS™ (Statistical Package for Social Sciences) system, by Key Point Portuguese agency, a contract research organization established in Portugal with recognized expertise in the field of processing, analysis and statistical interpretation.



## Study limitations and challenges

### Hospital approvals

In general the approval process consisted of four steps (with variations according to site-specific internal procedures—at times the second step required two approvals and/or the last two steps were combined).

- Approval by the director of the HIV service or clinic
- Approval by the hospital or hospital centre’s Clinical or Research Director
- Approval by the hospital or hospital centre’s Ethics Commission
- Approval by the hospital or hospital center’s Board of Directors

The study project was presented to the directors of the HIV services or clinics during the two first weeks of January 2013 in written form, and for the Lisbon hospitals when possible, in face-to-face meetings. This first approval step took between 11 and 39 days. Hospital Garcia da Orta (HGO) announced the study and informed its patients but given the lack of proper facilities “even for medical appointments” declined to participate.

The project was then submitted to the Clinical Directors. 10 of the 14 Clinical Directors responded. The average response time was 57 days, with a minimum of 5 and a maximum of 112 days. Although we received approval from the Clinical Director of the Hospital of the University of Coimbra (HUC) we had no interviewer from the Coimbra area and thus did not continue the local approval process.

Ultimately the Ethics Commissions and Board of Directors of 8 hospitals or hospital centers approved the study (HEM-CHLO, HF, HPH-ULSM, HPP-HC, HPV-CHLN, HSB-CHS HSI-CHSJ, and HSM-CHLN). The average time of response was 78 days, with a minimum of 14 and a maximum of 112 days – in this last case (HSB-CHS) the ethics commission and board approval coincided with the approval by the Clinical Director.

A ninth Hospital Center (HJU-CHP) issued a “conditioned approval” stating that:

All patients must be recruited by the MD in charge at CHP and all Terms of Responsibility, information material, flyers, and Informed Consent Form must be reformulated to include the signature of the MD in charge.

This was not necessary for, and in fact may conflict with, standard research ethics. The study proposal as submitted clearly limited the role of the MD to promoting the study and referring interested patients to the interviewers. The MD should not be a recruiter or have any further role in recruitment.



Additionally we were only informed of this condition on 8 May, two months after the study had begun. It was not viable, materially and cost wise, to reformulate documents already printed and in use.

## Variability of approval process and criteria

Unlike multicenter clinical trials, there is no single, central or delegated, approval entity for multicenter observational studies and surveys. As a result, it was burdensome and time consuming to cope with the long and diverse administrative and bureaucratic process, requirements, specifications and conditions of different hospitals.

The timing of the study, unfortunately, coincided with the integration of various hospitals into newly created hospital centres. During this extensive reorganization process new departments were set up to coordinate and approve research projects. Conflicting understanding of the lines of responsibilities and therefore confusion about which department should review and evaluate the project was a primary reason that one third of those hospitals did not respond to the proposal. This also contributed to the excessive approval time for some hospitals.

These delays necessitated a one month extension of the field work in order to obtain a sufficient number of interviews. This delay subsequently impacted the remaining project calendar.

## Retention of the interviewers

The long hospital approval process also challenged our capability to retain the interviewers and keep their trust in the project and their willingness and enthusiasm to start the work two, sometimes, three months after their training.

Interviewers from the Cascais and Oporto areas could start field work, in the local hospital and CSOs, by mid-March but those living in the Lisbon, only by the end of April and in Setubal and Faro only by the end of May. Two interviewers were lost in this process. An additional experienced interviewer was hired and participated in an individual training process. In the end the study was conducted by 15 interviewers.

## Sample bias

Hospitals that approved the study early (HPP-HC and HPH-ULSM) tend to have a disproportionately high weight in the sample, independently of the proportion of PLHIV they followed. Conversely, “late hospital” (HF, HSB-CHS and HEM-CHLO) had a disproportionately low weight.

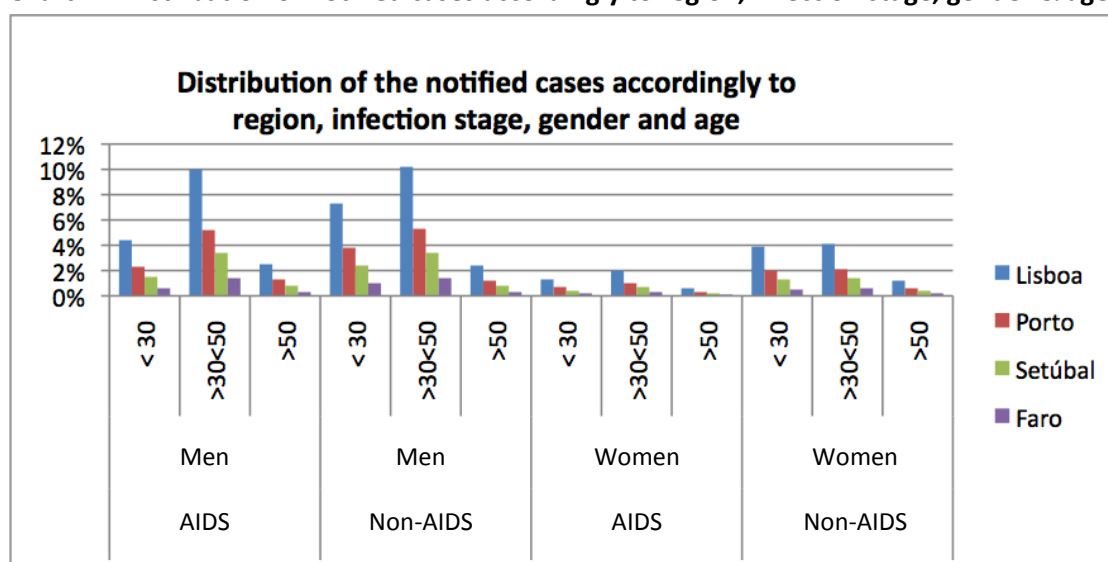
# Stigma Index



The geographical distribution was also effected by the level of commitment, enthusiasm and proactivity that hospital teams, CSO staff and directors and interviewers put in the study promotion and development. The late approval in some hospitals could be overcome by their efforts and an early approval didn't always mean a facilitating attitude from the hospital staff, nurses and MD nor a better performance of the interviewers.

Although the number of interviews made in Lisbon and Setubal through CSOs help minimize this bias, Lisbon PLHIV remain underrepresented. Ideally the geographical distribution, infection stage, gender and age of the sample should approximate the national country distribution of notified cases as shown in the following chart.

**Chart 4 – Distribution of notified cases accordingly to region, infection stage, gender & age**



Data was collected on the number, type and degree of stigma and discrimination situations experienced by PLHIV in Portugal in the various environments in which they live - family, social, employment, education, health care and social support, access to public and private services - as well as their level of knowledge about their rights and ways to defend them.

The individual experiences of stigma and discrimination in relation to testing, HIV disclosure, treatments and having children are quantified. These situations are analyzed globally and crossed by gender and age; length of time living with HIV; marital or relational status; level of sexual activity; key populations; level of education; professional situation; income levels; household size; geographical distribution and degree of food security.

Based on analysis of the data, conclusions are drawn on the impact and experience of stigma and discrimination in Portugal. Recommendations are proposed to improve, enhance and disseminate mechanisms for the defense of the human rights and to act preemptively in areas where stigma and discrimination exist.





## Chapter 2 – Background characteristics and household composition

Data collected included:

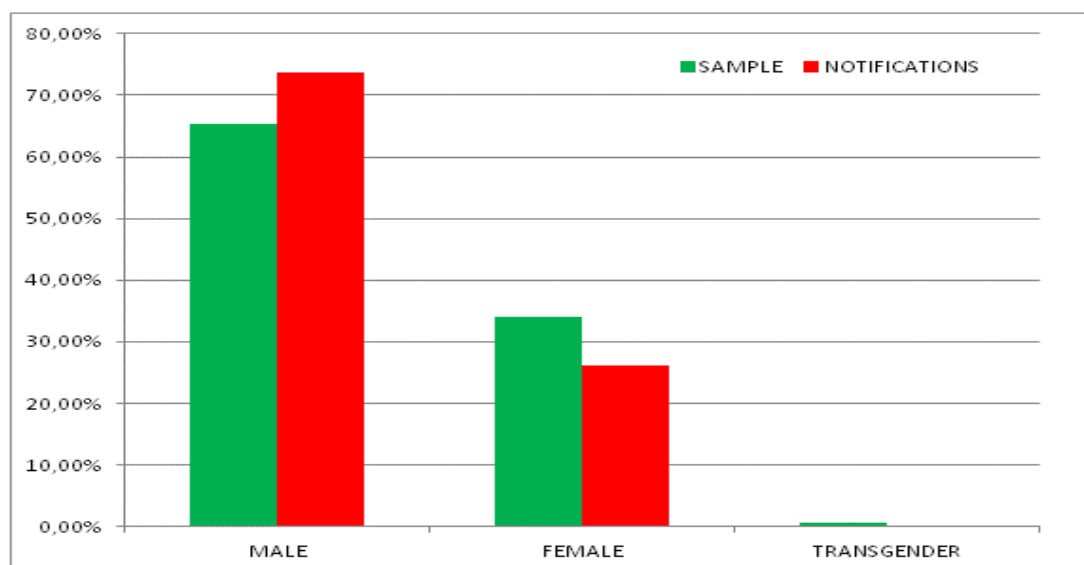
- Gender
- Age/age strata
- Education
- Relationship status
- Sexual activity
- Self-identity or belonging category

The analysis was crossed with self-identity or belonging category, the feature that showed more significant variations in the obtained data.

### Gender

The gender distribution was 66% men and 34% women, four respondents identified themselves as transgender. Although close to the distribution of notified cases between 1983 and 2010 the number of women in the sample is 30% higher than the notifications which may be, at least in part, result of the growing feminization of infection.

Chart 5 – Gender distribution



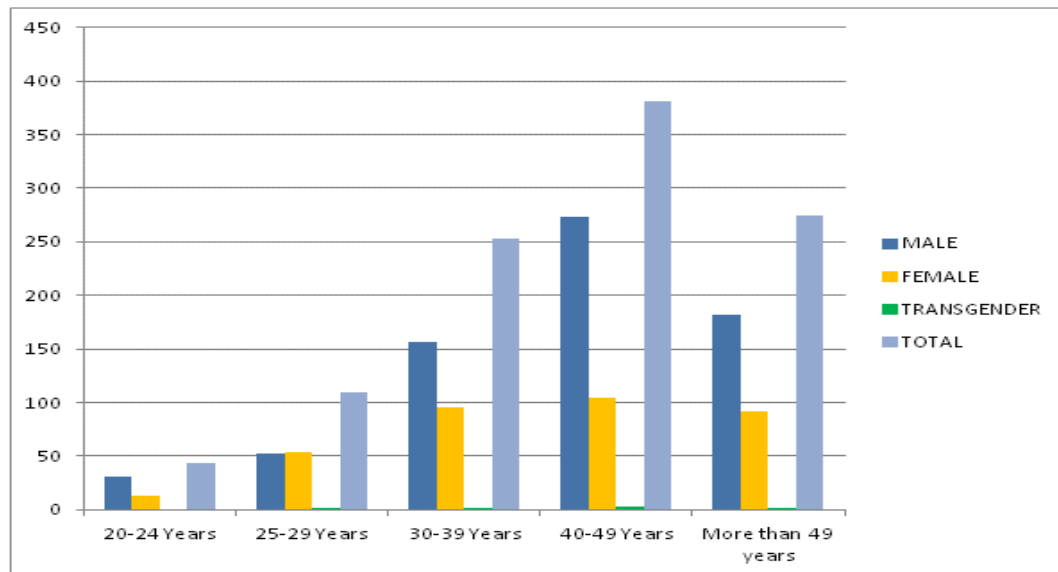
# Stigma Index



## Age

The gender and age distribution shows a higher weight than the expected for older groups, 40 to 49 years or more, and a very low percentage of coverage of younger age strata.

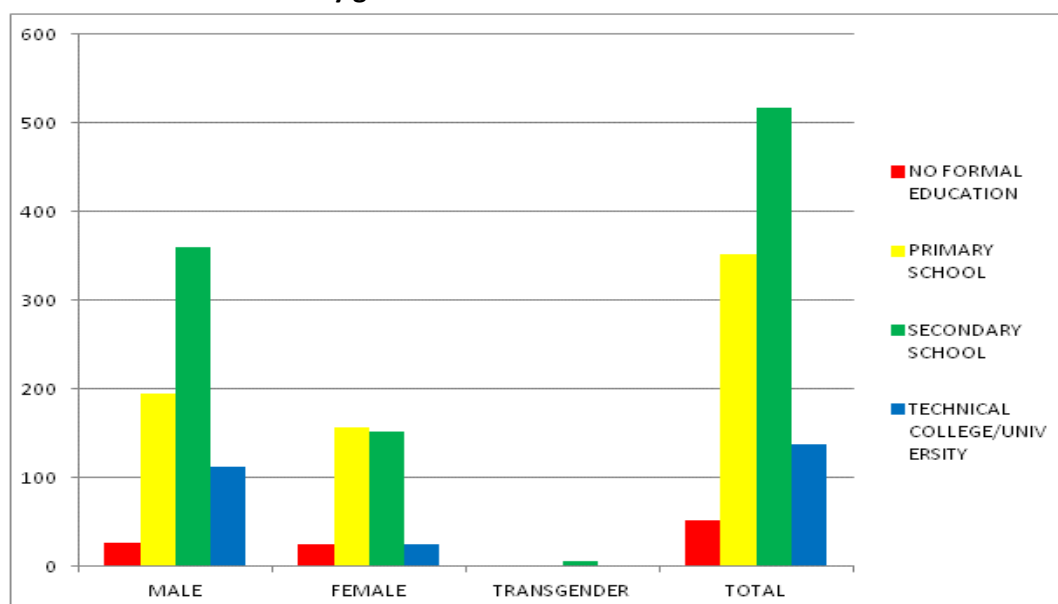
**Chart 6 – Age distribution of sample**



## Education level

The high level of secondary education for men should be noted, as well as the significant number of women who have “no schooling” or “primary education only” (the most important category for women).

**Chart 7 – Education level by gender**



# Portugal

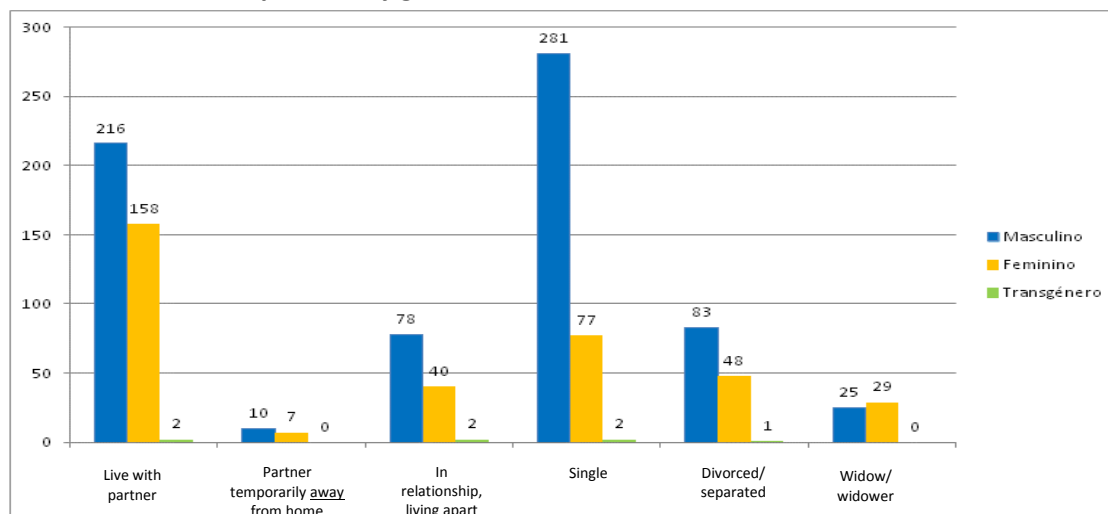


## Relationship status

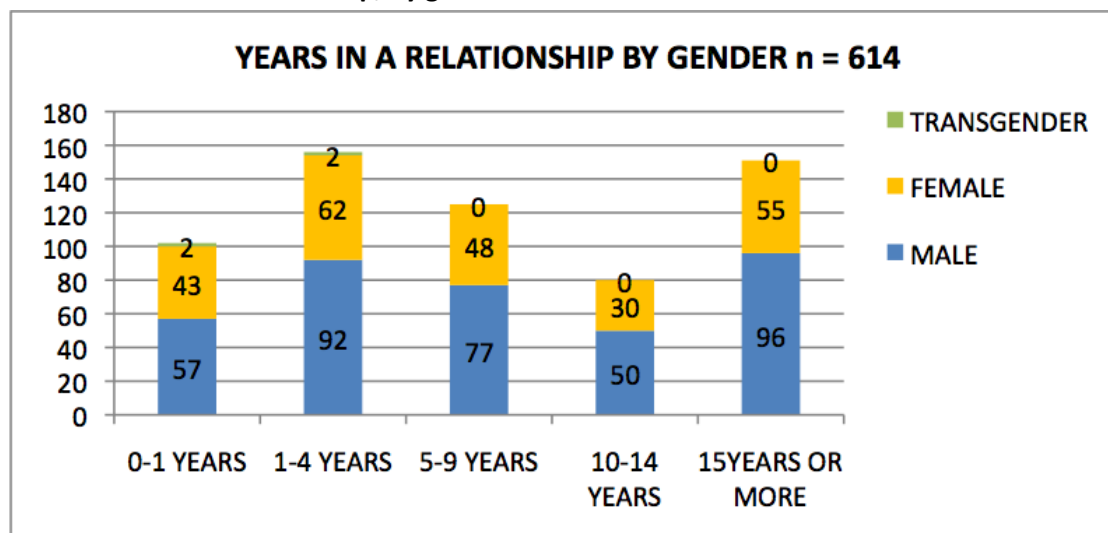
Most of the men live alone and are not in a relationship (single, divorced or widowed). Most of the women have a relationship whether or not they live together.

The years of relationship is distributed in a similar manner by gender, noting, however a tendency to long lasting relationships (particularly with more than five years) amongst men.

**Chart 8 – Relationship status by gender**



**Chart 9 – Years of relationship, by gender**



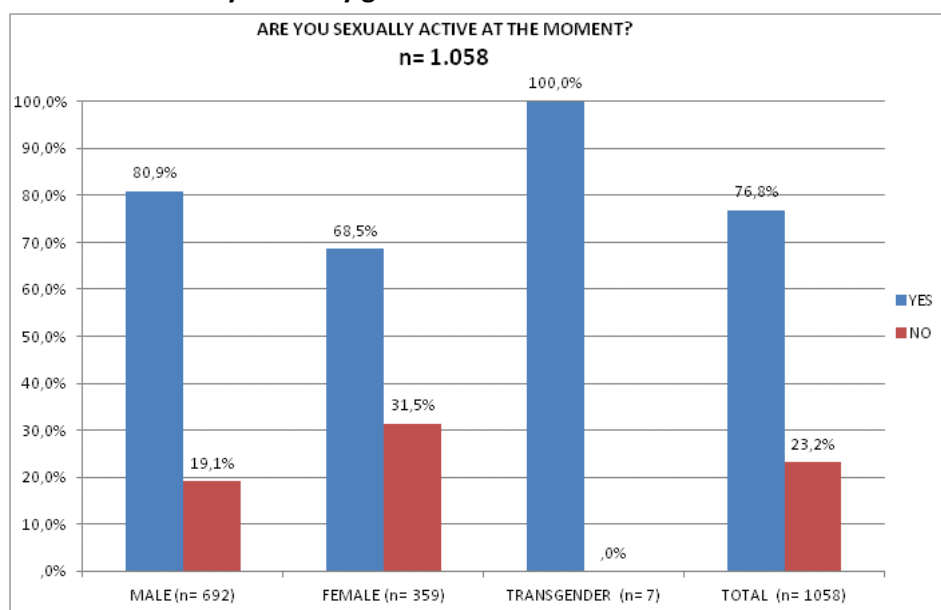
## Sexual activity

Over 80% of men, nearly 70% of women, and all transgender participants describe themselves as sexually active.

# Stigma Index



**Chart 10 – Sexually active by gender**

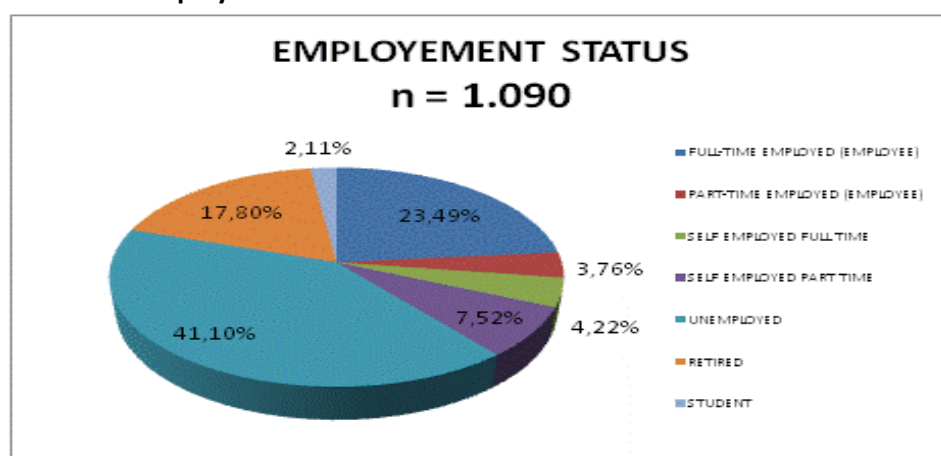


## Employment situation

The employment situation indicates a large degree of social and economic precariousness. Less than one quarter have full-time salaried work (23.5%). An additional 4.2% are self-employed full-time. Over 41% are unemployed. Combined with those who work part-time or on a casual basis, the majority of respondents find themselves in a precarious employment situation. One fifth of respondents are either retired (17.8%) or currently a full time student (2.1%).

Almost 23% of interviewees reported that they were not sure of how much they earned in the last year. Half of the remaining interviewees had less than €600 average monthly income.

**Chart 11 – Employment situation**



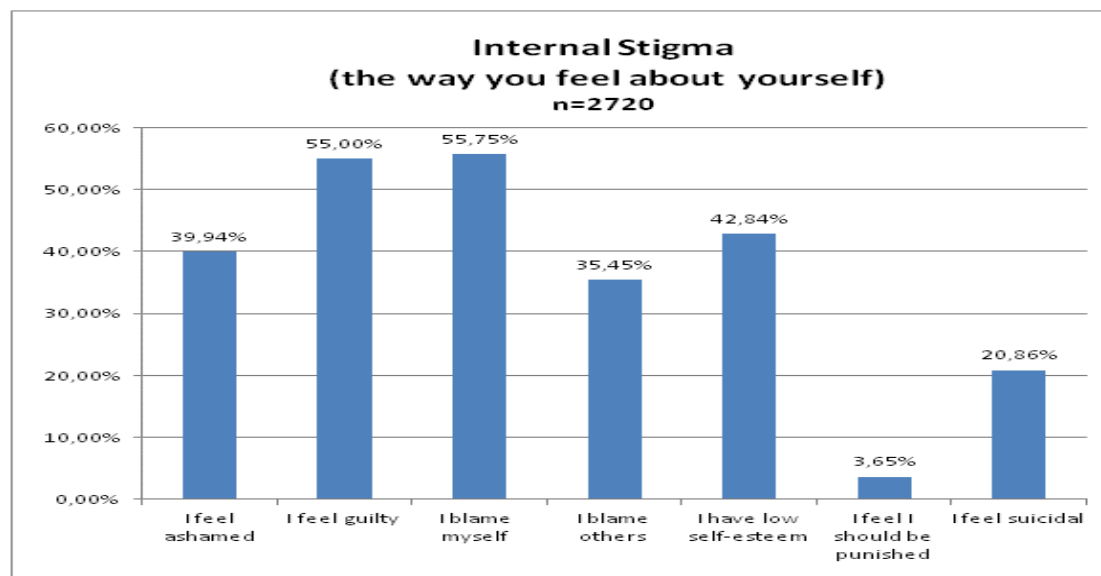


## Chapter 3 – Experience of stigma and discrimination

### Internalised Stigma and self-discrimination

The large majority of respondents are self-accusing or feel responsible for their HIV status and life situation. In analysis by gender it is noteworthy that females are twice as likely as males to express a tendency to suicide (31% of females to 16% of males). PLHIV who describe themselves as intravenous drug users (IDU) are more likely to note, "I feel like killing myself", "I feel low self-esteem" and "I feel I should be punished," revealing a greater depressive predisposition.

**Chart 12 – Internalised stigma and self-discrimination**



As a result of HIV status, the principal measure of self-discrimination was the decision by the majority of respondents not to have children. Combined with social and familial isolation, these factors impact negatively on work and health outcomes. Interviewees expressed concern about social disapproval and the opinions of others over their HIV status. These concerns surpassed fear of physical attack. A majority (60%) have not been able to confront those who discriminate against them.

Regarding support provided to other PLHIV by respondents, the sample is split 50/50 (50.9% gave support, 49.1% did not). Reviewing the results according to the length of time living with HIV, a direct relationship between the level of solidarity and time of infection was

# Stigma Index



observed: those who have been living with HIV for longer than 15 years were more than twice as likely to receive support than those living with HIV 1—4 years (64.7% compared to 30.6%).

## Self-evaluation of health status and communication with health professionals

A large majority of respondents report a positive state of health (33% very good and 30% good) - and it is reported as excellent or very good amongst those who did not suffer internal stigma (36%) compared with those who suffered (27%). Good communication with health professionals also correlates with positive outcomes, as shown by an increasing number of years of infection and a decrease of contacts.

## Access to ART and other treatments

There is a direct relationship between access to antiretroviral therapy (ART) and increasing age level, indicating an almost unanimous ease of access to ART (99%), however 16% report lack of access to medication for opportunistic infections. Most women of childbearing age who wished to have children (82%) had access to ART as prevention of vertical transmission (PVT), and almost all (94.7%) had access to information about healthy pregnancy and motherhood.

## Discrimination complaints

Most PLHIV are unaware of their rights, of protective legislation and of existing defense mechanisms. While a few CSOs and NGOs collect anecdotal data on discrimination, very few collect data in a systematic and comparable manner. These organizations also lack standard and efficient procedures to defend the rights of their clients.

The official data that is available is not utilized for statistical purposes that would allow for more in-depth analysis. The administrative agencies that collect data of discrimination have various methods and purposes for data collection, and therefore data is not comparable/compatible. The INR merely registers discrimination complaints received from public agencies or directly from the complainant, with no proactive action taken on the evaluation of the complaint or the investigative procedures.

## Discrimination in education

While there were relatively few instances of discrimination in education reported, these are still worrisome due to the universal and protective nature that the educational context should provide. It should also be noted that in most cases teachers were unaware of the interviewee's health status (this was known in only 38 cases). Nonetheless during the

# Portugal



previous year, 16 respondents reported having been forbidden to attend an educational institution, due to their HIV status. Two cases were also reported of respondents' children being denied access to an educational institution.

## Discrimination in the work place

Of the 97 respondents who were dismissed from their jobs, one third considered it due to their HIV status. An additional 56 respondents believed they were refused a job and 197 respondents had their job functions changed for the same reason. In all of these situations no other significant correlation was found with other characteristics (gender, age, etc.).

## Confidentiality in the work place

Between 93 and 99% of respondents state that neither work colleagues, employer or customers know their HIV status. However, 36% of respondents believe that a company may require employees to take an HIV test, and 12% believe that a company can administer an HIV test to employees without their knowledge.

## Reactions in the work place

Of those whose HIV status became known at their workplace, the majority felt supported by their colleagues, employers and customers. However 20% of these respondents report discriminatory or very discriminatory attitudes from their employers, 18% percent from clients and 13% from coworkers.



## Chapter 4 - Experience of testing, disclosure, treatment & having children

### Reasons and decisions for HIV testing

Slightly more than one quarter of the respondents (26.1%) stated that desire to know was their reason for obtaining an HIV test, while more than one fifth (22.4%) were tested due to suspicion of disease-related symptoms.

Slightly more than half of respondents (51.3%) were tested voluntarily, but almost 4 out of 10 (39%) did not receive pre- or post-counseling. There appeared to be a direct relationship between increasing age and mandatory testing or testing without knowledge. When sorted by other variables, over 70% of MSM report voluntarily deciding to be tested. On the other hand, inmates report being tested without their knowledge about one third (35%) of the time, or undergoing mandatory testing another third (31%) of the time.

### Discrimination in health care services

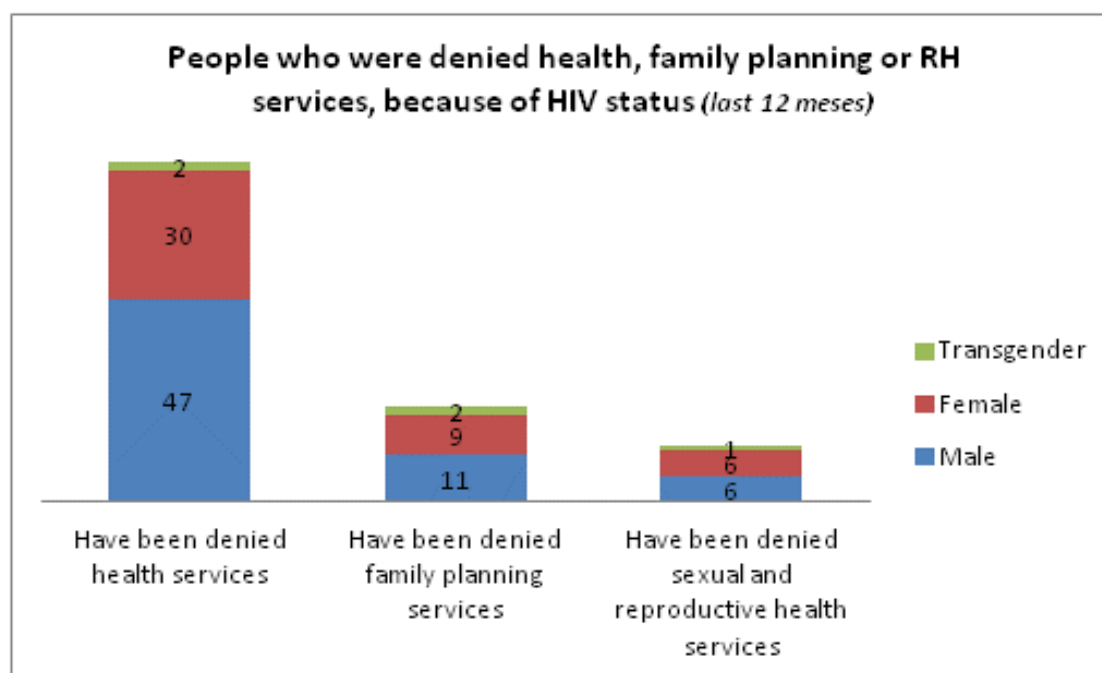
79 respondents report being denied health care due to their HIV status. Intravenous drug users (IDU) report the highest rate of refusal of health services (13%), followed by men who have sex with men (MSM), transgender and sex workers (10%). 147 respondents reported being advised not to have children (25% of women and 28% of sex workers), and 59 reported being pressured to undergo sterilization. Unlike in the workplace or school context, HIV status is known by professionals in 98% of healthcare interactions. Oftentimes, this is at the initiative and/or with consent of the PLHIV. Still, however respondents report discrimination in 3% of cases (n=30). Furthermore, 11% of respondents report that confidentiality regarding health information was violated without their consent, with 30% report not being sure if this happened. This situation is especially present amongst inmates (18%).



# Portugal



Chart 13 – Denial of health care due to HIV status





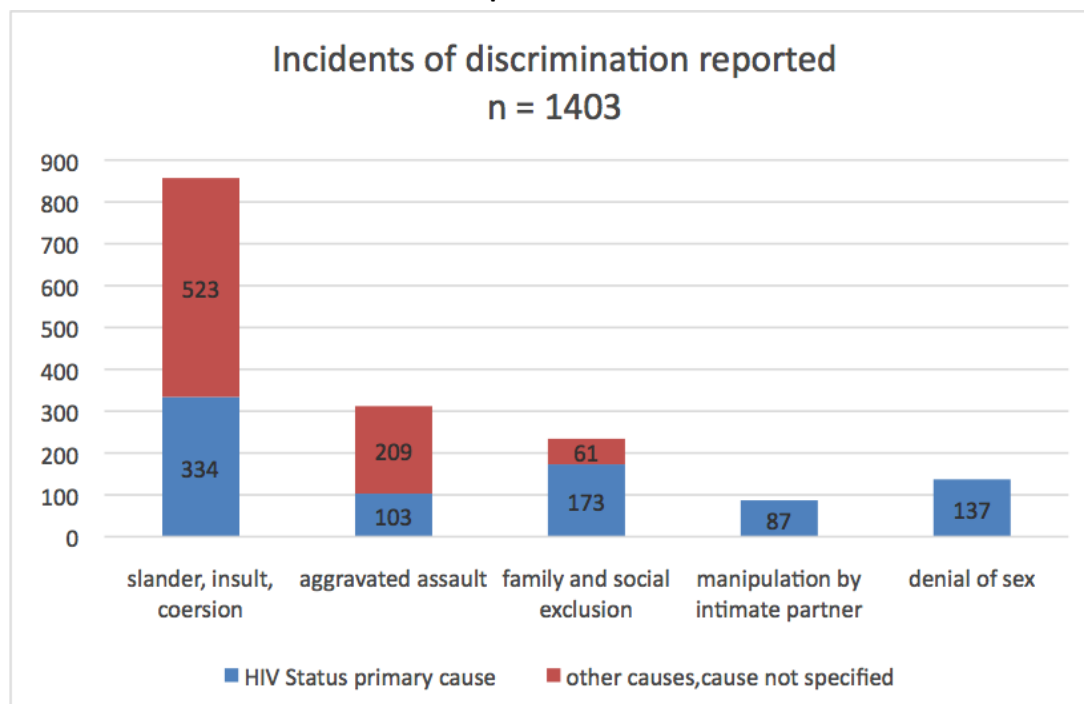
## Conclusions

1,062 respondents in this study reported 1,403 incidents of discrimination during the previous 12 months. More than 60% of these (857) were for slander, insult or coercion. An additional 22% (312) were for aggravated assault and 17% (234) for family, social or religious exclusion.

In three quarters of the cases of family, social or religious exclusion (74%), the respondent's HIV status was the cause. HIV status was also cited as the primary cause in 39% of cases of slander, insult or coercion and in one third (33%) of cases of aggravated assault. We can also add to these 87 cases of manipulation by intimate partner and 137 cases of sexual rejection, all due to HIV status.

The primary reasons for discrimination cited are fear of casual contact and fear of infection through social contact (approximately 27% and 20% respectively). 7% also cited religious or moral judgment as the cause. An additional 6% reported that the weak or sick appearance of the respondent was the cause.

**Chart 14 - Incidents of discrimination reported**



Most incidents of discrimination (44%) took place in the work place. The high number of work place incidents is even more striking considering that more than 60% of respondents

# Portugal



are either unemployed, retired or a student (41%, 18% and 2% respectively).

Fully one quarter (26%) occurred within the family or community, and 12% of instances of discrimination took place in the delivery of health care services. Most of the remaining cases took place in school. In 15% of the cases, the source of the discrimination was another PLHIV.

There is no significant relationship between the gender, age, duration of infection, level of education, residence, food insecurity and group identification variables with cases of discrimination or the sharing of test result - except that women tend to disclose their HIV status to their partners more than men. In 10% of respondents, HIV status was not shared.

Age and duration of infection showed a positive correlation with the decision to share information about HIV status. These same two variables, combined with education level, also showed a positive correlation to support received from family and in the social environment, and from employers and coworkers.

Only a minority of respondents demonstrated knowledge regarding their rights as a PLHIV and the laws that guarantee and protect these rights. Although some respondents have verbally confronted the person violating their rights, only a small percent have ever initiated administrative or legal proceedings to defend their rights or advocated against any public or political official acting contrary to the rights of PLHIV.

Article 13 of the Constitution of the Republic of Portugal states:

All citizens possess the same social dignity and are equal before the law.

No one may be privileged, favoured, prejudiced, deprived of any right or exempted from any duty for reasons of ancestry, sex, race, language, territory of origin, religion, political or ideological beliefs, education, economic situation, social circumstances or sexual orientation.

The history of democratization and decentralization in Portugal contributed to the development of both a top-down (vertical) and a sectoral (horizontal) network of institutions safeguarding and promoting rights in Portugal.

The primary government bodies for promoting and protecting rights are:

- High Commission for Migration (ACM)
- Commission for Citizenship and Gender Equality (CIG)
- National Institute for Rehabilitation (INR)

These institutions have sharply different ways of dealing with rights and protection against discrimination—in philosophy, in policies pursued, in the recognition, advocacy and practical implementation of the rights of persons, and in monitoring and penalizing discriminatory

# Stigma Index



actions. In the social sectors where discrimination occurs - work place, insurance and banking, education system, health care system, social security system, etc. – each ministry or sector has its own internal policies and enforcement mechanisms, as well as their practice of dealing with the government rights bodies and the police and judicial systems.

Moreover, the expansion of the protected categories under the framework of the rights laws to include "people with increased health risk," turned out to have negative and perverse consequences due to the terms used, and indicate several other deficiencies which require urgent amendment:

- Poor and incomplete categorization of discrimination cases
- Lack of sanctions applicable to public services in cases of non-compliance
- Lack of mechanisms for monitoring the implementation of the law that are independent from structures and places where discriminatory acts are denounced
- Lack of guidelines to ensure uniformity of criteria, transparency and impartiality in the process of investigation
- Lack of divulgation mechanisms for equal rights under the law that are continuous, consistent and focused on the related population
- PLHIV are often unaware of existing rights and defense mechanisms and may not have faith in the system



## Recommendations

### Recommendations to Parliament

- Revise Law 46/2006 on rights and discrimination:
  - Change “law that prohibits discrimination on the basis of disability and the existence of aggravated health risk” to “law that prohibits and penalizes discrimination on the basis of physical and mental disability and health status”
  - Replace the phrase “by reason of disability” with “by reason of physical and mental disability and health status” (Articles 1 – 7 and 15)
  - In Article 3, paragraph a, in addition to the phrase “subject to less favorable treatment” add “be threatened, debased or demeaned by reason of physical and mental disability and health status”
  - Include in Article 4 a reference to discrimination in family and/or social environments.
  - Update Article 8 to replace the former National Council for the Rehabilitation and Integration of People with Disabilities (SNRIPD) with the National Institute for Rehabilitation (INR)
  - In Article 8, paragraphs 2 and 3, clarify and strengthen to following points to sharpen the anti-discrimination mandate of the INR
    - Require publication of “mandatory non-binding opinion” on incidents of discrimination.
    - Require the evaluation of processes of investigation and/or disciplinary enquiries that are initiated by public authorities or private entities.
- Include the term “discrimination” in the official name of the INR to highlight that combatting discrimination falls within its mandate
- Require categorization of discrimination complaints in the Annual Report of the INR by:
  - causes of discrimination - physical disability, mental disability, health status, etc.
  - types of discrimination, subdividing the various types of prohibited discrimination mentioned in Articles 4 and 5 by various subcomponents, including
  - goods or services that were denied or prevented from being used
  - economic activity that was denied or prevented from being exercised
  - refusal of purchase or rental of housing



- refusal of credit
  - refusal of insurance contracting, etc.
- Identify the entity subject to the complaint, entity that dealt with the complaint, and the regulatory or supervisory entity.
- Include opinions of the case investigator, the regulatory entity and the final finding from INR, including the reasons
- In Chapter IV of the INR law, define the enforcement mechanism and penalty for those who do not fulfill their duty to notify the INR and/or initiate the inquiry procedure
- Review the Decree 34/2007 which regulates the current law in accordance with the suggested changes
- Promote wide and effective dissemination of the law, informing citizens of their rights, prohibited discrimination and how to initiate a complaint under the law

## Recommendations to the Government

- Strengthen oversight to increase effectiveness and efficiency in the inspection and/or regulatory activities of the INR.
- Require categorization of discrimination complaints in the Annual Report of the INR by:
  - Causes of discrimination - physical disability, mental disability, health status, etc.
  - Types of discrimination, subdividing the various types of prohibited discrimination mentioned in Articles 4 and 5 by various subcomponents, including
    - goods or services that were denied or prevented from being used
    - economic activity that was denied or prevented from being exercised
    - refusal of purchase or rental of housing
    - refusal of credit
    - refusal of insurance contracting, etc.
  - Identify the entity subject to the complaint, entity that dealt with the complaint, regulatory or supervisory entity.
  - Include opinions of the case investigator, the regulatory entity and the final finding from INR, including the reasons
- Review the procedures and requirements for conducting multicenter studies involving social health units towards the centralization of decision making, simplification of processes, standardization of criteria and the imposition of maximum time limits for decision making and approval processes.



## Recommendations to the National Program for HIV/AIDS Infection (PNIVS)

- Implement concrete and specific anti-discrimination training for the professional sectors where incidents of discrimination occur.
- Strengthen and revise the Labor Platform Against AIDS to prioritize anti-discrimination programs
- Promote and disseminate the anti-discrimination law, the rights of PLHIV, types of discrimination and ways to challenge discrimination.
- Initiate regular research studies of HIV and AIDS stigma and discrimination in Portugal – 3 to 5 studies in 5 years.

## Recommendations to Civil Society Organizations (CSO)

- Collect in a systemized and uniform manner information on incidents of discrimination
- Facilitate the consolidation of this information into an annual report, with wide circulation, enabling consistent monitoring of the degree of discrimination and the progress of anti-discrimination cases.
- Lobby and advocate with members of parliament, government and public administration for more effective and efficient anti-discrimination programs and policies for PLHIV.

## Disclaimer:

The People Living with HIV Stigma Index is designed as a research tool by which people living with HIV capture data on their experiences and perceptions regarding stigma and discrimination.

In this regard, the results can be said to comprise a snapshot of the level of HIV-related stigma and discrimination in a certain place and time. Through its implementation, the tool also serves to educate and empower People living with HIV on human rights related to HIV.

Survey questions therefore focus on experiences and perceptions and do not represent factual investigations, with follow up questions, into particular allegations, incidents or events nor are the answers to the questions subject to independent verification. As research participants interviewees have a right to anonymity and to confidentiality regarding their responses.

In addition to the empowerment function, appropriate uses of the data are for advocacy and in order to inform stigma/discrimination reduction programming and policy responses in the national response to HIV.

The data is not available as a source of allegations of individual instances of wrong-doing.

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Rua André Homem, Edifício SER+, n.º 60  
2750-783 Cascais,  
Portugal  
Website: [www.sermals.pt](http://www.sermals.pt)  
Email: [sermais.org@sermais.pt](mailto:sermais.org@sermais.pt)

