Original scientific article
Izvorni znanstveni članak

Acta Med Hist Adriat 2025; 23(1);141-165
https://doi.org/10.31952/amha.23.1.7

FIGHTING AIDS IN PORTUGAL: THE RESPONSES OF PUBLIC HEALTH AUTHORITIES (1983–2000)

BORBA PROTIV AIDS-a U PORTUGALU: REAKCIJE JAVNOZDRAVSTVENIH VLASTI (1983. – 2000.)[1]

Paula Basso*

SUMMARY

The first official case of HIV infection in Portugal was confirmed in 1983. Faced with the threat of a global epidemic caused by an unknown virus, Portugal responded to the WHO's call in 1985 by establishing institutions with the aim of supporting state decisions, conducting epidemiological studies, controlling the spread of the virus, diagnosing cases, disseminating information, and educating the population. Portugal has come a long way from initially denying the existence of the disease and refusing to disclose the positive result to patients. The serious case of infecting haemophiliacs with a batch of Factor VIII imported from an Austrian laboratory, resulting in the deaths of dozens of patients, forced the Portuguese public health authorities to create organisations able to face the fight against AIDS. By trying to control the serious drug addiction problem after the Portuguese revolution of April 1974, the conservative society was able to change its attitude and pass groundbreaking legislation worldwide and implement a successful programme to control AIDS infection among injecting drug users.

Issues such as the effectiveness of these measures in controlling the AIDS epidemic and their impact on Portuguese society at the end of the 20th century will be addressed in this paper.

***Keywords**: AIDS, HIV, drug users, public health, Portugal*

* Interuniversity Centre for the History of Science and Technology, Nova School of Science and Technology, Lisbon, Portugal. ORCID: https://orcid.org/0009-0000-8210-8952.
Correspondence Address: Paula Basso, Interuniversity Centre for the History of Science and Technology, Largo da Torre, 2829-516 Caparica, Portugal. E-mail: paula.basso@anf.pt.

Introduction

On 5th June 1981, the Centres for Disease Control (CDC) published a report detailing the unusual case of five previously healthy young homosexual men affected by *Pneumocystis carinii* pneumonia (PCP) in Los Angeles (C. for D. C. CDC, 1981b). Health authorities later detected an increase in cases of Kaposi's sarcoma (KS) among gay men in New York, which triggered alarm over these outbreaks of PCP and KS—rare and deadly diseases associated with immunodeficiency among the homosexual community (C. for D. C. CDC, 1981a).

After the first cases, the disease spread throughout the world by sexual, blood, and parental transmission to such an extent that by 1996, HIV/AIDS had become the leading cause of death among people aged 25 to 44, especially among impoverished populations in Africa, Asia, and South and Central America (Brandt, 2020; C. for D. C. and P. CDC & Curran, James W, 1996; Elizabeth & Fox, 1988; Engel, 2007; Greene, 2007; Grmek, 1994; Oppenheimer, 1988; Pépin, 2019; Quammen, 2015; Sharp & Hahn, 2011).

According to the latest global statistics presented by UNAIDS[1] in 2024, approximately 91 million individuals have been infected with HIV since 1981, with more than 44 million deaths, with the peak of HIV infection occurring in 1996. In 2024, there were approximately 40 million people living with HIV worldwide, 21 million of whom were in Eastern and Southern Africa, the region most affected by HIV infection («Global HIV & AIDS Statistics — Fact Sheet | UNAIDS 2024», 2025)

The first news story in Portugal claiming the existence of an AIDS case was published in *Diário de Lisboa* on 7 July 1983, and was immediately officially denied by the national health authorities, such as the *Direção-Geral da Saúde* (DGS) and the *Instituto Nacional do Sangue* (INS), which jointly sent an official denial to ANOP[2].

Two decades after this news, Portugal was still at the peak of HIV infection. It was the country in the European Union with the highest incidence rate of AIDS cases (105.8 cases per million inhabitants in 2001), before starting a downward trajectory (Centro de Vigilância Epidemiológica das Doenças Transmissíveis, 2004; Paixão, 2003). In 2002, tuberculosis incidence rates in Portugal were four times higher than in other European Union countries, and these levels are related

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1 UNAIDS or ONUSIDA is the Joint United Nations Programme on HIV/AIDS, established in 1996 with the aim of finding solutions and helping nations combat AIDS.

2 ANOP was the Portuguese News Agency that was abolished in 1986.

to socio-economic factors, inaccessibility of healthcare and immigration (Santana & Nogueira, 2005).

In Portugal, over the four decades of the AIDS epidemic (1983–2023), a cumulative of 68,627 cases of HIV infection were reported, with diagnoses recorded up to 31 December 2023; of these 23,955 progressed to AIDS stage. A further 15,918 deaths were reported (Santana & Nogueira, 2005, p. 36). There was a 56% reduction in the number of new cases of HIV infection and a 74% reduction in new cases of AIDS between 2013 and 2022 (Ministério da Saúde. Direção-Geral da Saúde/Instituto Nacional de Portugal, 2023).

To achieve this sustained downward trend in new HIV and AIDS cases over the past forty years, Portugal has implemented a range of measures to combat the epidemic. These included the formation of specialised teams, the establishment of institutions capable of achieving these results, and campaigns to mobilise the population.

From the initial denial of the disease, through the cases of contamination of haemophiliacs with a batch of Factor VIII imported from an Austrian laboratory, to the approval of innovative legislation that did not consider drug abuse as a crime but as a penalty, and finally the ability to implement a successful AIDS control programs among injecting drug users, Portugal has come a long way. And it is this path, particularly during the early 1980s and 1990s, that we aim to explore.

The methodology used to approach this subject was to study and analyse the documentation currently included in the Fundo Odette Ferreira at the *Arquivo Nacional das Farmácias*. This material was cross-referenced with epidemiological data from official reports published by the *Direção-Geral da Saúde* (DGS), the *Instituto Nacional de Saúde Doutor Ricardo Jorge* (INSA), the *Centro de Vigilância Epidemiológica das Doenças Transmissíveis* (CVEDT), the *Grupo de Trabalho da SIDA* (GTS), the *Comissão Nacional de Luta Contra a SIDA* (CNLCS), and the *Instituto para os Comportamentos Aditivos e as Dependências* (ICAD). In addition, Portuguese legislation, materials from information and education campaigns, as well as interviews, newspapers or television news and reports were reviewed in order to assess the impact of public health measures on the control of HIV and AIDS infection in Portugal.

The reality of the disease in Portugal and the formation of the Grupo de Trabalho da SIDA under the direction of Laura Ayres (1985–1990)

In the early 1980s, the reality of the disease was largely ignored by Portuguese public health authorities and surrounded by a wall of silence, with the medical profession refusing to make statements on this taboo subject. According to Rui Proença, director of the Infectious Diseases Department at Curry Cabral Hospital, "[Our] patients were a ghetto, the therapeutic options scarce or almost non-existent". The hospital administrations adopted a negative attitude towards AIDS. There was no access to disposable material, and the used syringes and needles were sterilised in pots of boiling water, heated by a Bunsen burner (Machado, 2021, p. 7).

Official entities such as the Ministry of Health, hospital administrations, and doctors themselves did not reveal the existence of AIDS patients in hospitals, the deaths, or the existence of people infected with HIV, which was discovered and identified in 1983 by Luc Montagnier's team at the Pasteur Institute in Paris. Secrecy prevailed, diagnostic tests were non-existent, and health authorities implemented control measures only late, due to the view that the problem was restricted to minority and marginalised groups in society and was not alarming compared to other pathologies. The population was not even informed about how to avoid infection (Ferronha & Catarina, 1985).

At the beginning of the 1980s, there were no HIV tests for blood donations in Portugal, reflecting the mentality of the time that personal appearance and seeming healthy were considered essential, since 'only those who feel and look healthy give blood' (Lacerda, 1985). Blood concentrates manufactured by multinational companies were produced from the blood of individuals in low-income countries, who donated it primarily for financial reasons. For this reason, in December 1985, the *Federação Portuguesa dos Dadores Benévolos de Sangue* appealed to the Minister of Health to end the import of these blood products (Muitos Vendem "Para Matar a Fome." Federação Internacional de Dadores Condena "Comércio de Sangue", 1985).

It was not until May 1985 that the *Instituto Nacional do Sangue* began testing for 'anti-HTLV-3 antibodies' («Nova Peste» está em Portugal—Testes à S.I.D.A. entram na rotina, 1985) on blood collected at mobile brigades and fixed stations, although due to its high price, it was not possible to carry out this procedure systematically. Furthermore, given the lack of knowledge about the incidence of the

virus among blood donors, those who might belong to high-risk groups were not asked to refrain from donating blood (Ferronha & Catarina, 1985, p. 15).

Additionally, because of this issue, Portuguese hospitals distributed several tests that were clearly insufficient in relation to the actual needs of blood donors, and health professionals faced the dilemma of which criteria to adopt for selecting donors for this test. The confidence of the hospital's Blood Services in donors' responses to the epidemiological survey that preceded donation was progressively undermined, and it became clear that HIV testing was mandatory for all donors, which only happened later.

Following the guidelines of the World Health Organisation and its call on 30 May 1985 to combat the new infection, Health Minister António Maldonado Gonelha (1935–2022) set up the Grupo de Trabalho da SIDA on 20 June of the same year. Portugal was one of the first countries to respond to the WHO's call and create a specific institution to combat the new HIV/AIDS infection.[3] This institution was initially led by Laura Ayres (1922–1992), as deputy director of INSA.[4]

The Grupo de Trabalho da SIDA's (GTS or AIDS Working Group) objectives were to gather information on new cases of HIV and AIDS infection, confirm or refute the diagnoses made, and implement strategies at the national level to prevent infection. The GTS thus established epidemiological surveillance as a priority

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3 Germany was a pioneer in the fight against HIV and AIDS, having set up the *Deutsche AIDS-Hilfe* in 1983, one of the first initiatives in Europe. In Spain, the Plan *Nacional sobre el Sida* (PNS) was set up in 1987 by the Ministry of Health with the aim of coordinating prevention, treatment and monitoring of the HIV and AIDS epidemic in the country. In Italy, the *Centro Operativo AIDS* (COA) was also established in 1987, with the same objectives of monitoring, prevention, treatment, and promoting awareness and education campaigns. In France, in addition to the *Groupe de travail français sur le SIDA,* created in 1982 to promote research and monitor the evolution of cases, the *Agence Nationale de Recherches sur le Sida* (ANRS) was founded in 1989 to fund and coordinate research in this area. In the UK, the British government began implementing HIV surveillance programmes as soon as the first cases appeared, but no specific institution was set up to combat AIDS. In the USA, the *Office of AIDS Research* (OAR) was founded in 1987 as part of the National Institutes of Health (NIH), responsible for coordinating federal research into HIV and AIDS. In 1985, Brazil officially recognised the first cases of AIDS, and the Ministry of Health created the National STD/AIDS Programme to respond to the epidemic.

4 Laura Ayres (1922–1992), a doctor and virologist, established the Virology Laboratory at INSA in 1955 and coordinated the first National Serological Survey between 1979 and 1980, which was awarded the Ricardo Jorge Public Health Prize in 1983. In 1983, she became deputy director of INSA, responsible for the creation and development of CVEDT (1985) and the AIDS Reference Laboratory (1987). She was the first coordinator of the AIDS Working Group, implementing the first public health policies against this epidemic in Portugal (Cunha-Oliveira, 2018, p. 65).

and strategy for combating AIDS, which included identifying sources of information, collecting and processing data, making recommendations to the authorities, and spreading information.

The objectives of the AIDS Epidemiological Surveillance Programme were also defined as: detecting cases of AIDS and para-AIDS in Portugal and monitoring their incidence; describing the epidemiology of AIDS; providing information to the Health Services on the situation in the country; and providing data to the Ministry of Health, the WHO, and the *Cooperative Centre in France* (Centre for Epidemiological Surveillance of Communicable Diseases, 1986, pp. 1–2).

In August 1985, Pedro Franco, head of the *Instituto Nacional do Sangue* and a member of the GTS, stated that 'the results of the tests are not revealed even to the person concerned' (SIDA, 1985b).

SIDA

Resultados dos testes não são comunicados aos interessados

Ainda não surgiram resultados positivos e já se vai no segundo milhar

O dr. Pedro Franco, director do Instituto Nacional de Sangue, disse-nos esta manhã que os testes «anti-SIDA» que estão a ser efectuados em Portugal já vão no segundo milhar, e que os seus resultados não são comunicados aos interessados, para se evitar o estabelecimento de situações de pânico. Os testes não funcionam, em caso nenhum, como diagnóstico, fornecendo uma mera indicação sobre a existência de anticorpos provocados pelo vírus responsável pela SIDA. A presença de anticorpos, por outro lado, também não é indicação suficiente sobre a natureza de qualquer doença. O grupo coordenador recentemente criado, e de que faz parte o dr. Pedro Franco, encaminhará, de futuro, as pessoas «suspeitas» de poderem ter contraído a doença para serviços que estão a ser destinados a esse efeito. Ainda não apareceu qualquer resultado positivo nos testes feitos pelo Instituto Nacional de Sangue. Entretanto, outras fontes médicas confirmam a existência de um mínimo de 20 casos de SIDA já identificados em Portugal, embora alguns dos doentes já tenham morrido. Pág. 11

Figure 1. "AIDS, test results are not communicated to those concerned." Diário de Lisboa, 21 August 1985.

In August 1985, the newspaper *Tal & Qual* criticised the lack of response from state bodies, in particular the lack of awareness campaigns among the populations most exposed to the virus and access to HIV diagnostic tests. Laura Ayres, as coordinator of the AIDS Working Group, even stated that it would not be logical for the tests to be carried out at the national level, nor would it be financially bearable, and that "her commission will try to prevent or prohibit private laboratories from being authorised to carry out anti-AIDS analyses" (Morais, 1985).

The media began to take an interest in the issue, publishing more and more articles on AIDS and putting pressure on the Ministry of Health, forcing a public clarification with an express request for a full text to be published on 30 August 1985 in the newspaper *Diário Popular* (SIDA, 1985a).

At the beginning of September 1985, the GTS published its first normative circular (No. 35/85) and proposed various measures such as the creation of notification sheets to be sent to central hospitals and general practitioners for a correct assessment of the problem; protocols for serological surveys to find out the prevalence of infection; safety standards for health professionals to be sent to hospital services, laboratories, nursing stations, and the community; screening for antibody carriers in blood and organ donors; control of products administered to haemophiliacs; and the development of laboratory and clinical services to study patients and their contacts ('SIDA', 1985a).

To achieve this, and given that the disease was described as "terrifying to part of the population" ('AIDS consultations start in hospitals – Assistance for high-risk groups', 1985), Laura Ayres also announced that outpatient AIDS consultations for members of "high-risk groups" in the dermatology and infectious diseases sectors would be made available in properly equipped hospitals, without specifying which ones.

Given the public's social alarm, anonymity in the detected cases was essential for communicating the information, because, according to Laura Ayres, 'we do not want to create a new wave of lepers' (SIDA já causou quatro mortes e há sete casos em observação – Mário Soares no Curry Cabral faz ponto da situação, 1985).

On 7 November 1985, the President of the Portuguese Association of Haemophiliacs (APH) denounced the stance of the GTS for completely ignoring his association and refusing to provide any information on the number of people infected with HIV or the deaths that had occurred in Portugal, unlike the practice in other European countries. He also criticised the position taken by Pedro Franco, who, as National Coordinator of the *Comissão Nacional de Hemofilia*, on behalf of the *Instituto Nacional do Sangue*, claimed that he had nothing to do with haemophili-

acs, as they had their own centres and were treated in hospital blood departments (Lopes, 1985).

On 27 June 1985, the APH delivered a document to the *Comissão Nacional de Hemofilia* indicating the need for immediate screening of cryoprecipitates and national donors. Pedro Franco believed these measures could not be implemented because no justifiable reasons existed. This warning was also ignored by the Portuguese Ministry of Health, and in January 1986, many haemophiliacs were infected with Factor VIII concentrate based on donated plasma from an Austrian laboratory and dozens of patients died.[5] This case was denied for years by the official authorities. It was only in June 2000, after a long court case, that the Portuguese state recognised the error that had occurred in public hospitals and approved compensation to be awarded to the infected haemophiliacs and their families (Ministerial Order no. 321/2000 | DR, 2000).

On 14 November 1985, the *Centro de Vigilância Epidemiológica das Doenças Transmissíveis* (CVEDT) was created with the functions of surveillance of communicable diseases based on laboratory data and other epidemiological information; establishing liaison with hospital laboratories; processing the data obtained and providing feedback to laboratories, primary and differentiated health care services and the Ministry of Health; establishing communicable disease surveillance programmes in liaison with primary and specialised health services; organising training activities in the form of courses, seminars, and lectures for health professionals; establishing contacts with similar centres and the WHO, and carrying out research projects. The GTS began to operate within the scope of CVEDT, without prejudice to its direct dependence on the Minister of Health (Ministerial Order 861/85 | DR, 1985).

In 1985, at the dawn of a new infectious disease, hospital conditions in Portugal were still somewhat precarious, and there was a huge lack of knowledge among doctors and nurses. As the number of hospitalised AIDS patients increased, problems arose for which neither the health professionals nor the hospital structures were prepared. In most hospitals, there was only one bathroom per ward, and no isolation areas were available for patients. Material for injections was still sterilised in pots of boiling water, and gowns were washed at the health professionals'

[5] In January 1986, despite warnings from the APH, the Ministry of Health awarded a contract for the purchase of Factor VIII concentrate, based on donated plasma, to the PlasmaPharm Sera laboratory in Austria. One of the batches of the medicine was contaminated with HIV and ended up being administered to 137 haemophiliac patients in various Portuguese hospitals, particularly the São José Hospital, between June 1986 and February 1987, 35 of patients became infected and 23 died by the year 2000. ('Caso dos hemofílicos', 1991; Rodrigues dos Santos, 1992).

homes. There was no adequate training to deal with AIDS, and, given the lack of knowledge about how HIV is transmitted, fear set in. Changes to hospital procedures and routines became essential, as did the creation of isolation zones, the purchase of disposable needles, syringes, and gowns and the use of gloves and masks when caring for patients. Adequate training for health professionals was also essential to reduce the risk of infection ('Apenas um caso mortal com SIDA - No Hospital Curry', 1985, pp. 714–734).

On the other hand, the very long and demanding treatment of AIDS patients completely changed the routine of hospitals organised for short or medium stays. They also had their own characteristics that required the nursing staff to adapt, such as 'a session with a sexologist to inform the staff about transsexuality'. As one account noted, 'the nurses themselves found it difficult to understand a patient who, being a man, dressed as a woman' (Figueiredo, 1989).

With regard to safety standards for health professionals, and given the lack of any recommendations from official public health bodies until September 1985, a circular was distributed on the initiative of paramedical professional groups to 'services and institutions linked to the treatment of AIDS patients or blood services' ('"Precauções" aconselhadas ao pessoal de laboratório e enfermaria', 1985). It provided basic notions on the modes of contamination and the precautions to be adopted. This circular reflected the lack of information among health professionals on how to deal with these patients, and advised the same procedures used for hepatitis B patients.

In 1987, the *Laboratório de Referência da SIDA* (AIDS Reference Laboratory) was created at the *Instituto Nacional de Saúde, Doutor Ricardo Jorge* (INSA), with the aim of ensuring epidemiological surveillance, diagnosis, and confirmation of HIV and AIDS infection. If there was any doubt about the results, the AIDS Reference Laboratory sent them to the U.S. Centres for Disease Control (CDC) for further validation. It also carried out quality control of the laboratory kits used on the Portuguese market to detect HIV-1 and HIV-2 (Figueiredo, 1989). From the outset, it was led by biologist Francisca Avillez (b. 1948) and was fundamental in monitoring and researching AIDS in Portugal.

In February 1988, even before the haemophiliac case had shocked public opinion, the then-new director of the *Instituto Nacional do Sangue*, Benvindo Justiça, criticised the INS, namely the methods used to carry out collection, classification, and transfusion, and was immediately dismissed by the Minister of Health, Leonor Beleza (1985–1990). Justiça reported that "every day in Portugal, patients

die because they receive unscreened blood transfusions" (*Leonor Beleza demite Diretor do Instituto Nacional do Sangue, por alertar contra risco de SIDA*, 1988).

In the early years of the AIDS epidemic, the disease seemed to be restricted to a few people and therefore aroused little interest. However, when it began to appear in children and people with haemophilia, panic set in and the realisation dawned that a broad public awareness campaign was needed.[6]

In August 1989, the GTS launched a campaign entitled 'SIDA ou Vida, Decida!' ('AIDS or Life, decide!') with posters in the main Portuguese cities aimed at alerting young people to the problem of AIDS in the summer, and especially aimed at young women.

However, this campaign was not explicit in its way of communicating with the public, and the information was conveyed in a veiled and disguised way, neither appealing directly to the use of condoms, nor informing about other ways of transmitting HIV.

All the information material on HIV and AIDS produced by the GTS was not really appealing in graphic and communication terms, and it was not suitable for conveying information to the public, especially young people. The content provided was presented in a way that was too technical and specialised to be easily understood, and the message did not easily reach the public, contributing to the Portuguese population's ignorance and lack of knowledge about AIDS.

According to a patient admitted to Santa Maria Hospital, who had lived abroad for some time, the information made available about the disease was poor: 'When I came back, the Portuguese lived in a different dimension. The mentality is that

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6 One of the most striking and pioneering national campaigns in Europe was in 1986 in the UK, with the slogan 'Don't Die of Ignorance'. The campaign involved the mass distribution of leaflets to every household in the UK and television adverts explaining the risks and ways of preventing AIDS, with a focus on condom use and HIV awareness. In 1987, the first campaign was launched in France on a large scale in the media, with the motto "Le SIDA, il ne passera pas par moi" (AIDS will not pass by me), encouraging the use of condoms. Also in 1987, Germany launched a national campaign entitled 'Gib AIDS keine Chance' (Don't give AIDS a chance), which became one of the longest lasting in Europe, focusing on safe practices, sex education, and combating stigma. In 1988, Brazil launched the 'Use camisinha' (Use a condom) campaign with adverts on television, radio, and the distribution of free condoms. In the U.S., the CDC launched the America Responds to AIDS campaign from 1987 to 1996, to raise awareness among a diverse public defined by identity or behaviour, from heterosexual single mothers to teenagers of all races, young African American adults, and people living in rural areas. The campaign reached millions of people, becoming a central element of the 'everyone is at risk' strategy for the U.S. AIDS prevention.

the disease only infects others. In terms of information, Portugal is still underdeveloped.' (Figueiredo, 1989, p. 35)

Moreover, according to the psychiatrist at Santa Maria Hospital, Nuno Félix da Costa, the populations most at risk, such as prisoners and drug addicts, had no access to the information made available about AIDS (Figueiredo, 1989, p. 35).

Given the objectives set for the GTS of AIDS epidemiological surveillance, education, information, training, planning, and organisation of hospital services, as well as the development of laboratory diagnostic means, the overall performance in 1980s was slightly below expectations.

The difficulties in implementing these measures were enormous, the resources were scarce, and there was a certain resistance in society to tackling taboo subjects such as sexuality, drug addiction, and homosexuality, which made all the actions of the GTS difficult.

The comissão nacional da luta contra a sida under the leadership of laura ayres and machado caetano (1990–1992)

However, in April 1990, in view of the inexorable advance of the epidemic in Portugal, the AIDS Working Group was reformulated and renamed the *Comissão Nacional da Luta Contra a SIDA* (CNLCS or National Commission Against AIDS) to be coordinated by the Ministry of Health (República, 1990). Given the lack of specific treatment and prevention of HIV and AIDS infection, the importance of information and education was reinforced as the only means of halting the progression of the disease.

In the summer of 1990, the publicity campaign in the media, now launched by this new institution, was aimed at alerting the population to the use of condoms as a means of preventing the disease. This initiative was publicised through a press conference, and there was a noticeable embarrassment at the approach to topics such as sexuality ('Conferência de imprensa do Grupo de Trabalho da Sida, para anunciar campanha de prevenção na rádio e televisão', 1990).

On 28 May 1991, the Minister of Health announced that AZT, the first drug used to treat AIDS, would be distributed free of charge in hospitals. Given the difficulty of accessing information and the particularly delicate nature of the disease, the Ministry of Health launched the AIDS Line in July 1991 as a means of confidential and anonymous information ('AIDS Prevention', 1991).

Faced with the alarming increase in the number of infected women, the CNLCS launched a campaign in June 1991 aimed at women of childbearing age, encouraging them to find out their immunological status before becoming pregnant.

In August 1991, a Residence for AIDS patients *(Residencia de Santa Rita de Cássia)* was inaugurated, as a result of a protocol signed in November 1989 that enabled the creation of the Solidarity Project with the aim of integrating AIDS patients and carriers into the community and supporting people and families affected by HIV and AIDS in the city of Lisbon.

On 16 January 1992, Laura Ayres died, and Joaquim Machado Caetano was appointed Coordinator of the *Comissão Nacional da Luta Contra a SIDA*. However, this organisation's leadership was short-lived, and in November 1992, Machado Caetano resigned as Coordinator of the CNLCS in disagreement with the AIDS policies pursued by the then Minister of Health, Arlindo de Carvalho.

Odette ferreira and the coordination of the comissão nacional de luta contra a sida (1992–2000)

Odette Ferreira (1925–2018)[7], a professor and researcher at FFUL, accepted the Minister of Health's proposal to be the Coordinator of the CNLCS. In scientific terms, she had actively participated in the discovery and isolation of a new AIDS virus as part of Luc Montagnier's team at the Pasteur Institute in Paris, and her international experience would be invaluable in giving the CNLCS a greater dimension and breadth of participation in global organisations and projects.

The previous leaderships of the GTS and the CNLCS were faced with significant blocking forces and various difficulties in implementing the appropriate measures to halt the spread of AIDS among the Portuguese population. The way it is transmitted (blood, sex, and injecting drug use) did not make it any easier to act in a society still dominated by conservative morals and prejudices against homosexuality and marginalisation, combined with drug addiction. Despite the efforts of the previous teams, ignorance, fear, and the stigma of the disease still prevailed.

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[7] Odette Ferreira (1925–2018), a pharmacist, professor, and researcher at FFUL, was a pioneer in the study of HIV/AIDS in Portugal. In 1985, as part of Luc Montagnier's team at the Institut Pasteur de Paris and thanks to scientific collaboration between her research group and doctors at Egas Moniz Hospital in Lisbon, she discovered and isolated HIV type 2. In the 1990s, she held the position of Coordinator of the CNLCS, during which time Portugal reached the peak of the epidemic. In this challenging context, she was responsible for implementing several innovative public health measures that had a decisive impact on combating the spread of the disease.

Odette Ferreira and her team defined the strategy in the fight against AIDS, focusing on the prevention of sexual transmission of HIV, the prevention of transmission through blood, and the prevention of perinatal transmission. It also aimed to reduce the social and personal impact of HIV and AIDS infection, prevent risks, change behaviours, mobilise national efforts, and strengthen international cooperation (Centro de Vigilância Epidemiológica das Doenças Transmissíveis, 1992).

However, what really made the difference was the vision of Odette Ferreira and her team members that everyone should be involved, not only researchers, governments, and health institutions, but also civil society, in order to prevent the progression of AIDS.

On 12 July 1993, the Minister of Health approved the National Plan to Fight AIDS with four main guidelines (CNLCS, 1993, 1995): information and training, with emphasis on promoting the concept of 'safe sex' and reinforcing information campaigns aimed at the general population; combating discrimination as the main theme of the campaigns; specialised human support in the treatment of patients through the creation of day hospitals, home, and psychological support for HIV-positive individuals and patients, special help for HIV-positive drug addicts and back-up residences; support for scientific research in the area of AIDS (CNLCS, 1993).

In this National Plan to Fight AIDS, there was also a special focus on health education for young people to promote healthy lifestyles and responsible behaviour in defence of health (Sargento, 1994).

Figure 2. Boas Férias, or Good Vacations (Europe against AIDS). July 1994.

Between December 1992 and April 2000, the CNLCS team implemented various measures and actions, developed projects and achieved numerous objectives that were defined according to eight different areas: epidemiological surveillance (monitoring the evolution of HIV infection; characterising the specific features of the AIDS epidemic in Portugal; and carrying out epidemiological studies on especially vulnerable groups) (Centro de Vigilância Epidemiológica das Doenças Transmissíveis, 1995); information and health education (dissemination of messages that are easily understandable and decodable by the population and the increased weight of communication aimed at target audiences, such as young people and the homosexual community (Santos Ferreira, 1992); representation and international cooperation (the immigrant community of African origin was highlighted as one of the preferred targets for promoting information on HIV and AIDS infection, as well as collaboration and support for Portuguese-speaking African countries (O. Ferreira, 1999, p. 12); social intervention and support (collaboration with NGOs in implementing education and training campaigns and actions aimed at various target groups, as well as psychosocial, home and residential support for HIV-positive people and AIDS patients) (CNLCS, 1995, p. 9); intervention in improving the provision of health care (improving the quality of life of hospitalised patients and protecting medical and nursing staff by modernising, adapting or building all central and district hospitals, as well as building day hospitals, improving the quality and humanisation of health care) (CNLCS, 1995, p. 8); public health campaigns and strategies to combat AIDS (campaigns against social discrimination and the exclusion of infected people and AIDS patients, combating ignorance about how HIV is transmitted, which is still so prevalent in Portuguese society, training and counselling actions aimed at specific groups of the population considered to be more exposed to the risk of infection and transmission of the virus, such as prostitutes, drug addicts, and immigrants, support for civil society through the CRIA Programme – "*Conhecer, Responsabilizar, Informar, Agir*" (Know, Take Responsibility, Inform, Act) (O. Ferreira, 1999, pp. 11–12), with the aim of supporting projects and integrated actions in the fight against AIDS, the creation of anonymous and free screening centres, the creation of a national network of Anonymous HIV Detection Centres, with the aim of supporting integrated projects and actions in the fight against AIDS, as well as campaigns and initiatives that mobilised civil society, with lighter and more cheerful language in posters, radio spots, and television adverts ('Antes prevenir', 1997); scientific research projects (support and encouragement for the development of scientific research projects that promote progress in knowledge about HIV and AIDS infection and make a significant contribution to effectively combating the epidemic and improving treatment for patients).

The syringe and needles exchange programme and the problem of drug addiction in Portugal

The project with the greatest national and international impact was undoubtedly the *Programa de Troca de Seringas* (PTS or Syringe and Needles Exchange Programme) at Pharmacies. In the 1990s, the change in the pattern of AIDS patients, with a greater incidence in drug addicts, implied a drastic change in policies to combat HIV and AIDS infection.

In Portugal, the problems of drug abuse exploded with the revolution of April 1974, the process of decolonisation and the return of a million people to the metropolis. It was a revolutionary period in which the country went through a series of political, social, and economic upheavals, coupled with an environment of avidity for experimentation and risk, drug consumption increased ('Nova escalada da droga - Preparação clandestina de ópio começa em Portugal', 1977).

Portugal was completely unprepared to deal with the problem of drug use and addiction. With the exponential increase in injecting drug use in the 1980s and the start of the AIDS epidemic in 1981, the problem worsened, with deaths from overdoses and AIDS multiplying.

In the 1980s, the use and sharing of unsterilised syringes and needles was common among heroin addicts, who cleaned their injection equipment only with water. With the use of injectable heroin taking hold from the beginning of the 1980s, syringes and needles in the streets, on beaches, pavements, near schools, and everywhere else created a serious public health problem that needed to be urgently controlled. There was a hostile attitude towards this new group in Portuguese society.

The first treatment and prevention services in Portugal were set up at the end of the 1970s, with the creation of three centres in Lisbon, Porto, and Coimbra. Private drug addiction recovery centres also emerged, some of them adopting somewhat controversial therapeutic approaches and taking advantage of the vulnerability of drug addicts and their families (Bento & Bastos, 2025).

With the growing problem of heroin use among young people, the Taipas Centre (*Centro das Taipas)* was set up in 1987 as a specialised unit of the Ministry of Health for the treatment of drug addiction with an integrated approach and inpatient capacity. Later came the Algarve, Leiria, and Porto Drug Addiction Centres and methadone substitution therapy (1998). In prisons, the situation was even more dramatic, and there was little information about AIDS.

Faced with this dramatic situation on the ground, Odette Ferreira realised that she would have to involve other individuals and institutions in public health, especially in terms of logistics and distribution, and she stated: "Pharmacies would be the best support; they were all over the country." (Reis, 2012, p. 31)

Figure 3. Poster for the launch of the Syringe Exchange Project, (Diz Não a Uma Seringa em Segunda Mão or Say no to a second-hand syringe), Out a Dez 1993.

On 27 September 1993, a protocol was signed that resulted from a partnership between the Ministry of Health, through the CNLCS, and the *Associação Nacional das Farmácias (*the National Pharmacy Association), for the development of a programme "within the scope of health promotion and disease prevention", with the aim of reducing the risk of HIV and other contagious diseases (hepatitis B and C) transmitted through intravenous drug use among individuals with drug addiction[8]. These institutions agreed to jointly develop the "Say no to a second-hand

[8] Protocol between the National Commission for the Fight Against AIDS and the National Pharmacy Association, 27 September 1993.

syringe" project, which aimed to prevent the transmission of HIV via syringes among the drug-using population[9].

Initially, the Protocol would only be in force between 1 October and 31 December 1993, but the high number of syringes exchanged (around 500,000) proved the seriousness of the situation.

Contrary to all expectations, this project did not end on 31 December 1993, as planned, but has continued to this day, with the fundamental collaboration of Portuguese pharmacies. At first, according to Odette Ferreira, nobody believed it would be possible to implement this project on the ground. The population perceived it as "giving syringes to shabby people, with people outside saying that they were stealing and we were going to help them" (Reis, 2012, p. 31), or as meaning that they were going to sell drugs in pharmacies ('Vender droga nas farmácias', 1993).

This *Projeto Troca de Seringas* also represented a fight against discrimination by guaranteeing injecting drug users access to a differentiated, safe healthcare space with opportunities for preventive approaches and assistance.

The European Union considered it the best project presented by a member state, not only because of its innovation but also because it was possible to develop it simultaneously throughout the Portuguese territory through the network of community pharmacies (CNLCS, 1995, p. 7), integrating users of injectable illicit substances into society and obtaining medical care, social support, and treatment programmes.

Another important contribution of the *Programa Troca de Seringas* was the reduction in crime associated with drug addiction, especially when complemented with adherence to the programme to reduce heroin consumption by replacing it with methadone.

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9 The *Programa de Troca de Seringas* (PTS) or Syringe Exchange Programme (SEP) is a harm reduction strategy implemented in several countries to reduce the transmission of infectious diseases, such as HIV and viral hepatitis, among injecting drug users. The first country to implement SEP as a response to the HIV and AIDS epidemic was the Netherlands in 1984, in the city of Amsterdam. This was followed by Denmark (1986); the United Kingdom (1987) in just a few cities; Australia (1987), which was a pioneer in implementing a national programme as an effective public health strategy; Germany (1988), which implemented SEP in just a few cities; Canada (1989), starting in Vancouver and then expanding to other parts of the country; Switzerland (1988–1990); Spain (1989), with a gradual and decentralised implementation, with some regions and cities leading the initiative, such as Barcelona and Madrid; the United States (1988–1990), only in a few cities such as New York and San Francisco, with the federal programmes having some resistance due to political issues; France (1990), which adopted SEP after a worrying increase in HIV infections among injecting drug users; Brazil (1990), implemented SEP in only a few states; Italy (1993); Portugal (1993), as part of a broad reform of illicit substance use policies; Norway and Sweden (1990s).

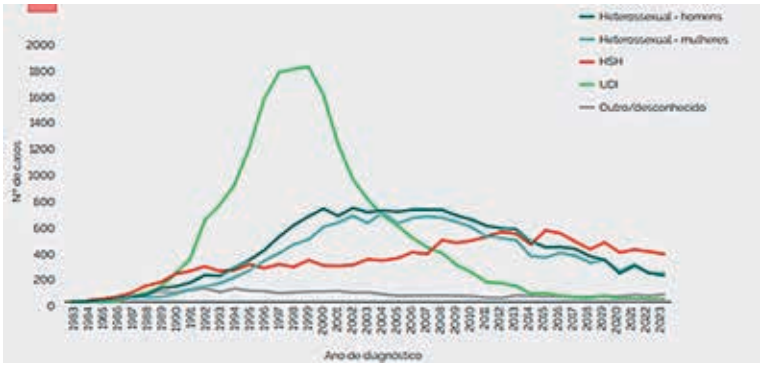

Figure 4. Cases of HIV infection, distribution according to mode of transmission and year of diagnosis (1983–2023). Source: DGS/INSA (Direção-Geral da Saúde & Instituto Nacional de Saúde Doutor Ricardo Jorge, 2024, p. 50)

Although not specifically mentioning the Portuguese PTS, the WHO recognised the significant impact of this type of initiative on public health in the fight against AIDS («Guide to Starting and Managing Needle and Syringe Programmes», 2007). PTS has led to a significant reduction in new cases of HIV infections among individuals who inject drugs, from 57.3% in 1998 to 2.3% in 2021. (Graph 1) Between 2014 and 2023, there was a reduction in AIDS cases among injecting drug users (89%) (Direção-Geral da Saúde & Instituto Nacional de Saúde Doutor Ricardo Jorge, 2024, p. 61). In this way, it was possible to recognise Portugal worldwide as an example of good practice in adopting policies to address addictive behaviours and substance dependence.

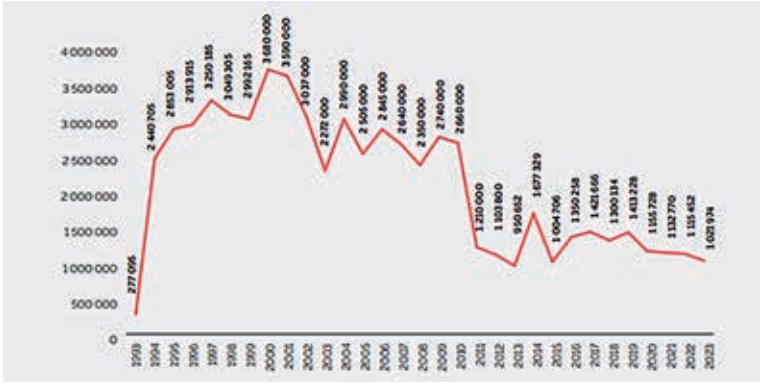

Figure 5. Number of syringes distributed under the PTS (1993 – 2023). Source: DGS/INSA (Direção-Geral da Saúde & Instituto Nacional de Saúde Doutor Ricardo Jorge, 2024, p. 72)

In addition to the successful implementation of the PTS, Portugal was also innovative in the way it approached the problem of drug addiction, with the implementation of the 'Portuguese Model' of the national strategy against drugs and addiction. The innovative and humanist idea that drug addiction was a disease and should be approached as a public health problem from a social perspective was defended by Odette Ferreira from 1993 onwards (Ferreira, 1994) and by other doctors and individuals. This attitude, which broke with established prejudices, changed consciences and mentalities and altered society's perception of drug addicts as criminals to patients in urgent need of treatment, detoxification, and social reintegration[10].

The change in mentality that occured in Portugal in the 1990s was fundamental in the pioneering approval of legislation (República, 2000) that did not criminalise drug abuse and in the understanding that drug addiction was a disease and should be treated, and not criminally persecuted. Only drug dealing should be considered a crime.[11]

Figure 6. Portugal's radical drugs policy is working. Why hasn't the world copied it? Illustration by Johanna Parkin (Guardian Design): Source: "The Guardian"[12]

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10 The 'Portuguese Model' of the national strategy against drug abuse and addiction argued that the consumption of illicit substances should not lead to imprisonment and that the focus should be on the treatment and social reintegration of drug addicts. From the outset, the therapeutic 'Portuguese Model' demonstrated great scientific rigour, incorporating human involvement from technicians and patients, which led to remarkable effectiveness and proven results. Today, it is internationally recognised for its scientific rigour, remarkable effectiveness, and example of success.

11 Considers that the consumption of narcotic drugs and psychotropic substances is an administrative offence and ensures the health and social protection of individuals who consume such substances without a medical prescription.

12 Susana Ferreira, «Portugal's Radical Drugs Policy Is Working. Why Hasn't the World Copied It?», *The Guardian*, 5 de dezembro de 2017, sec. News, https://www.theguardian.com/news/2017/dec/05/portugals-radical-drugs-policy-is-working-why-hasnt-the-world-copied-it.

In 1999, a Commission was set up to draw up the first National Strategy to Combat Drugs, and, after much effort, the Commission proposed legislation to repeal the 1993 law that criminalised drug abuse. This was a pioneering law (República, 2000) at the global level that decriminalised, but did not penalise, the consumption and possession of drugs for personal use.[13]

Conclusion

In the 1980s, Portugal, coming out of a revolutionary period that shook up all the country's social, political, and economic structures, began to control HIV and AIDS infection by denying the existence of the disease due to its relationship with communities excluded from society, such as homosexuals and drug addicts.

However, faced with the evidence of infection among haemophiliacs, Portugal was one of the first countries to respond to the WHO's call in 1985 and create institutions and teams motivated to halt the progression of this infection, as well as to involve the entire civil society in multiple ways to achieve this ambitious goal.

Despite all the difficulties encountered by the *Grupo de Trabalho da SIDA* and the *Comissão Nacional de Luta Contra a SIDA,* and the resistance of conservative Portuguese society to tackling taboo subjects such as sex and drug abuse, Portugal managed to implement public health policies in the fight against HIV and AIDS between 1983 and 2000. This resulted in a greater understanding of the disease and its prevention methods, with extensive campaigns to mobilise the population. In terms of social intervention and support, Portugal managed to improve the situation of HIV-positive individuals and patients, and investment in prevention and education made a decisive contribution to controlling the epidemic.

Portugal was also able to successfully implement an innovative programme to control AIDS among injecting drug users and to pass pioneering legislation that did not penalise consumption and that recognised drug addiction as a disease rather than a crime. In this way, the 'Portuguese model' enabled Portugal to be recognised worldwide as an example of good practice in adopting policies to address addictive behaviours and substance dependence.

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[13] In 1999, the Commission for the National Strategy to Combat Drugs was created, which ran until 2001 and was chaired by Alexandre Quintanilha. It included Lourenço Martins, Cândido Agra, Daniel Sampaio, João Goulão, Joaquim Rodrigues, Júlio Machado Vaz, Manuela Marques, and Nuno Miguel. The then coordinator of the 'Life Project', Alexandre Rosa, played an important role, as did legislators Pedro Silva Pereira, and Rui Pereira. See: (Oliveira, 2016)

In 2000, Portugal was still a country with one of the highest prevalence rates of HIV and AIDS infection in the European Union (Figueiredo, 2000). However, in the 2000s, a significant deceleration phase began, to which the performance of the CNLCS greatly contributed, resulting in a decrease in the number of new cases. Later, in the 2010s, this phase led to greater control of the AIDS epidemic.

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SAŽETAK

U Portugalu je prvi službeni slučaj HIV infekcije potvrđen 1983. Suočen s prijetnjom globalne epidemije uzrokovane nepoznatim virusom, Portugal je odgovorio na poziv SZO-a 1985. osnivanjem institucija s ciljem podrške državnim odlukama, provođenja epidemioloških studija, kontrole širenja virusa, dijagnosticiranja slučajeva, širenja informacija i edukacije stanovništva. Portugal je prešao dug put od početnog poricanja postojanja bolesti i odbijanja otkrivanja pozitivnih rezultata pacijentima. Ozbiljan slučaj zaraze osoba koje boluju od hemofilije serijom faktora VIII uvezenog iz austrijskog laboratorija, koji je rezultirao smrću desetaka pacijenata, natjerao je portugalske javnozdravstvene vlasti da osnuju organizacije sposobne za borbu protiv AIDS-a. Pokušavajući kontrolirati ozbiljan problem ovisnosti o drogama nakon portugalske revolucije u travnju 1974., konzervativno društvo uspjelo je promijeniti svoj stav i donijeti revolucionarne zakone širom svijeta te implementirati uspješan program za kontrolu infekcije AIDS-om među intravenskim korisnicima droga. U ovom radu bit će obrađena pitanja poput učinkovitosti ovih mjera u kontroli epidemije AIDS-a i njihova utjecaja na portugalsko društvo krajem 20. stoljeća.

Ključne riječi: *AIDS, HIV, korisnici droga, javno zdravstvo, Portugal*