
HIV Outcomes Spain: Road-testing the recommendations



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HIV OUTCOMES Working Group

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INTRODUCTION

The HIV Outcomes project was born in 2016, from a consensus among several international and European entities and institutions to advance the development and implementation of the 4th 90 on quality of life agreed within the framework of UNAIDS. These entities and institutions include: AIDS Action Europe; AFEW International; European AIDS Treatment Group; Hannover Medical School; University of Milan; ISGlobal Hospital Clinic of Barcelona, Gilead Sciences, ViiV Healthcare, European Center for Disease Control and the European AIDS Clinical Society.

The mission of HIV Outcomes is to improve the health of PLHIV in Europe, their wellbeing and quality of life, while at the same time enhancing the sustainability of European health systems.

RECOMMENDATIONS

With this mission, on November 29, 2017, five recommendations were approved and presented on the long-term health needs, well-being and social health care of people living with HIV (PLHIV). The recommendations are the result of a year-long collaborative process that has gathered the perspectives and experiences of people living with HIV, health and clinical professionals, public health practitioners, and the broader HIV community. Two expert roundtables were held – in December 2016 and June 2017, respectively – to identify priority issues in the long-term health needs and well-being of PLHIV. In September 2017, an expert workshop was used to develop and discuss draft recommendations. The final recommendations were subsequently presented to the European Parliament with the multilateral support of Members of the European Parliament. The next step is to disseminate the recommendations at the national level with a view to identifying best practices and challenges in improving the quality of health care and quality of life for PLHIV.

RECOMMENDATIONS:

1. Adopt an integrated, health outcomes and patient-centred approach to long-term HIV care.
2. Promote state monitoring of long-term HIV health care and health outcomes.
3. Support cohort studies to provide information on the health of PLHIV.
4. Combat stigma and discrimination within health systems.
5. Improve the involvement of the HIV community in setting national priorities.

METHODOLOGY

This report has been developed through the review of technical documents, scientific articles and taking into account the opinion of key experts in the response to HIV in Spain. Among them were public authorities, both at the state and regional level, representatives of major political parties, academics, physicians and community activists. The report was supervised by the Steering Committee of the HIV Outcomes project in Spain. This Committee is made up of the following people:

- Dr. Julia del Amo, Director, National AIDS Plan, Ministry of Health.
- Dr. Santiago Moreno, Head of the Department of Infectious Diseases,
- Toni Poveda, CESIDA Director
- Ramón Espacio, CESIDA President
- Dr. María José Fuster, SEISIDA Executive Director
- Dr. Juan Carlos López Bernaldo de Quirós, SEISIDA President
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- Dr. Jeffrey Lazarus, Researcher, ISGlobal
- Tania Furtado, Director, Government Relations, Gilead
- Ricardo Moreno, Managing Director Spain, ViiV Healthcare

CONTEXT – HIV IN SPAIN

The number of PLHIV in Spain is currently estimated to be between 140,000 and 160,000. About 13% are not diagnosed, according to the latest estimates. In 2016, it was estimated that the number of PLHIV on antiretroviral therapy (ART) was 116,408¹.

In terms of new HIV diagnoses, based on latest published data², a total of 3,244 new diagnoses were reported in 2018, with an estimated rate of 8.65 per 100,000 people after correcting for the delay in reporting. 85.3% of the new diagnoses are men with an average age of 36 years. The average age for women was 38 years. Men who have sex with men (MSM) are the most frequent category of transmission, with 56.4% of the total, followed by heterosexual people, with 26.7%. Finally, people who inject drugs (PWID) represent 3.2%. 31.9% of new diagnoses are in the 30-39 age group and 37.6% were born outside Spain. The autonomous communities of Madrid, Catalonia, the Canary Islands and Andalusia have the highest number of new HIV diagnoses.

The trend, from 2009 to 2018, is downward, especially in categories such as PWID, sexual transmission being the most common form of transmission, especially in the group of young MSM between 25 and 34 years where the highest rates are observed. Late diagnoses also decreased slightly, although it continues to represent a high percentage of the total. The overall rate of new HIV diagnoses in Spain, has improved over recent decades, but it continues to show a rate above the average of the European Union and Western European countries, with people from other countries representing between 37% and 42% of new diagnoses.

According to the National Register of AIDS cases, there are 468 new AIDS diagnoses after correcting for a delay in notifications. This represents a rate of 1.4/100,000 inhabitants. 82.9% were male, with an average age of 43 years. From the beginning of the epidemic in Spain until June 30, 2019, a total of 88,135 cases of AIDS have been reported, with a growing trend in people whose origin is not Spain.

This data shows that the profile of the infection has changed with respect to the early years, when the infection was acquired mainly by people who used injected drugs and there were far fewer cases in the immigrant population. In addition, advances in treatment of the infection have led to vertical transmission of HIV, i.e., from mother to child, being virtually eradicated.

Spain is close to achieving the goals set by the UNAIDS global strategy for 2020, although, according to the latest estimates, there is still a 13% undiagnosed fraction (i.e., 87% are diagnosed, a slight improvement over the past). With respect to the 2nd 90, 97.3% of people are receiving treatment, which is a great improvement, and 90.4% have suppressed viral load. However, 47.6% of new diagnoses were late diagnoses, being higher in the case of women and higher as the age of diagnosis is more advanced.

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RECOMMENDATION 1:

The model of care for people living with HIV in Spain

Thanks to the advances in ART, the life expectancy of PLHIV has risen and is increasingly approaching that of the general population¹. The current scenario, marked by the increase in life expectancy and the ageing of PLHIV, is characterised by new demands for care, such as the management of comorbidities² and the need to facilitate a good health-related quality of life (HRQOL)³. All this makes it necessary to move towards a model of chronic care, centred on the patient and on outcomes, which responds to long-term challenges.

In Spain, the care provided to PLHIV is characterized by the effective resolution of acute episodes. PLHIV have received, and continue to receive, high quality health care provided by professionals with a solid background and extensive experience in HIV². However, the current model of health care is not prepared to anticipate the complications of chronic disease. In fact, hospitals in Spain are not providing the most efficient and optimal care for PLHIV that includes all the components of long-term patient² management models. In addition, there is significant variability in the provision of care between centres and by autonomous community⁴.

The model of HIV care in Spain consists of four distinct phases in which different objectives are pursued and in which different professionals participate. The first two phases are aimed at identifying and diagnosing patients, while the third and fourth phases focus on clinical care and monitoring of PLHIV. In the first two phases, agents from both the health and community fields participate. The management of clinical care is the responsibility of the hospital's infectious disease units or services. The configuration of the teams in these units is variable. In general, they are composed of experts in infectious diseases, nursing staff, hospital pharmacists and administrative personnel. In some hospitals, other professional profiles are also involved, such as psychologists, psychiatrists, nutritionists and/or social workers. In addition, some hospitals have incorporated peers, health educators and in some cases cultural mediators and interpreters for the immigrant population, thanks to programmes promoted by NGOs. The monitoring of PLHIV is managed primarily from the infectious disease units, with a limited role for primary care. Other specialties are involved, when considered necessary, through referrals from patients^{2,4}.

Experts in Spain recognise that the country has a fragmented model that makes it difficult to provide optimal care for PLHIV. This excessive fragmentation hinders equitable access to health services for PLHIV, which can be exacerbated depending on where the person lives. The need to redefine care processes is recognised, improving coordination, communication and integration between the different professionals responsible for monitoring PLHIV. Areas of improvement identified by the experts in Spain, include the need to establish a system of stratification of patients to help establish priorities and define the types of interventions adapted to the level of complexity, shared clinical history, or develop technological tools for telemedicine. In addition, the underutilisation of nursing staff in many HIV units is recognised despite the positive impact of their care on PLHIV. It is also appreciated that there is a path of improvement in listening to the voice of the patients to guide interventions based on their preferences⁴.

Other deficits identified in the current model of care are the shortage of programmes to support self-management of health. This is an essential component of chronic care models and, in fact, is the approach with the highest degree of effectiveness⁵. HIV self-management involves tasks of managing medical, behavioural, and emotional issues associated with the disease⁶. Most of the existing programmes in Spain are provided by NGOs. In addition, the programmes under way do not include the promotion of self-efficacy and behaviour change (which have been shown to be more effective), that are predominantly based on providing information.

There are important gaps in the response provided by the current health model to certain problems suffered by PLHIV that negatively affect their HRQOL, such as sleep problems, fatigue, sadness, or anxiety, among others⁷, which are very prevalent in this population. These symptoms are related to psychosocial problems closely related to HIV and negatively influence HRQOL, survival, and other indicators of morbidity⁸. However, these problems are not identified or sufficiently addressed in routine clinical practice⁸.

In sum, recognising the excellent quality of medical care received by PLHIV in Spain, it is clear that progress is needed towards a model of care and clinical management that provides an adequate response to the chronic nature of HIV. Chronic care models recognise that the management of a chronic disease implies a multidimensional approach, with interrelated interventions that optimise the management of the disease, improve health outcomes, and are efficient in economic terms⁵. It is therefore necessary to promote the integration of services and multidisciplinary professional teams, enhance patient participation in his or her care and strengthen community involvement ².

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RECOMMENDATION 2:

Monitoring of HIV in Spain

Epidemiological surveillance in HIV and AIDS is carried out through two population-based surveillance systems under the General Directorate of Public Health of the Ministry of Health and the National Center of Epidemiology of the Carlos III Healthcare Institute, where the HIV, STI and Hepatitis Surveillance Unit acts as a focal point in collaboration with the regional systems of epidemiological surveillance.

The register of AIDS cases was the first state-wide record. It has collected data on the annual diagnoses of AIDS cases since 1981, following the case definition agreed internationally. This system also provides information on the incidence of advanced disease.

Since 2003, the Information System on new HIV diagnoses (SINIVIH) has collected information on new HIV diagnoses from nine Autonomous Communities. Its coverage has increased since it was established, reaching 100% for the full year¹.

In addition to the previously mentioned surveillance systems, there is another information system on people diagnosed with HIV who receive care in public hospitals because of their HIV infection. This system, called the Hospital Survey of Patients with HIV², collects clinical, epidemiological and behavioural information of PLHIV on an annual basis. It is also managed from the HIV, STI and Hepatitis Surveillance Unit.

As a complement to the information provided by this system, the Ministry of Health's Basic Minimum Set of Data for Discharge from Hospital (BMSD), which provides information on the morbidity of patients admitted to hospitals in Spain⁴, is periodically analysed.

From the analysis of secondary data sources, information is obtained on other aspects related to HIV infection, such as mortality. The sources produced by the National Institute of Statistics and through the BMSD provide information on HIV³ mortality in Spain and in-hospital mortality in patients with HIV infection. Thus, it has been observed that the causes of mortality in PLHIV have varied from AIDS-related pathologies to causes related to chronic illness – similar to those of the general population. These include non-AIDS tumours, cardiovascular disease or liver disease⁴.

There is good coordination between the surveillance system and some of the state-wide cohorts of PLHIV (recommendation 3). The combination of both sources of information has made it possible to calculate, among other things, the indicators of the 90-90-90 targets⁴, as well as the prevalence of primary resistance to antiretroviral drugs in Spain⁵.

Despite the implementation of these surveillance systems and their good coordination with research structures, there are certain difficulties that prevent having complete and updated information on cases of HIV infection and AIDS. First, the decentralised nature of epidemiological surveillance in Spain implies the need to coordinate with the various territorial surveillance systems, which implies greater difficulty in collecting and combining data to achieve state indicators. On the other hand, the fact that some of these regional systems are under-resourced leads to delays in notification, meaning that the epidemiological data cannot be considered definitive until after a period of two to three years. Strengthening the surveillance structures would make it possible to reduce this delay and would allow for the incorporation of additional information in a timely manner into these systems, such as HRQOL.

In Spain, HRQOL is not routinely monitored in clinical practice, although it is considered increasingly important following the proposal to incorporate an additional quality-of-life goal, the 'Fourth 90', into the goals of the global HIV⁶ elimination strategy. The growing interest is reflected in the initiatives being promoted by various institutions. In Spain, the Spanish Interdisciplinary AIDS Society (SEISIDA) is the entity that has carried out most studies related to HRQOL using large samples of PLHIV. In a study

involving just over 1,400 PLHIV, the dimensions of HRQOL with lower scores were psychological health, social relations and, the spiritual or existential dimension. The specific areas most affected were economic resources, satisfaction with sexual life, stigma, concern for the future, negative feelings and sleep problems. Women, heterosexual PLHIV, those with less education and income, and those who had been living with HIV for the longest time had⁷ the worst HRQOL.

HRQOL is a complex concept made up of many dimensions and multiple areas or facets. There are several studies that highlight the need to identify the problems that PLHIV have, and therefore the aspects of their HRQOL that can be negatively affected. Longitudinal studies have found that low HRQOL scores predicted lower survival, higher rates of hospitalisations and other indicators of morbidity^{8,9}. As well as psychosocial issues such as stigma or economic deprivation, medical conditions such as pain, sleep problems, mental health problems (especially anxiety and depression due to their prevalence) or frailty, may impair HRQOL more than specific co-morbidities. A higher number of comorbidities correlates with a lower HRQOL^{10,11}. Likewise, several studies show a high prevalence of different symptoms such as sleep problems, fatigue, sadness, or anxiety, among others¹². These symptoms are related to psychosocial problems closely related to HIV and negatively influence HRQOL, survival, and other indicators of morbidity¹³. However, these problems are not identified or sufficiently addressed in routine¹³ clinical practice. Moreover, there are studies that show a very high discrepancy between the symptoms reported by patients and those that their physicians thought they had¹³. HRQOL can be undermined by the difficulty PLHIV face in defining what is happening to them or what they are feeling; the lack of knowledge or solutions to the problem on the part of the health professionals (and therefore a tendency to avoid asking about certain topics); the deficits in the relationship between the health professional and the patient; and structural problems.

Incorporating monitoring of HRQOL or other patient-reported measures that serve to identify problems related to HRQOL is important for patient-centred care, to improve commitment and long-term¹⁴ health. In addition, it is an essential aspect for improving the efficiency of the health system¹⁵. Therefore, interest in measuring HRQOL on a routine basis is growing in Spain and large cohorts of Spanish PLHIV, such as the CoRIS and PISCIS cohorts, have begun or will begin to monitor it regularly. The digitalisation and advances in automation of the electronic medical record facilitate the incorporation of these HRQOL measures, so institutional leadership is needed to mobilize the widespread implementation of this practice.

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RECOMMENDATION 3:

Research and cohort studies in Spain

Spain has good scientific structures, collaborative networks and cohorts that can contribute to understanding the evolution of the health of people living with HIV. Among these structures, the main network coordinated around HIV is the Spanish AIDS Research Network (RETIC-RIS) that includes research groups throughout Spain.

In total, in Spain there are three cohorts of adult patients with HIV infections (CoRIS, VACH and PISCIS)¹. These are open, prospective and multicentric cohorts. The cohort of the Network of Research on AIDS (CoRIS) includes patients without previous treatment for HIV recruited in HIV units of public hospitals, and has a biobank of biological samples². In 2020, there were more than 16,000 participants in 46 hospitals in 13 Autonomous Communities. For its part, the VACH cohort follows a similar number of PLHIV, and includes participants regardless of whether they had received previous treatment or not³, while the PISCIS cohort includes a high number of pre-treated or naïve⁴ patients from Catalonia and the Balearic Islands. In addition, there is a fourth cohort, CoRISpe, which follows children and adolescents living with HIV.

In addition to collecting clinical, socio-demographic, analytical and therapeutic information, these cohorts have robust research infrastructures that allow them to nest specific projects to answer relevant research questions. For example, the CoRIS cohort has conducted several studies on HRQOL, one of which has been funded by the Strategic Health Action, to measure HRQOL in all its participants. All the cohorts are coordinated with other cohorts at the European level and allow the development of new lines of research that generate knowledge about various aspects of the infection.

In 2020, the SIPrEP information system was launched. It aims to collect epidemiological, clinical, therapeutic and behavioural information on people receiving pre-exposure prophylaxis (PrEP). It was established in the context of a public programme of PrEP in the Spanish⁵ territory in the framework of a collaboration between the National Plan on AIDS, regional HIV plans, the national centre of epidemiology, the research network on AIDS and SEISIDA. (see Annex 1).

Funding for networked research in the field of HIV has been progressively reduced. The economic crisis that shook Spain has generated significant cuts in research since 2010. Cutbacks in R&D spending in Spain was much higher than in other European Union countries and Spain has still not recovered to pre-crisis investment levels⁶. These cuts, along with those expected due to the current health crisis, threaten research in the field of HIV. Prior to the Covid-19 crisis, the need for HIV research to define alliances with other fields of biomedicine⁶ was recognised as a priority. This would help redefine and advance key aspects of the long-term health of PLHIV. In addition, it must not be forgotten that advances in HIV research have had, and are having, an important impact in other areas. Therefore, strategic and investment measures are needed so as not to slow down the scientific response to HIV, which has been greatly diminished in recent years. Along with this, the creation of strategic alliances with other biomedical fields is essential to maintain quality and innovation in HIV-related research.

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RECOMENDATION 4:

The Spanish response to HIV related stigma and discrimination

PLHIV in Spain are a group that lives in a social context where prejudice and discrimination against them are a documented reality. These prejudicial attitudes are translated into different forms and expressions of stigma that range from the most intimate to the most institutional. The stigmatisation of PLHIV starts from the origins of the infection. The perception of the seriousness of the infection, erroneous beliefs about transmission through social contact, and the attribution of blame, lead people living with HIV to face rejection. This can have a profound negative affect on their lives. In addition, PLHIV are a heterogeneous group, with interacting characteristics such as gender, age, sexual orientation, and nationality, among others, that expose them to overlapping stigmas. Stigma has significant negative consequences on the health of PLHIV, having a direct impact on the high levels of anxiety and depression they suffer, on their social isolation, and on their quality of life^{1,2}.

Stigma also influences HIV prevention in a number of ways. For example, fear of rejection leads to avoidance of health care, and stereotypes contribute to underestimation of HIV risk. Stigma also leads to the denial of prevention services to specific populations, such as immigrants, and to delays in the adoption of new prevention strategies. Fear of rejection, in turn, contributes to the concealment of infection and to coping strategies such as avoiding diagnosis or avoidance of medical or social services². Stigma is a barrier, sometimes invisible, to accessing diagnostic, prevention and treatment services. In Spain, several studies have been conducted to analyse structural stigma and the public. In 2005, a study conducted by FIPSE Foundation found discriminatory practices in the internal regulations and protocols of various institutions³. It has been documented that PLHIV suffer discrimination, different treatment or limitation of their rights in various areas. Until very recently, there were barriers to accessing public services, especially to the state security forces and the armed forces, for which HIV was an automatic disqualifier. PLHIV were also excluded from health or life insurance, with a knock-on impact on other rights. For example, in Spain, in order to buy a house using a mortgage, it is necessary to take out a life insurance policy. The inability to take out life insurance results in the exclusion of PLHIV⁴ from homeownership.

In addition, failure to update legislation and policy to reflect the latest scientific knowledge influences many of these discriminatory practices. Outdated views of HIV are also behind the criminalisation of unintended sexual transmission of HIV. This criminalisation is classified in Spain through the crime of injury and its aggravated type (Articles 147 and 149 of the Penal Code). In most Spanish sentences on sexual transmission of HIV, the probability of transmission of the virus is considered to depend on repeated sexual acts without the use of a condom. If the person with HIV has not communicated their HIV status to the sexual partner, he or she is considered to be contemplating the risk of transmission, even if he or she does not wish to do so. If HIV transmission occurs, the person is convicted of a crime of injury. However, the scientific evidence is clear that PLHIV with undetectable viral load do not transmit HIV. This means that even if the PLHIV do not use a condom, they know that they do not transmit HIV and therefore do not pose a risk. Despite this, very few Spanish sentences consider this important aspect. In addition, HIV criminal policy focuses only on the responsibility of PLHIV rather than on shared responsibility, even though this view is more effective for individual and public⁵ health.

Regarding public stigma in Spain, SEISIDA carried out two surveys with representative samples of the Spanish population in 2008 and 2012 to analyse the magnitude of stigma and the variables that influenced it. They found a significant percentage of the population said they felt uncomfortable in the presence of a person with HIV and also that, if necessary, they would try to avoid contact with them. The prejudice of the population was translated into more serious discriminatory attitudes expressed through support for discriminatory policies aimed at social and even physical segregation. The analysis of the

evolution in 2012 showed a downward trend in the various expressions of stigma. In spite of this, about 29% of the population stated that they would try to avoid contact with a PLHIV in their daily lives. In addition, beliefs and other factors that influence negative attitudes towards PLHIV, such as erroneous beliefs about transmission routes or lack of contact with PLHIV⁶, remained stable. It is expected that the survey will be repeated in the coming months to analyse the evolution of these attitudes in recent years.

With regard to stigma in health services, there is evidence of hot spots of discrimination such as surgical interventions where, sometimes, HIV patients are treated last; dental care, where there are still cases of denial of care; and hair implant treatments that are denied to PLHIV, always within the scope of private health care, rather than public. There also continues to be limitations on access to certain health techniques and procedures such as platelet-enriched treatments and assisted reproduction techniques. However, there are no studies that monitor and measure the magnitude of stigma suffered by PLHIV in the health care sector. A study carried out by SEISIDA in 2010, in which more than 700 PLHIV participated, showed that just over 20% reported having suffered some type of discrimination. Another study by SEISIDA in 2012, which surveyed nearly 1,700 health professionals, found that attitudes were quite positive. However, there was some indication that there might be subtle biases. In this regard, about 30% said they would not use the same health measures with PLHIV as with other patients. The results showed that the professionals who had the most prejudice were those with the lowest level of training. Erroneous beliefs about HIV transmission and lack of professional experience with PLHIV led to greater perceived risk and increased stigma.

One conclusion that can be drawn from all the above is the need to regularly monitor the various manifestations of stigma in Spain.

The response of Spanish public authorities to stigma and discrimination is articulated through actions from the Ministry of Health and the Departments of Health of the Autonomous Communities, as well as from community and scientific organisations. A specific objective to reduce stigma and discrimination was incorporated into the 2008-2012 Plan thanks to civil society advocacy. Since then, all the plans have embraced this objective.

In Spain, after a few years marked by the weakening of the response to HIV due to the reduction of resources, activities and political will², from 2018 several milestones have been reached in the response to stigma (see Annexes 2 and 3). All of these advances have been the result of the advocacy work of the various social actors working for a human rights-based response to HIV. However, some violations persist even in the light of those measures already adopted, requiring follow-up and additional actions. For example, in 2019, the exclusion of PLHIV from the municipal police force national examinations or from obtaining a cab license in some cities⁷ was still in place.

Finally, it is worth mentioning the Agreement of the Government Council of Ministers updating the catalogue of medical causes for exclusion from access to public employment, where HIV, along with other chronic diseases, has been removed from the regulations governing access to public employment in all Ministerial Departments⁸.

In Spain, the decentralisation of the health system in 17 autonomous systems, implies the need for a reinforced coordination between territories that guarantees no inter-territorial discrimination in health care support. For this reason, the coordinating role of the Ministry of Health and the Interterritorial Council of the National Health System is vital in addressing stigma and discrimination that may occur in our health system. This must be achieved while overcoming the legal barriers caused by the recent regulatory changes in 2012 and 2018 related to public health care and its application in the autonomous regions. In any case, Spain's commitment to the Sustainable Development Goals for 2030 implies, according to their wording, not leaving anyone behind. The evaluation of response indicators to stigma

incorporated into the system by all agents would be a good starting point for setting commitments and measuring results.

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RECOMENDATION 5

Community involvement in response to HIV

In Spain, NGOs have a fundamental role in the response to HIV. There are numerous NGOs distributed throughout Spain, which are heterogeneous and respond to a multitude of problems associated with HIV and the different groups that suffer from it. There are local NGOs and there are also federations and foundations that operate at the regional or state level. Therefore, community involvement in the response to HIV is well established in Spain¹. The most far-reaching coordinated effort is the state coordinator of HIV (CESIDA), a federation created in 2002 that brings together 76 entities that in turn represent more than 120 organizations working in the field of HIV.

At the formal level, the Spanish National AIDS Plan (PNS) has an Advisory and Consultative Committee (COAC), a body for communication and participation of NGOs in the development of Strategic Plans for HIV infection and AIDS². The vice-presidency of this body is held by an NGO representative. The objectives of the COAC are to represent civil society in the PNS, to discuss the actions of the PNS, to propose actions, to analyse the institutional response to HIV, and to know the budgets and activities programmed by the PNS.

Civil society participates in working groups organised by the PNS to address specific issues (such as chemsex, PrEP, HCV screening, or the Social Pact for Non-Discrimination and Equal Treatment associated with HIV). It also participates in the review of a diverse range of documents (recommendations, consensus documents, guidelines, etc.).

After a few years of inactivity, in 2018 the National Commission for Coordination and Monitoring of AIDS Prevention Programmes was reactivated. The Ministries of Health (PNS), Education, and Interior (Penitentiary Institutions), representatives of public health of the Autonomous Communities, professional associations, scientific societies, civil society, represented by the entities that make up the COAC, and other agents of interest are represented in this body.

The involvement of the community through NGOs is encouraged through regular funding calls offered to entities working in the field of HIV both at regional and state level. The PNS is focused exclusively on the state level. The Ministry of Health budget allocated to grants for HIV prevention and control programmes conducted by NGOs suffered a significant cut due, among other reasons, to the past economic crisis. Thus, this budget went from 4,152,000 euros in 2011 to 1,100,000 euros in 2013, recovering to reach 2,000,000 euros in 2017. This amount remains stable from that date until today³.

In addition, there was the elimination of specific transfers to the Autonomous Communities for HIV prevention projects, with an amount of 4,808,100 euros⁴. The elimination of this transfer meant the disappearance or reduction of subsidies from the autonomous governments to finance prevention and control programmes implemented by local entities, and in some cases the disappearance of structures similar to the PNS in the Autonomous Communities. The agreements with penitentiary institutions and the Spanish Youth Council were also eliminated.

Finally, it should be noted that the cuts also meant a substantial reduction in the human resources of the PNS, which to this day remain unrecovered.

Although there are formal bodies for NGO participation at the state level, their existence at the regional level is more disparate. This is due to several factors. Among them is the dissolution of departments analogous to the National AIDS Plan in some Autonomous Communities within the General Directorates of Public Health, leading to the weakening of the response to HIV and AIDS in health policies. On other occasions, the lack of autonomous NGO platforms to facilitate dialogue is the factor that hinders community participation and involvement in the response to HIV.

The factors mentioned above do not obviate the existence of participation and dialogue between NGOs and health authorities in the Autonomous Communities (with the Autonomous Plans in those Autonomous Communities where they exist or with the Directorate Generals of Public Health). Thus, for example, in Catalonia there is the Interdepartmental Commission on AIDS, a body analogous to the National Commission for Coordination and Monitoring of AIDS Prevention Programmes at the state level. The Comitè 1r de Desembre - Plataforma Unitària d'ONG Sida de Catalunya (unitary platform of HIV NGOs in this region) is the intermediary, with the Programme for Control and Care of HIV, STIs and viral hepatitis (PCAVIH) of the Public Health Agency of Catalonia. The Comitè 1r de Desembre meets regularly with the PCAVIH to address all issues on the agenda. In other Autonomous Communities this participation is more informal, limited in many cases to the treatment of specific topics or situations and participation has varied at different times.

There are some additional factors that influence the participation and involvement of civil society. In Spain, there are still a significant number of NGOs working specifically in the field of HIV, many of which were born in the early years of the pandemic and have been adapting to the changing reality of HIV. In some cases, the character of these entities, the scarcity of resources and the workload may result in a lack of proactive participation with local or autonomous administrations, although it is true that there is wide geographical variability. For example, initiatives such as Fast Track Cities⁵ have facilitated in the city of Seville the formation of a working group at the municipal and regional level, promoted by Adhara, an Andalusian entity. Finally, it is important to highlight the advocacy work which has been carried out by local entities that articulate common work and efforts.

Regarding the implementation of new policies for the attention of PLHIV, there are more weaknesses at the level of the Autonomous Communities. This is probably a consequence of the specific atomisation of health care for PLHIV, which depends more on hospital management and the will of the UEI. It is also due to the specific nature of HIV, which means that the natural interlocutors for NGOs are the Directorate Generals for Public Health, which have no competence in the area of health care. These are in the hands of the Health Care Directorate Generals or similar departments with which there is no continuous dialogue.

However, the community actively participates in the provision of services that are not strictly health care orientated and that are directed to this population, especially to people with social vulnerability. There is some coordination with the administrations in the form of agreements, subsidies, or other types of agreements.

This can also be extrapolated to the state level given that the competences of health are transferred to the Autonomous Communities, although the Ministry of Health is responsible for coordination and basic legislation, such as the inclusion of new benefits, drug authorisation and legislation that may in some way affect the care of PLHIV.

Finally, it should be noted that NGOs coordinate and work together with other key actors in the community and scientific response to HIV. Among them, the Spanish Interdisciplinary AIDS Society (SEISIDA), which is composed of health professionals and other related disciplines, and members of NGOs working in the field of HIV. Today in Spain, NGOs, scientific societies (including SEISIDA and GESIDA), along with public and private institutions, often articulate and promote spaces for dialogue on the basis of specific projects and relevant objectives in the response to HIV. Promoting these synergies and enhancing community participation in all areas of the HIV response strategy, including the political agenda, is an essential element of overcoming the remaining challenges.

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ANNEX 1: GOOD PRACTICES

Implementation of PrEP in Spain: the result of a collective effort

Context

Since the regulatory agencies approved the use of Tenofovir/Emtricitabine as pre-exposure prophylaxis (PrEP) for HIV, the various administrative steps for its implementation have been taken in Spain. But this has been slow in coming. The implementation of PrEP in Spain, and the implementation of an information system that allows monitoring, are examples of how it is possible to advance public health policies on HIV, through social and scientific entities with the support of the administration.

Introduction

With the scientific evidence in favour of PrEP use in HIV-exposed people, and the approval of TDF/FTC use as pre-exposure prophylaxis by both the FDA in 2012, and by the EMA and the Spanish Agency of Drugs and Health Products in 2016¹, the scientific community and civil society expected PrEP implementation in a short period of time. However, not all the necessary political and administrative elements were in favour of PrEP implementation in Spain. The community and scientific societies identified the need to work together to identify and address barriers to PrEP implementation.

Objective

Achieving effective implementation of PrEP in Spain.

Methods

Within the framework of the meeting of the Spanish Interdisciplinary AIDS Society (SEISIDA) in 2018, meetings were initiated between people from non-governmental organisations and representatives of scientific societies in the field of HIV. This working group called itself PrEP Think Tank². This working group functions as an "ethical lobby", identifying barriers to PrEP implementation and proposing advocacy measures. The actors involved in this working group carried out formal studies of the political-administrative³ situation, knowledge and desire for use, and need for PrEP^{4,5}, or analysis of possible implementation⁶ models. The PrEP Think Tank developed arguments and supported the elaboration of a Resolution asking for the implementation of PrEP. This Resolution was supported by all political groups. The change in the political context in the Central Government, in 2018, incorporated elements more favourable to this implementation and integrated many of the products and reflections that had emerged from the Think Tank.

Results

In October 2019, the Ministry of Health approved public funding for TDF/FTC as pre-exposure prophylaxis within the health system. All the actors involved were engaged in the elaboration of an implementation guide for PrEP programmes in Spain, which was published in February 2020⁷. An information system was designed to monitor the implementation and follow-up of PrEP programmes (SIPrEP) also with the involvement of key actors⁸. In July 2020, the National AIDS Plan signed a collaboration agreement with SEISIDA to jointly finance actions dedicated to the promotion of PrEP in Spain for four years. Despite all of this, the implementation of PrEP in Spain continues to be uneven among Autonomous Communities and it is necessary to continue promoting this strategy.

Recommendations

The cooperation of social and scientific entities and the administration is an example of good practice that has allowed progress in the implementation of PrEP in Spain. The involvement of all stakeholders has fostered a culture of cooperation that has been maintained beyond the implementation of PrEP. This involvement will continue to be necessary to monitor the implementation of the strategy and ensure it reaches vulnerable populations.

Moreover, the development of formal analyses to identify specific barriers is an example of good practice in achieving progress in the HIV response.

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ANNEX 2: GOOD PRACTICES

The Social Pact for non-discrimination and equal treatment associated with HIV

The Social Pact for non-discrimination and equal treatment associated with HIV is a pioneering initiative at the national level that aims to eliminate the stigma and discrimination associated with HIV and AIDS, "guaranteeing equal treatment and opportunities, non-discrimination, respect for fundamental rights and diversity for people with HIV". This Pact, promoted by the National AIDS Plan of the Ministry of Health, was developed in collaboration with all social and institutional agents involved in the response to HIV. This document sets a general objective of eliminating stigma and discrimination along with specific objectives developed for its achievement. These objectives seek to be met by defining the following lines of action:

- A. Promote equal treatment and opportunities for PLHIV infection: monitor situations of discrimination; ensure that medical certificates do not include serostatus as an indicator of infectious disease; promote equal access to benefits and services; extend guarantees of legal protection; promote policies to avoid discrimination in employment; respond to situations of discrimination produced from the health field; ensure access to assisted reproduction techniques and adoption; and promote the free movement of PLHIV.
- B. Work towards social acceptance: reduce social stigma; prevent HIV stigma and discrimination in the educational field; guarantee the right to privacy and intimacy of those living with HIV.
- C. Reduce the impact of stigma on PLHIV by promoting their empowerment.
- D. Generate knowledge to guide policies and actions against discrimination by regularly conducting studies that provide relevant information in this regard.

The Pact is reviewed by a body formed by the signatory entities and social groups. The monitoring of, and adherence to, the Social Pact can be done via its web page <https://pactosocialvih.es/>

ANNEX 3:

Some Spanish Milestones in Response to Stigma and Discrimination

The following are some recent milestones in Spain's institutional response to stigma and discrimination that complement the actions outlined in Recommendation 4:

- Approval, in December 2018, of the 'Social Pact against Discrimination and Equal Treatment Associated with HIV' promoted by the Ministry of Health through the National AIDS Plan, which contains measures agreed upon from 2011 with all actors involved in HIV (see Annex 2).
- Approval of Law 4/2018 of June 11 which eradicated discrimination on the basis of HIV (or other health conditions) when contracting certain legal businesses, benefits or services, such as insurance.
- Adoption, in November 2018, by the Council of Ministers of an agreement to eliminate certain medical causes of exclusion, such as HIV, in access to public employment, such as the State security forces.
- Update of the recommendation guide for health professionals with HIV during the first quarter of 2020.
- Approval in February 2019 of Order PCI/154/2019, which involves updating the selective testing of public officials in order to eliminate certain medical causes of exclusion in access to public employment. The elimination of HIV as a cause of enforceable medical exclusions is the first item in these instructions. The elimination of these exclusions has become fully effective with the 2020 Public Employment Offer.
- Agreement with the IMSERSO (December 3, 2019): Joint institutional declaration of the Interterritorial Councils of the NHS and SS for care of dependent persons on access of PLHIV to residential facilities for the elderly and/or disabled.
- Approval by the Council of Ministers of the Royal Decree-Law 7/2018. This reversed the Government's expulsion of immigrants from the public health system in 2012, thus ensuring that all people living in Spain with HIV have free access to antiretroviral therapy. However, this rule has not yet been fully developed by way of regulations, in the same way as previous health reforms.
- Approval of regional laws on the protection of rights and the fight against LGBTI-phobia (Law 23/2018 of November 29, on equality of LGBTI people in the case of Valencia Community; Community of Madrid Law 2/2016 of March 29, on Identity and Expression of Gender and Social Equality and Non-Discrimination of the Community of Madrid, and Law 3/2016, of July 22, on Comprehensive Protection against LGTBI-phobia and Discrimination on Grounds of Sexual Orientation and Identity in the Community of Madrid).