

Intelligence

Unit

The Economist Challenges in Spain's HIV management





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## **Executive summary**

Like many other countries in both the developed and developing world, Spain has made significant progress in treating the human immunodeficiency virus (HIV) and in identifying those most at risk.

However, for the first time, nearly half of HIV-infected people on Spain are over the age of 50<sup>1</sup>; they are facing special challenges resulting from the accumulated toxicities of earlier treatment and from social difficulties and exclusion—primarily affecting those infected in the earliest wave of the epidemic. Spain's populations most at-risk of contracting HIV are also changing, but practices to encourage early detection and testing are not being adjusted in a timely manner.

This report, Living and ageing with HIV: challenges in Spain's HIV management, has been written by The Economist Intelligence Unit (EIU) and is sponsored by Gilead Sciences. It is informed by the insights of a panel of experts on HIV in Spain and five in-depth interviews. The report's aims: to assess the current knowledge and understanding of HIV/AIDS, of late diagnosis, of ageing and comorbidities in Spain and to identify any current gaps in the provision of healthcare services to patients in Spain.

The key findings of the research are:

- Better treatments have improved the quality of life for HIV patients, yet the accumulated toxicities of earlier treatments have made older HIV patients are more susceptible to comorbidities.
- Demographics are also shifting for Spain's populations most at-risk of contracting HIV. An updated approach to outreach and early detection is needed to reduce the spread among these groups.
- Social and institutional stigmas around HIV are still prevalent. They are creating obstacles to care that affect the employment opportunities and quality of life of patients.
- Confronting the new-and old-medical and social problems in Spain will require a more integrated approach to healthcare, involving teams with specialised knowledge of both the medical and social issues.

### Introduction

The picture of HIV in Spain has transformed. Populations most at risk of contracting HIV have changed significantly since the 1990s, bringing with them new issues of detection and social inclusion. Many of those who were already infected have now aged, with the unique medical problems associated with older people living with HIV (PLHIV)—defined as those 50 years of age and older—becoming increasingly clear.

Better treatments have improved the quality of life for ageing patients treated with antiretroviral therapy (ART), but the accumulated toxicities of earlier treatments have resulted in older patients not only facing the usual problems of ageing, but have made them more susceptible to conditions such as renal, cardiovascular and bone diseases. Consequentially, comorbidities, or the presence of more than one illness occurring in the same person, are particularly common among this group.

The implications of an aging HIV patient population are also becoming clear to Spain's National Health Service, HIV patients and healthcare providers. The prominence of illnesses associated with ART-treated patients may prompt changes in the management of HIV beyond virological suppression to include the management of chronic medical conditions. This will require more complex medical management, which may fuel concerns about shrinking health care budgets in the future.

Against this backdrop, both newly diagnosed and ageing HIV patients in Spain are facing specific problems of loneliness and social exclusion as well as institutional exclusion that their age cohorts are less likely to experience. To help stem the infection rate and to improve their quality of life, the country will need to organise better coordination of healthcare as well as better education outreach and awareness campaigns.

### CHAPTER 1: Improving detection of HIV patients

Improving the detection of and prompt diagnosis of HIV infection has been a key aim of activists and multinational health organisations globally for some time. In 2014, the Joint United Nations Programme on HIV/AIDS (UNAIDS) established the 90-90-90 targets, which call for 90% of all people living with HIV to know their HIV status, 90% of all people with a diagnosed infection to be on ART and 90% of those receiving ART to be virally suppressed by 2020. When all three targets have been achieved, at least 73% of all people living with HIV worldwide will be virally suppressed. The targets are seen as a milestone towards the United Nations Sustainable Development Goals framework.<sup>2</sup>



Spain's performance is mixed with regard to the 90-90-90 targets: while only 82% of the Spanish HIV population has been diagnosed; 92% of Spanish HIV patients are receiving treatment for the virus, with viral suppression just shy of the target (88%). In total, based on 2015 data it was estimated that 66% of Spain's HIV population was virally suppressed (UNAIDS overall 2020 objective = 73%)

Yet these achievements mask a troubling trend. The number of new diagnoses while decreasing slightly between 2010 and 2015—is still higher than it was during the previous decade,<sup>3</sup> suggesting that more needs to be done to "bend the curve" and achieve meaningful reduction in new infections in Spain. Indeed, experts point out, the recent rise in new infections indicates that the battle against HIV in Spain has not yet been won, although the higher numbers also indicate improvements in testing for the virus in recent years.



#### Shifting demographic trends

Several factors complicate the fulfilment of detection goals Spain. The newly diagnosed are older than they used to be—with 14.4% over 50 in 2015, compared with 7.7% in 2000<sup>4.5</sup>—and over half are diagnosed late. In addition, men having sex with men (MSM) make up the majority of new infections, illustrating the need for engaged outreach with this group. An estimated 150,000 people living with HIV in Spain—a prevalence of 0.4 per 100 in 2014.<sup>6</sup>

These shifts are exacerbated by the challenge of diagnosing individuals as soon as possible after they are infected. Although the median age of diagnosis is 36 in Spain, the median age of infection is 33, according to Michael Meulbroek, chair of Projecte dels NOMS-Hispanosida, Spain's most well-known HIV/AIDS communitybased organisation, and a treatment counsellor and educator at peer education programme INFOTRAT.



In Spain, men having sex with men are the biggest group of those affected by HIV; they are dominant in those newly infected over the past 15 years.<sup>7</sup> Detection efforts have been focused on this group, as well as on young people, adolescents and migrants. However heterosexual transmission is "not negligible in Spain," says Dr Julia Del Amo, professor of research in biomedical sciences at the National Center for Epidemiology at the Institute of Health Carlos III in Madrid. She adds that this group is largely related to women infected by male partners who are often drug users or migrants from Latin America and sub-Saharan Africa.

However, people define themselves differently at different points in their lives, according to Jeffrey Lazarus, associate researcher at the Barcelona Institute for Global Health (ISGlobal), and affiliated professor at CHIP, the World Health Organisation Collaborating Centre on HIV and Viral Hepatitis at Rigshospitalet, the University of Copenhagen. For example, he points out that someone who injected drugs 20 years ago will not define themselves as a drug user today, or even necessarily as a former user, yet their infection status may place them in that transmission group. There is also some overlap between at-risk groups, he notes, as migrants and drug users make up at least part of the MSM population, for example.

Those affected at the beginning of the HIV epidemic in Spain were also more likely to come from backgrounds of social exclusion. Today, the profiles of recently infected populations are likely to be more varied, according to Julio Gomez Caballero, a social worker and director of the Federación Trabajando en Positivo. "The ways of infection have changed; it used to be drug users, but now the majority is sexually related," he says. "We need to change the way we disseminate information about activities that are risky for HIV."

Mr Gomez notes that while most new cases are among MSM populations, they are diagnosed relatively quickly and early; while heterosexual transmission might be lower, the HIV diagnosis often comes later. Overall, some 46.5% are diagnosed late in Spain.<sup>8</sup>

Mr Lazarus further notes that regional discrepancies in infection within Spain add a dimension to the virus and its treatment. These incongruities can affect the "clinical cascade of care," a model outlining the sequence of steps that people living with HIV experience from initial diagnosis to viral suppression. In the region of Madrid, which is the most affected, an estimated third of those living with HIV remain undiagnosed.

### A moving target

Part of the complexity of addressing HIV challenges in Spain comes from the difficulty of identifying and managing very different populations infected with the virus.

**Modes of transmission:** Men having sex with men (MSM) account for more than half of new infections, with heterosexual transmission making up an additional quarter and drug users making up a much smaller percentage. For about one in five people with HIV the mode of transmission has not been determined.

HIV generations: There are sharp differences between those infected in the 1980s toward the start of the epidemic and those infected more recently. The earliest two generations make up a significant part of people living with HIV over 50 (PLHIV 50+), and are more likely to suffer more from both age-related comorbidities and conditions related to long-term ART treatment. As such, they are more likely to need more extensive medical and social support. For those recently infected, their overall health is likely more dependent on how much of a delay there is in diagnosis and the start of treatment.

#### Better detection and quick diagnosis remain challenges

Shifting demographics among those infected with HIV require an updated approach to outreach to and detection within vulnerable groups. This is proving complicated, however, because of a number of factors, including reduced funding for awareness campaigns and complacency among some younger groups who are at risk.

"If we want to change the curve and bring infections down, we have to work on getting closer to infections, and we have to be aware of where infections are taking place," says Mr Meulbroek. "We need to care about young people, but not all young people are getting infected by HIV—[primarily those infected are] gay young people."

Critically, funds designated for research, raising awareness and prevention of HIV were drastically reduced as a result of the financial crisis, according to Ramon Alejandro Morillo, a pharmacist. In the absence of studies and mass media campaigns, changing perceptions of HIV among young people have aggravated the problem. Many regard HIV not as a lethal disease but "rather, a chronic condition, which is treated with simple medication that has no side effects", he adds.

Although the Spanish Ministry of Health recommends broader efforts to test for HIV in primary care settings, the devolution of healthcare provision to Spain's 17 regions means that there is a lack of consistent practice in test offerings. In the Basque country, for instance, healthcare authorities have collaborated with community pharmacies to offer rapid tests at the pharmacies, but this approach has not been replicated elsewhere. Self-testing and partner notification, which exist in some other European countries, are not in place in Spain.

Prophylactic treatment of those who may be at high risk of exposure to the virus offers the potential to reduce the spread of HIV and has been recommended by recent WHO guidelines, but has not yet been implemented in Spain.<sup>9</sup>

#### **HIV Generations**

The difference in when and how soon HIV patients are diagnosed and treated has significant impact on the patient's quality of life.

Mr Meulbroek suggests four distinct HIV "generations".

The **earliest** generation managed to survive the initial wave of HIV when there was no effective treatment, leaving them frail and unable to continue working, with smaller social networks.

The **second** generation had their virus detected when the first effective treatments were coming into use, but had to cope with significant toxicity and side-effects, leaving them with health problems today.

For the **third** generation, diagnosed during a period of effective and easily-tolerated treatment, life expectancy is almost as good as a person without HIV.

A **fourth** generation consists of those whose are not yet infected, but who are likely to be diagnosed after a relatively short period of infection, start treatment very early and present with an aging process similar to those of the general population as they age.

### CHAPTER 2: Ageing and HIV; confronting comorbidities

# HIV is associated with a number of comorbidities, including hypertension, cardiovascular disease (CVD), kidney disease, chronic obstructive pulmonary disease (COPD) and mental health problems such as depression and anxiety.

The physiological effects of the virus—including persistent elevations in levels of systemic inflammation and immune activation, despite viral suppression—mean that many of these comorbidities are found in ART-treated HIV patients at a much earlier age than in the general ageing population. These factors are exacerbated by the long-term effects of antiretroviral drugs and higher rates of unhealthy lifestyles among HIV-infected patients.

"People who were infected in the 1980s and 1990s started treatment, if available, very late. Moreover, the first treatments were more toxic and had a lot of adverse effects. So, people with HIV in the earlier years had a lot of years when the virus was replicating without control, and as a consequence, this is the generation that will have more problems than their peers," says Mr Meulbroek.

A study of 2,635 HIV patients in the Basque region of Spain found that more than half of the sample was between 46 and 65 years of age and that 76% had at least one other chronic condition. "By 50 [in this population], you have the same comorbidities found in a population of those aged 65 in the broader community," says Roberto Nuño-Solinis, director of Deusto Business School Health at the University of Deusto in Bilbao.<sup>10,11</sup> Dr Nuño-Solinis also noted that a separate study in the Basque country, looking at socioeconomic differences in the burden of chronic conditions, found that the region's HIV population had the worst social conditions among a list of 52 medical conditions evaluated.<sup>12</sup>

Much of the health outlook for older people living with HIV depends on how recently they were diagnosed.

"Most patients that are 50 or older have typically been diagnosed and started treatment later, meaning they face the added challenge of HIV-related comorbidities *and* ageing comorbidities," says Professor Lazarus. By contrast, he says, "If you started treatment quickly after you contracted HIV, you're in pretty good shape. You are though, of course, dealing with ageing issues like the rest of us."

Mr Meulbroek also points out that for the first generation of people living with HIV, where there was initially no effective treatment, survival with disabilities and little chance of returning to normal employment was the norm. Many of this group had already reached the age of 35 by the time effective treatment became available, and most had spent much money on what treatments were available and most had lost many friends—leaving them in shaky financial circumstances, without a chance to re-enter the labour market and without a broad support network.

"Most patients that are 50 or older have typically been diagnosed and started treatment later, meaning they face the added challenge of HIVrelated comorbidities and ageing comorbidities." "You see a lot of people from that generation who don't have a lot of friends, so loneliness is a problem," he says. "Not having a very good economic situation is bad, but not having a good social situation is worse."

#### **Healthcare gaps**

Despite improvement of HIV treatment, some recent changes in Spain's health system have made it increasingly complicated for older HIV patients to find their way through the referrals and to receive proper treatment for comorbidities and other related health problems.

In particular, Mr Meulbroek says, the combination of budget cuts and reorganisation of health services to "make them more rational and controllable" means that HIV clinics can no longer refer patients with cardiovascular disease, bone problems or suspected cancer to other specialists within the hospital; instead, they must go back to their GP for a referral to a specialist, a process that can take up to several months.

Moreover, the lack of a HIV sub-specialty in infectious diseases in Spain causes its own difficulties, he says. As a result, internal medicine specialists make up the majority of those who treat HIV patients in the country—and many of those with the most experience are nearing retirement age, according to Mr Meulbroek and Dr Del Amo.

The absence of integration between different specialists is also a key concern when it comes to treating HIV patients, who often have complex medical needs. "Every specialist looks at the issue from his or her point of view and gives medication, but there's no coordination between specialists, and most of the time those specialists don't know anything about HIV, or whether there might be any drug interaction," Mr Meulbroek says.

Dr José Arribas, head of the Infectious Diseases unit and research director of HIV and Infectious Diseases at La Paz Hospital and an associate professor of medicine at Autonoma University School of Medicine in Madrid, says that Spanish healthcare generally works well for HIV patients already in the system. These patients typically receive high-quality, accessible treatment and visit specialists at least twice a year. But he believes more could be done to make navigating the system easier for patients.

Making it easier for patients to renew prescriptions without necessarily having to go to the hospital is part of this process, as is an overall striving for more "simplified care", Dr Arribas adds. However, fewer medical visits could be problematic for older HIV-infected patients, who are also likely to suffer from non-HIV-related comorbidities and would therefore need access to a broader range of medical specialists and healthcare providers.

"We need to be innovative about patient management," says Dr Del Amo. "Do all people need to come in every three months? Primary care is probably not the solution because it is so overburdened, but we can be more innovative at the hospital level and we need to spend more money for complex patients."

Virtual consultations, telemedicine and telepharmacy are some of the tools the healthcare system should be considering to improve patient care, Mr Morillo says. And for those with cognitive issues and mental health problems, better psychological support will be necessary in the future, Mr Gomez says.

#### **Fragmented healthcare systems**

Those interviewed noted that guidelines for management of comorbidities set out by the European AIDS Clinical Society (EACS) provide a valuable template for care.<sup>13</sup> To execute the plan, more specialised nurses and peer support will be necessary. This, in turn, will require increased financial and human resources as well as better coordination of healthcare services.

There are many existing challenges to such coordination among healthcare providers. Mr Meulbroek says that in order to advance Spain will need to facilitate a breakdown of the reliance on individual "competences" in favour of a greater focus on a team approach. He notes that Spanish laws prohibit testing for HIV by someone who doesn't have specific training, which creates additional obstacles to improving diagnosis rates. The lack of training is also significant for nurses, who are more likely to establish confidential lines of communication with patients.

"We organise a symposium each year for people with HIV on current topics, including comorbidities, and what we have seen during the last few years is that nurses are coming to our symposium because they want to learn and it's difficult for them to go to conferences," he adds.

More frequent engagement with national action plans can help push the broader agenda of integrated care, reinvigorate the role of peers and provide an opportunity to look at the way the entire health system approaches the virus, Professor Lazarus observes.

Above all, investment should be directed to evidence-based measures, Mr Meulbroek says. This is especially important in a straitened financial climate, in which the healthcare system faces pressures—instead of funding the same projects as it has done in the previous year—and non-governmental organisations (NGOs), which serve marginalised populations, have had their funding reduced by 75% since 2012 (to  $\leq 1.5m$  from  $\leq 5.4m$ ).

Moreover, the tendency toward fragmentation of care—where high-quality medical treatment is provided but little investment is made in preventive or social care—is a problem for Spain, as it is for many of its neighbours.

"More frequent engagement with national action plans can help push the broader agenda of integrated care, reinvigorate the role of peers and provide an opportunity to look at the way the entire health system approaches the virus."

### CHAPTER 3: Towards a "social approach": exclusion, stigma and tackling discrimination

Much can be done to improve education about and reduce the stigma around HIV, which would greatly benefit the infected population. This is particularly true for older HIV patients, who suffered from the stigma of HIV and are now experiencing that stigma plus the complications that come with ageing—they are at greater risk of social vulnerability and, by extension, of early death.

Younger generations of HIV patients in Spain, recently diagnosed and often employed, increasingly worry about how a diagnosis may affect their career and the attitudes of co-workers, says Mr Gomez.

Meanwhile, the frequency of and intensity of medical care, sometimes involving two or three hospital visits a month, contribute to concerns about job retention amongst some patients.

Indeed, the tremendous improvement in terms of healthcare and treatments for those with HIV over the past decade has not been matched by a concomitant reduction in the associated stigma, experts say, adding that pervasive discrimination against those with the virus remains a challenge for Spain.

"Maybe HIV is a little less stigmatised, but there is still much institutionalised discrimination in Spain," says Professor Lazarus, noting that current laws prohibit jobs in the police force, fire service, military and taxi driving ranks to those with the virus, as well as difficulties with access to mortgages and life insurance. For the most marginalised populations, stigma can also undermine adherence to treatment, which is needed for sustained viral suppression.

However, we see some signs of improvement. In a 2012 court case in Seville in which a male sex worker was accused of transmitting the HIV virus, the judge ruled that the defendant was in treatment and therefore virally suppressed, and acquitted him of the charge, says Dr Del Amo.

The process of reducing stigma is intricately connected with improving services for more marginalised groups. HIV outreach, be it education or testing, should be embedded into all services for those who inject drugs, says Professor Lazarus. For example, in Barcelona, harm reduction centres take a more holistic approach by offering their users haircuts, showers and other forms of care in addition to clean needles and syringes. They believe this to be more conducive to building a relationship with their clients and reducing stigma they may face on the street. "Ultimately, we are trying to make health systems people-centred, and that means the system must be attentive to all of their needs, from daily hygiene to complicated comorbidities," Professor Lazarus says. "The process of reducing stigma is intricately connected with improving services for more marginalised groups. HIV outreach, be it education or testing, should be embedded into all services for those who inject drugs."

#### Stigmas obstruct access to care

There are other frustrating obstacles to care, including a royal decree introduced in 2012<sup>14</sup> that withholds access to healthcare for other than prenatal and emergency care for undocumented migrants. The decree was applied fully in some autonomous regions, but not in others, thus worsening inequalities in healthcare among vulnerable migrant groups.

Although Spain's Senate modified that decree to grant access to healthcare to all for conditions involving public health (including HIV and sexually transmitted diseases),<sup>15</sup> awareness of the decree has inhibited many migrants, including those with HIV, from seeking care or testing, Mr Gomez and others say.

The result of all of these factors: Those from wealthier and less marginalised populations are likely to make better use of the public health system, according to Dr Nuño-Solinis.

Meanwhile, the increasing burden of non-HIV-related comorbidities will create additional demands on healthcare services by increasing the numbers of screening tests and prescriptions required for geriatric HIV-infected patients. These added pressures on tight healthcare budgets, in turn, could lead to greater stigma for vulnerable populations.

Ultimately, those working with HIV patients say, the three "90s" of the UNAIDS targets should be supplemented by a fourth: Ensuring that patient management helps those with the virus achieve a better quality of life. This will involve implementing measures that enable comparisons between Spain and other countries and between HIV patients and the rest of the population.

Spain would not be alone in that goal. The 2004 Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia specifically mentions the improvement of quality of life as a target.<sup>16</sup>

## Conclusion

Like many of its European neighbours, Spain has made significant advances in identifying and treating its HIV-infected population, but the recent economic crisis and a lack leadership from competent authorities have slowed the country's progress. Worryingly, without interventions, the situation for HIV-infected individuals in Spain appears set to worsen.

Efforts to meet the UNAIDS 90-90-90 targets in Spain and tackle the problems facing those ageing with HIV will require further and increased investment in diagnostic efforts and preventive care. This will involve a reversal of the ongoing sharp cuts to funding of NGOs working in harm reduction and other groups treating the most marginalised HIV patients.

A commitment to a more integrated approach to HIV—ranging from prevention to diagnosis to treatment—will also be necessary to keep new infections in check, manage comorbidities, including those related to the normal ageing process, and help those living with the disease improve their quality of life. As part of this process, better treatments suitable to the populations currently infected with HIV will be necessary.

Finally, quality of life remains a serious issue for the HIV-infected population. There must be more concerted efforts to reduce the social stigma and discrimination associated with the virus. The institutional stigma that is especially pervasive in Spain must also be confronted at a high level to allow HIV-infected populations to return to or remain in the workforce, to be better integrated socially and to ensure that they get the full spectrum of health services they need.

These changes will not happen without targeted interventions. All will require strong political will to educate the Spanish public, policymakers and healthcare providers on the reality of living with HIV today.

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London 20 Cabot Square London E14 4QW United Kingdom Tel: (44.20) 7576 8000 Fax: (44.20) 7576 8476 E-mail: Iondon@eiu.com New York 750 Third Avenue 5th Floor New York, NY 10017 United States Tel: (1.212) 554 0600 Fax: (1.212) 586 0248 E-mail: newyork@eiu.com Hong Kong 1301 Cityplaza Four 12 Taikoo Wan Road Taikoo Shing Hong Kong Tel: (852) 2585 3888 Fax: (852) 2802 7638 E-mail: hongkong@eiu.com Geneva Boulevard des Tranchées 16 1206 Geneva Switzerland Tel: (41) 22 566 2470 Fax: (41) 22 346 93 47 E-mail: geneva@eiu.com

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