

# PORTUGAL

## Statistical data

Population size of the country was estimated at 10.197.000<sup>155</sup> (year 2020).

Estimate number of PLHIV is 41.305<sup>156</sup>.

The state of the 90-90-90 treatment target in 2019<sup>157</sup> was as follows:

- Percentage of PLHIV diagnosed (first 90 target): 92 %
- Percentage of PLHIV on treatment (second 90 target): 90,2 %
- Percentage of PLHIV with undetectable viral load (third 90 target): 93 %

## Main epidemiological trends

The most recent data from the epidemiological surveillance of HIV in Portugal show that in 2019<sup>158</sup>, 778 new cases of HIV infection were diagnosed, equivalent to 7,6 new cases per 100.000 inhabitants. 172 new AIDS cases and 197 deaths occurred in 2019. A total of 61.433 cases of HIV infection are cumulatively registered, of which 22.835 cases are at the AIDS stage. In the same time period, 15.213 deaths in relation to HIV/AIDS were reported.

New diagnoses in 2019 occurred mostly in residents of the Lisbon Metropolitan Area (50,4 %), with a diagnosis rate of 13,7 new cases per 100.000 inhabitants. Out of the reported cases, 69,3 % accounted to men.

In 97,3 % of the cases, the transmission occurred through sex, with 57,8 % reporting heterosexual contact. Cases in men who have sex with men (MSM) accounted to 56,7 % of diagnosed male cases. Infections associated with injecting drug use constituted 2,1 % of new diagnoses.

Between 2009 and 2018 there was a 47 % reduction in the number of new cases of HIV infection and 65 % reduction in the number of new cases of AIDS. Notwithstanding this descending trend, Portugal stands out for its high rates of new cases of HIV infection among European Union countries.

## Relevant anti-discrimination legislation applicable in healthcare settings

Legislation that shall protect PLHIV against discrimination in healthcare settings can be found at multiple legislation levels (constitutional level, primary legislation, and also in some soft law instruments). The legislation is not formulated as HIV-specific; protection is provided through general anti-discrimination provisions.

### Constitutional level

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<sup>155</sup> UN Department of Economic and social Affairs, Population Division. *World Population Prospects 2019*. Available at: <https://population.un.org/wpp/Download/Standard/Population/>

<sup>156</sup> Direção-Geral da Saúde, Instituto Nacional de Saúde Doutor Ricardo Jorge. *Infeção VIH e SIDA em Portugal – 2020*. Available at: <https://www.insa.min-saude.pt/relatorio-infecao-vih-e-sida-em-portugal-2020/>

<sup>157</sup> Ibid

<sup>158</sup> Due to the COVID-19 pandemic, the 2019 data was not yet updated by the Portuguese National Health Authority for the years of 2020 and 2021. It is expected that the number of new HIV infections has increased in these past two years.

**The Constitution of Portugal**<sup>159</sup> foresees several protections against discrimination that are also applicable to PLHIV. Nevertheless, such protection was not drafted or intended to be HIV-specific, but rather to apply to all types of discrimination. Article 13 is a general clause on the principle of equality. Paragraph 1 introduces the principle of equal treatment before the law. Paragraph 2 prohibits discrimination founded on an extensive and non-exhaustive list of protected grounds.<sup>160</sup>

Article 26 of the Portuguese Constitution provides that all citizens have constitutional protection against any and all forms of discrimination. This includes any type of discrimination in healthcare settings.

In addition, Article 26 of the Portuguese Constitution anchors the principle of human dignity and the right to privacy. It states that regardless of the human being background and of any other condition, all people have the right to enjoy a “privacy sphere”, whether in the context of domestic, family, sexual or affective life. The protection of medical confidentiality also falls within the scope of this article.

The constitutional right of privacy and protection against any kind of discrimination combined provide all citizens with a powerful constitutional weapon against any offenses or abuses by healthcare institutions regarding anyone’s health status, including the HIV+ status.

#### Primary legislation level

Some national bills foresee protection against discrimination that is also applicable to PLHIV. Nevertheless, none of these provisions was drafted to be HIV-specific.

**Law No. 46/2006**<sup>161</sup> prohibits and punishes discrimination based on disability and the existence of aggravated health risk. This law covers situations in which a person has no disability as of yet, but has a health problem or condition that could develop in a way that might result in a disability in future. The provisions of this law apply to any economic, social, cultural or other rights and protect against discrimination by any person – all natural and legal persons, public or private.

**The Labour Code of Portugal**<sup>162</sup> dedicates several articles to impose equality and non-discrimination rules on worksites. Apart from establishing a general framework for equal treatment, the Portuguese Labour Code also prohibits discrimination in regard to employers’ medical tests for occupational medicine. In Article 19 it expressly states that medical staff that carries out such medical exams is forbidden to disclose any results to the employer, and it is only responsible for informing the employer if the employee is fit to work or not.

**The Criminal Code of Portugal**<sup>163</sup> does not protect against discrimination of PLHIV directly, but it foresees some offenses against behaviours that could lead to an intrusion of someone’s personal life and the right of privacy. Any arbitrary or unjustified disclosure or discrimination against PLHIV by healthcare staff constitutes an attack on someone’s intimacy and private life and it can be qualified as a crime of invasion of privacy under Article 192 of the Portuguese Criminal Code or even the crime of violation of secrecy under Article 195 of the same legal document.

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<sup>159</sup> Constitution of Portugal (seventh revision). Available at:

<https://www.wipo.int/edocs/lexdocs/laws/en/pt/pt045en.pdf>

<sup>160</sup> Judgment of the Portuguese Supreme Court of Justice dated December 11<sup>th</sup>, 2011. No. 343/04.4TTBCL.P1.S1.

<sup>161</sup> Law No. 46/2006, as amended (Portugal). Available at: <https://dre.pt/dre/detalhe/lei/46-2006-540797>

<sup>162</sup> The Labour Code (No. 7/2009, as amended; Portugal). Available at: <https://dre.pt/dre/legislacao-consolidada/lei/2009-34546475>

<sup>163</sup> The Criminal Code (No. 48/95, as amended; Portugal). Available at: <https://dre.pt/dre/legislacao-consolidada/decreto-lei/1995-34437675>

## **Legislation that may provide basis for discrimination against PLHIV in healthcare settings**

No legislation that could directly or indirectly discriminate against or provide basis for discrimination against PLHIV/AIDS in healthcare settings was reported.

### **Means of reporting discrimination in healthcare settings (legal and other remedies)**

#### Complaint procedures

All healthcare facilities in Portugal are obliged to have a complaint book<sup>164</sup> available in a visible place to all patients. The main goal of the complaint book is to provide all patients a simple and clear way to report any unpleasant situations whenever they are assisted by the healthcare staff.

Healthcare institutions are obliged to disclose all complaints written in the complaint book to the Authority for Food and Economic Security (ASAE), the state authority that controls compliance for the legislation and consumer rights in all the public attendance services and also in all public administration services and bodies. It is also possible for the healthcare patients not to write a complaint *in loco*, but rather to do it online, as all healthcare institutions are obliged to have an online complaint book<sup>165,166</sup> as well.

Whenever they constitute a crime or violation of legal obligations, these complaints may lead to infraction proceedings and, depending on the gravity of the infringement, criminal proceedings against the healthcare institution can be triggered. In case of discrimination due to someone's HIV-status, as it infringes both constitutional and human rights, it is also possible for anyone to directly write a letter to the Portuguese Attorney General's Office.

#### Legal intervention

In addition, anyone whose rights have been infringed or who has been a victim of any type of discrimination can file a civil lawsuit against whoever infringed those rights or who has deliberately discriminated. The Portuguese law does not limit the extent of claims for monetary compensation – the awarded amount depends on the severity of each case. Generally speaking, monetary compensation in Portugal is quite low (specially compared to compensation commonly awarded in the UK or the USA).

### **Obligation of PLHIV to disclose their HIV+ status in healthcare settings**

There is no legislation in Portugal that requires any person to disclose his/her health status, including the HIV status. In other words, there is no legal obligation for any person to disclose that they are HIV+ to healthcare workers.

However, in specific situations the duty to disclose the HIV status might occur. A case-by-case assessment shall be done by the PLHIV whenever they use healthcare services, especially when their life might be in jeopardy. For instance, no one is ever obliged to disclose his/her HIV status during a dentist appointment, even if such question

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<sup>164</sup>The complaint book is also available on-line in English at <https://www.livroreclamacoes.pt/inicio>.

<sup>165</sup> Decree-Law No. 74/2017, as amended (Portugal). Available at: <https://data.dre.pt/web/guest/pesquisa/-/search/107541411/details/maximized>

<sup>166</sup> Online complaint book for healthcare settings is available at <https://www.ers.pt/pt/utentes/formularios/reclamacoes-online/>.

is directly asked by the healthcare workers. On the other hand, it might be relevant for a patient to disclose his/her HIV status to healthcare workers if he/she has to be hospitalised (in order to adhere to the ARV treatment).

### **Confidentiality and accessibility of personal data related to HIV**

HIV-related data is not accessible to third parties unless there is a prior informed and clear consent from the HIV+ patient. Sharing HIV-related data with other healthcare facilities is also strictly prohibited. If the obligation of secrecy is violated, significant penalties could be imposed. As institutions dealing with personal data, all healthcare institutions must adhere to the EU General Data Protection Regulation which lays down rules relating to the processing of personal data (e.g. collection, recording, organisation, structuring, storage, etc.). Any data concerning health (including the HIV status) is classified as sensitive personal data under the EU General Data Protection Regulation and is protected as such.

### **Prohibitions and limitations on working in specific healthcare professions for PLHIV**

Under Portuguese law, there are no restrictions for the employment of PLHIV in the healthcare sector. However, there is a relevant internal regulation of the Portuguese Health Authority<sup>167</sup> regarding the Department of Quality System for Blood Establishments. This regulation states that “*professionals affected by any infectious disease or with continuity lesions on the exposed surface of the body should be formally prevented from intervening in the preparation of blood components and be subject to subsequent clinical evaluation*”. The Centre for Anti-Discrimination sent a letter to the Health Authority requesting for clarification in order to better understand whether there is a real discrimination for PLHIV to carry out blood collection and/or handling service. Until this day, the Centre for Anti-Discrimination has not received any answer to its letter. As soon as the COVID-19 pandemic is under control, a new request will be made.

### **Private insurance policies concerning PLHIV**

PLHIV encounter difficulties in access to life or health-related insurance policies as they are frequently denied to them or, alternatively, the insurance premiums are disproportionately increased. The Centre for Anti-Discrimination recently received a complaint from a person whose insurance coverage was denied by a health insurance company exclusively because he revealed that he was HIV+. Due to that disclosure, the insurance company automatically refused any coverage to any treatment that could anyhow be related to the HIV+ status. Such instances of discrimination are unfortunately still common.

Notwithstanding the foregoing, new positive development in this matter occurred in Portugal during the second half of 2021. A bold innovative act<sup>168</sup> was approved by the Portuguese Parliament and promulgated by the President of the Republic. This act enshrines the so called “right to be forgotten” allowing for people who have

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<sup>167</sup> Regulation of the Health Authority of Portugal No. 021/2017. Available at:

[http://www.ipst.pt/files/IPST/INFORMACAO\\_DOCUMENTACAO/Norma\\_21\\_2017\\_DGS\\_especificacoes\\_sistema\\_qualidade\\_servicos\\_sangue\\_medicina\\_transfusional.pdf](http://www.ipst.pt/files/IPST/INFORMACAO_DOCUMENTACAO/Norma_21_2017_DGS_especificacoes_sistema_qualidade_servicos_sangue_medicina_transfusional.pdf).

<sup>168</sup> Law No. 691/XIV/2 (Portugal). Available at:

<https://app.parlamento.pt/webutils/docs/doc.pdf?path=6148523063446f764c324679626d56304c334e706447567a4c31684a566b786c5a79394562324e31625756756447397a5357357059326c6864476c32595339694e325a6c596a55304f5330784e446c6c4c5451325a575174596a426b5a53316a4e7a686d4d324577593251785a5463755a47396a&fich=b7feb549-149e-46ed-b0de-c78f3a0cd1e7.doc&Inline=true>

overcome serious illnesses (e.g. cancer) or have successfully mitigated situations of aggravated health risk or disability (e.g. HIV) to have data regarding these previous illnesses or health risks disguised from insurance companies and credit institutions.

From a practical standpoint, insurance companies will be forbidden to collect this kind of health-related personal data (thus, they will not be able to reflect such information into the insurance policy conditions) if a person living with HIV has been undergoing a continuous and effective therapeutic protocol (i.e. has had an undetectable viral load) for over 2 years.

For PLHIV, this act – which comes into effect on January 1<sup>st</sup>, 2022 – guarantees that they cannot be subject to an increase in insurance premiums. Furthermore, as no HIV-related data can be collected by the insurance companies once the infection is being successfully treated, this act shall also ensure that PLHIV are not denied insurance coverage. For the still very discriminative insurance market, this act represents a turning point.

### Common forms of discrimination in healthcare settings

Since PLHIV do not have a general obligation to disclose their HIV+ status, instances of discrimination in healthcare setting do not occur often. All known cases reported to the Centre for Anti-Discrimination took place in specialist outpatient care, most of them in dental care settings. These cases of discrimination involved refusal-of-care, separation of other patients, and providing treatment at the end of the office hours.

1) The reported **refusal-of-care** cases most often occurred in connection to PLHIV who use drugs or to PLHIV who are also transgender, as the stigma and discrimination around drug use and transgender people is still a real problem in Portugal. A case was reported in 2020, in which an HIV+ patient was denied a biopsy because the medical doctor who was responsible for performing such procedure alleged a *“high risk of doing the procedure due to the fact that the patient was HIV+”*.

2) The reported cases of **separation of PLHIV from other patients** took place in Santa Maria Hospital, based in Lisbon which provides healthcare services of all specialties, including dental surgery<sup>169</sup>. PLHIV in Portugal facing economic and financial difficulties have, by law, access to dental treatment for free under the dentist-cheque programme (other population groups that have access to this programme are (i.) children until the age of 18; (ii.) pregnant women; and (iii.) people who are/were diagnosed with oral cancer).<sup>170</sup> Although the dentist-cheque programme does not list why a specific patient has access to it, it is easy for healthcare staff to deduce the reason. The Centre for Anti-Discrimination received several complaints of PLHIV regarding the fact that although there are several dental cabinets available in the hospital, PLHIV were only being headed to cabinet No. 16, even if that would imply longer waiting hours or even if the other cabinets were available. After further analysis, it was found that a serious case of HIV discrimination was happening in the dental surgery section of the hospital – deliberately separating PLHIV patients from other patients.

3) The reported cases of **providing treatment at the end of the office hours** also occurred in dental care settings. The Centre for Anti-Discrimination received several complaints regarding dental clinics that, also due to the dentist-cheque program, would only treat HIV+ patients at the end of the office hours. When approached by the

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<sup>169</sup> Frequent reports of this form of discrimination date to several years ago. The situation was addressed, tackled and currently there is no record of recurrence.

<sup>170</sup> Order of the Ministry of Health No. 7402/2013 (Portugal). Available at: <https://dre.pt/dre/detalhe/despacho/7402-2013-2947076>

Centre for Anti-Discrimination to provide an explanation for this behaviour, most of them stated they were providing treatment to PLHIV last to protect the health and safety of all other patients.

### **Case studies**

No litigation cases dealing with discrimination against PLHIV in healthcare settings, that would have significant impact on legislation, policies, or practices in Portugal, were reported in the questionnaire.

### **Good practices in the national context**

#### Activities to increase legal literacy of PLHIV and healthcare staff

Most PLHIV in Portugal are unaware of their rights and obligations, as well as most legislation that protects them in healthcare settings. Additionally, most hospitals and healthcare facilities in Portugal do not have any procedures in place to treat and to deal with PLHIV in such premises; namely, in crowded public areas such as receptions and secretariats where sensitive personal data disclosures and conversations are held.

Stigma and discrimination in healthcare settings towards PLHIV is not a common issue in Portugal, although there are still some isolated cases. These mostly occur regarding PLHIV who are also drug users, immigrants, or transgender. It might be concluded that the main problem in healthcare settings around PLHIV in Portugal is not the stigma and discrimination *per se*, but rather the ignorance around the HIV topic, that unfortunately is still disseminated among the healthcare staff.

To tackle these issues, the Group of Activists for Treatments (hereinafter "GAT") has been implementing several activities that have shown positive impacts on fighting discrimination and stigma towards PLHIV in healthcare settings and can nowadays be considered as good practices.

#### 1) Support group available to newly diagnosed PLHIV

A group of volunteers in Portugal provides emotional support and further assistance to people who receive their first HIV+ diagnosis. They are also available to accompany the PLHIV in their initial doctor appointments for their ARV treatment. These volunteers are quite comfortable with the healthcare settings procedures and are aware of the current legislations and policies in place regarding HIV treatment and hospital environments, so that they can address any discrimination or stigmatizing behaviour (by educating everyone on the good practices to follow). It has become clear that this support has helped several PLHIV in the beginning of their treatment – especially empowering PLHIV and mitigating any situations in which someone stops going to ARV treatment appointments due to fear of discrimination. It has also shown to be an incredible asset on educating both healthcare workers and PLHIV on their rights and obligations.

#### 2) Guidance to PLHIV who have the status of immigrants

GAT provides guidance to PLHIV in Portugal that are also immigrants and still do not have a regular status in the country. These individuals do not have the national health number that allows for free access to the national health system and, consequently, to have free access to ARV treatment. GAT has drafted and translated in 10 different languages a Q&A flyer to clarify some vital topics related to access to healthcare for PLHIV and viral

hepatitis<sup>171</sup>. This is a very useful tool, especially for individuals who do not speak Portuguese and who need to have urgent access to the Portuguese National Health System, but their immigration status is still irregular.

### **Issues and bad practices in the national context**

In Portugal, there is little data available about bad practices directly or indirectly related to PLHIV in healthcare settings (other than the issues described in the previous sections). To tackle this issue, Portugal's Health Authority launched in 2020 a replication of the Stigma Index<sup>172</sup> research study to better assess the real issues and draft priorities for the years to come. However, due to the COVID-19 pandemic, the Stigma Index research had been interrupted and thus the data collection period was later extended until the end of January 2022.

In 2020, the Centre for Anti-Discrimination dealt with over 30 complaints regarding situations of discrimination or violation of PLHIV's rights in healthcare settings. The overwhelming majority of these complaints were directly related to discrimination against PLHIV by creating unnecessary and unjustified barriers to free and fast access to doctor appointments and ARV treatment. The Centre for Anti-Discrimination also received several complaints regarding the undue payment of user charges to PLHIV in healthcare setting when all doctor appointments and treatment are free of any charges as per the legislation in place.

It is quite clear, that most cases of discrimination and stigma against PLHIV are not deliberated. The main problem in healthcare settings around PLHIV in Portugal is the lack of knowledge regarding the topic of HIV as well as the lack of knowledge on the legislation, policies, and guidelines in place to prevent stigma and discrimination which leads to instances of bad practices.

### **COVID-19 impact on PLHIV**

#### Access to HIV care

Due to the COVID-19 pandemic constraints in healthcare, the barriers in access to either consultations and/or treatment increased significantly, as the ART treatment is only available in the State Hospitals' pharmacies. Due to the frequent changes of personnel, operating hours as well as the measures introduced in order to tackle the COVID-19 pandemic, PLHIV faced challenging times.

In 2020, the Centre for Anti-Discrimination dealt with 30 complaints regarding situations of discrimination or violation of people's rights in healthcare settings. Most of those complaints are directly related to the consequences of the COVID-19 pandemic, namely difficulty in booking medical appointments and access to medication.

Notwithstanding the foregoing, there was no change in the legislation in response to the COVID-19 pandemic that has affected PLHIV disproportionately and/or discriminatorily.

#### Inclusion of PLHIV in priority vaccination groups<sup>173</sup>

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<sup>171</sup> GAT Portugal. *Publications: Leaflets*. Available at: <https://www.gatportugal.org/publicacoes/folhetos>

<sup>172</sup> SER+, GNP+. *Avaliação do Índice de Estigma das PVV em Portugal*. Available at: <https://cad.vih.pt/wp-content/uploads/2020/06/stigma-index-portugal-relatorio-final-portugus-1-1.pdf>

<sup>173</sup> Ministry of Health of Portugal. *Campanha de Vacinação Contra a COVID-19*. Available at: <https://covid19.min-saude.pt/wp-content/uploads/2021/05/i027514.pdf>

COVID-19 vaccination in Portugal follows a 2-phase vaccination scheme in which priority vaccination groups have been established based on “vulnerability”.

In Phase 2, from April 2021, immunocompromised PLHIV were included for priority vaccination.