The impact of economic austerity on the HIV response in Portugal: a community perspective

A Working Paper

Contents

1. Introduction

Over the last two years, the country has faced increasing challenges in ensuring HIV prevention[1] and access to treatments. Legislation provides for universal access policy and social protection measures for persons living with HIV, e.g. home support and minimum income. Maintaining existing services and even of a scaling up, especially of those directed at vulnerable groups is a necessity. However, budget cuts in social welfare and social interventions are contravening to the response to HIV. Last year, the minimum income was decreased by 30 percent.

Portugal is one of the four European Union countries (Cyprus, Greece, Ireland, and Portugal) who signed-up for a bailout programme from the European Commission (EC), European Central Bank (ECB), and International Monetary Fund (IMF). As a result, the country is going through a drastic austerity plan resulting in budget cuts, including reduction of pharmaceutical spending, decreasing civil society interventions in the field of HIV prevention, testing, health literacy (adherence and retention). Several public structures were also restructured, including the National AIDS Programme (NAP) and the former Institute for Drugs and Drug Addiction (IDT, nowadays SICAD). The country experiences increases in taxes, growth of unemployment, poverty and homelessness and decrease in social supports measures.

The purpose of this country brief is to provide a local community perspective on the response to the epidemic in Portugal, the challenges lying ahead and possible actions by the different stakeholders. It is based on existing reports, official presentations and interviews with health sector professionals, persons living with HIV, civil society organisations and pharmaceutical companies representatives in December 2013.

2. The epidemiological situation in Portugal

2.1. Late and under-reporting of HIV cases

In 2012, the number of new HIV diagnosis reported, 721 suggest a decrease in new cases[2]. However, the numbers of previous years indicate an underreporting of new HIV cases. Underreporting is due to notifications delays. This means that the data changes over the next three years[3]. An analysis of the National Health Institute's National Surveillance Report (INSA) from 2012, points to the underreporting in previous years. In 2012, INSA has collected 1 625 notifications, of which only 776 corresponded to new HIV infections diagnosed in 2012.

[1] Funding for HIV prevention was already limited prior to the budget cuts.

[2] http://www.ecdc.europa.eu/en/publications/Publications/hiv-aids-surveillance-report-2012-20131127.pdf

[3] In the 2009 National Report, stated 1 055 new infections, whereas the 2012 Report reported a total of 1 708 of new HIV infections reported in 2009.

Therefore, one can expect to see an increase in the reported number of new infections in 2012 over the upcoming years when the new registry SI.VIDA is completed

In a recent interview, the National AIDS Programme (NAP) Director, António Diniz, declared that "between 1983 and 31 October 2012, 43 350 HIV/AIDS cases were notified in Portugal. This represented an increase of 10 000 cases in only 5 years, considering that in 2007 Portugal had 32 491 reported people diagnosed or living with HIV/AIDS"[4]. He referred to three 3 main regional areas of the HIV epidemic, "40% of HIV infections are registered in the great Lisbon area, 20% in the Porto area and 15% in Setubal. The percentage has increased both in the heterosexual and homosexual groups. Apart from sexual orientation, there has been a decrease in the incidence of HIV infection among people who inject drugs (PWID)". However, Portugal had the highest HIV incidence rate in Western Europe among PWID between 2009 and 2010.

2.2. Late HIV diagnosis

According to a partial study the rate of late diagnosis remains above the European average, at around 65%. The average of the CD4 counts in five of Portugal's main hospitals at the time of diagnosis is between 183 and 264 CD4 cells[5]. This is especially serious among migrant men and IDU (2007-2009).

In 2010, 23 966 tests were performed in anonymous centers, in 2011, 19 700 tests, and 2012, 18 151 tests[6]. Rapid tests were performed at formal centers (the CAD Network). The rate of reactive result in these formal centers is around 1% and represent, depending on the years, between 10 to 20% of the new HIV/AIDS diagnoses in Portugal every year (200-300 new cases). In 2010, NGOs started to offer HIV screening, with the approval of the project CheckpointLX (performing 2 000 test year with 5% reactive test rate).

2.3. Key affected groups

The trend towards a reduction of new HIV diagnosis among PWID, about 10% of new HIV infections, is counterbalanced by reported increases in relapses (heroin related mostly), and by a financing gap in harm reduction, e.g. needle exchange programme (NEP). The National Report from SICAD[7] on drug use, released on the 17 December 2013, confirms indications of a significant increase in drug relapses (4 012 people that had already been on treatment for drug addiction entered the healthcare services again). It is also reported that "a relevant percentage

[4] http://www.publico.pt/sociedade/noticia/portugal-entre-os-paises-europeus-com-maior-taxa-de-novos-casos-de-vihsida-1575591#/0

[5] Presentation By Alexandre Lourenço (Central Administration of the Health System) – HIV Portugal 2013 – Annex B2
[6] Presentation By Joana Bettencourt (National Aids Programme) - HIV Portugal 2013 – Annex B1
[7] Former Institute for Drugs and Drug Addiction, currently "Service for Intervention on Addictive Behaviors and Dependences"

of consumption material sharing persist among people who use drugs" and that "especially over the last two years, a bigger heterogeneity in the ages of clients that have initiated treatment (…) with a younger group of new users and one another group, of relapsing clients, that is progressively older". [8], Moreover, needles have ceased to be exchanged in pharmacies. The number of syringes distributed decreased in 2012 and probably further decreased further in 2013. According to ANF (National Association of Pharmacies), in the first 8 months of 2013, there was a substantial reduction on the number of syringes exchanged. The overall numbers were 31, 5% inferior to those of 2012, a percentage that represents 272.000 less syringes exchanged in this period[9]. A weak NEP provides fertile ground for new HIV/Hepatitis C infections among drug users, similarly to what happened in Greece and Romania.

The HIV prevalence among men having sex with men (MSM) remains a major concern. It is growing in absolute figures (24% of new infections[10]). The European MSM Internet Survey[11] (EMIS) reported prevalence of around 9% and TLS study finds a prevalence of around 19% in a sample of 400 MSM in Lisbon.

Underreporting data in the MSM populations should be taken into account, especially considering the 2,4 men to women ratio in terms of newly HIV infections. This ratio has been over 2 men per woman since 2001, and was previously over 3, due to a highly concentrated epidemic among PWID in the nineties, where there were more PWID men than women where men were extremely more present than women. The high prevalence of the HIV/AIDS among PWID still remains high (16 350 according to the 2012 SICAD National Report[12]) despite the progressively lower number of new HIV infections reported in this group.

Additional difficulties in access to health by vulnerable groups include stigma and discrimination. In a recent report from the study "Stigma Index Portugal" (a study that assessed situations of stigma and discrimination among PLHIV, conducted by the AIDS Anti-Discrimination Centre (a GAT/Ser+ project), roughly 30% of the participants reported cases of stigma and discrimination which occurred in healthcare services or related to healthcare professionals[13]. Despite not being related to infectious disease doctors, these reports of discrimination have an impact in terms of the services used by PLHIV, which can also strongly impact their well-being.

[8] http://www.idt.pt/PT/IDT/RELATORIOSPLANOS/Paginas/SituacaodoPais.aspx, (p. 15).
[9] http://www.anf.pt/index.php?option=com_content&task=blogcategory&id=13&Itemid=26&limit=6&limitstart=6
[10] http://repositorio.insa.pt/bitstream/10400.18/1622/3/Relatorio_SIDA_2012_WEB.pdf
[11] http://www.emis-project.eu/
[12] http://www.idt.pt/PT/IDT/RELATORIOSPLANOS/Paginas/SituacaodoPais.aspx, p. 53
[13] http://www.publico.pt/sociedade/noticia/quase-um-quarto-das-pessoas-infectadas-com-vih-disseram-ter-sido-excluidas-da-familia-1613421

3. The response to the epidemic

3.1. The HIV/AIDS programme

In 2011, the total budget allocated to the HIV/AIDS programme roughly amounted to 6-7 million Euros. It derives for the main part from a percentage on gains made by the national lottery. The programme includes the purchase of rapid tests, condom and lubricant; the production and printing of materials; the salaries of NAP members; small research grants and a funding line for NGOs (4 million Euros in the ADIS/SIDA programme). The cost of ARV purchase and health personnel expenses were supported directly by the national health budget.

Over the last few years, some Portuguese civil society has played a key role in providing services in the field of HIV/AIDS. Civil society organisations ensured tailored prevention projects aimed at vulnerable populations, rapid testing initiatives aimed at vulnerable groups, health literacy and support services such as harm reduction, condom distribution, social and psychological support, treatment information, among others. These services were co-financed (up to 75%) by the ADIS/SIDA budget line of the NAP until 2011. There are no new projects since 2011 and most of the projects have closed or are ending. A call for proposals was opened late December 2013 with a budget of 1 million Euros.

The distribution of **prevention-related material** targeting key affected/vulnerable populations, e.g. condoms, lubricant, and health literacy, is done via civil society projects. The materials themselves, except specific tailored information for some groups, are supplied by the NAP. Yet, in the last two years there have been significant problems with the distribution, with stock-outs of ARVs, lubricant and female condoms.

Harm reduction work among people who use drugs has mainly been carried out by NGOs with the financial support SICAD (formerly IDT). The institution is going through heavy restructuring.

3.2. Access to testing

HIV screening is not yet a reality neither in primary care, nor in emergency services (a 2011 study in three emergency units showed 1 to 2% of HIV prevalence). HIV testing guidelines associated with indicator diseases do not exist either. The only exception is the routine screening of pregnant women.

Community-based testing has grown over the last 3 years and has proven useful in reaching out to undiagnosed people in key affected groups. However, there are still no official guidelines for the implementation of these initiatives in informal settings. Civil society organisations

provide rapid testing without formal guidance, standard report system, standard training or procedures for quality control. Moreover, the financial support remains very limited.

3.3. Participation in policy and decision-making

Many people living with HIV (PLHIV) remain distant from advocacy and are not actively **participating in policy and decision-making**. Civil society groups and PLHIV are represented in decision-making organisms and/or commissions or consultation groups but in non-systematic manner. It often mainly consists of a small group of long-term activists.

A National HIV Civil Society Forum for HIV/AIDS was established in 2007. So far, it has not played a determinant role in influencing public policies but a few organisations have successfully influenced policy and legislative measures. Though, the implementation of the measures remains to be improved.

National strategies and plans rarely include collaboration with most affected communities and/or groups. Priorities are defined by the public structure. There are some improvements in the public consultation of the draft versions of the documents, but the consultation of actors still occurs too late in the process.

Standard public response is limited to the national network of official centres for anonymous testing (CAD), and to treatment response, with social support being handled within the hospital where the patients are followed.

3.4. Treatment costs and access to quality medicines

The standard first line treatment costs remain around 7,000 Euros per year and 10,000 or more Euros per year for second line treatments. Recent data has indicated that expenses for ARV drugs in 2012 amount to 226 million Euros, which represents twice the amount spent in 2005 (112 million Euros)[14]. This increase in treatment costs is related to efforts to improve screening and the availability of HIV testing (and the introduction of HIV rapid testing in 2005), which resulted in an increase of new HIV diagnostics. An estimated 20-25 000 people are currently undiagnosed in Portugal. The increasing amount of the budget spent on medicines points fosters sustainability issues.

Treating co-infections, such as Hepatitis C for example, also is made difficult by the delayed availability of innovative drugs (an average of 4 year period in Portugal). Recently, the chair of the professional Doctors' Association (Ordem dos Médicos), stated that "If I had hepatitis C I

[14] Presentation By Alexandre Lourenço (Central Administration of the Health System) – HIV Portugal 2013 – Annex B2

would prosecute the Health Ministry for denying the right to innovative treatments (…) [some patients] were sentenced to death due to the delay in the drug approval"[15].

In spite of sustained advocacy of civil society, severe budget restrictions and difficulty in price negotiation between the state and pharmaceutical companies hinder access to affordable quality drugs and sustainable universal coverage of healthcare.

3.5. Universal coverage

The law guarantees universal access to healthcare and treatment. In practice, however, the bureaucracy for people not in the system (irregular migrants, homeless and displaced people) limits their access. Being enrolled in the national health system and having a health card is a requirement to have any type of access to health. However, it is a too lengthy bureaucratic process that has to be done outside of the Health system. Proof that the person is living in Portugal for over 90 days needs to be presented at the local council where the person is living; it requires 2 witnesses and a fee.

4. Impact of economic austerity

4.1. Funding for services directed to most at risk populations and social protection

In 2012, the same percentage of gains from the national lottery[16] was allocated to the NAP to support prevention efforts in the field of HIV/AIDS, which helped it maintain a similar (with slight decrease with people gambling less) budget level. However, the State Budget contribution to the ADIS/SIDA programme decreased and there has been no new call for proposals in 2011, 2012 and in 2013. Until 2011, the programme had a total allocation of 4M€ (for both one year projects and multiyear projects). No new projects to work directly with PLHIV and/or MARP for have been funded in the last two years. Project that received funding before that have ended or are near the end. Some projects have been sustained thanks only to the voluntary work of the NGOs' human resources.

A new system of approval of financial spending which requires permission from the Ministry of Finance has negatively affected the timeliness of purchases and investments. At the end of last year, the NAP faced a condom stock out that left both public services and NGO's without primary prevention materials to distribute.[17] This situation lasted months and had the potential to have disastrous consequences but civil society found a way to gather material to distribute with the support of the AIDS Health Care Foundation.

[15] http://www.ionline.pt/artigos/portugal/jose-manuel-silva-ha-doentes-hepatite-c-serem-condenados-morte
[16] 8%, according to the "Portaria" nr. 359/2012 from 31 October 2012
[17] See http://sida.dgs.pt/informacao1/material-iec1.aspx. the 3rd link shows the graph (official source – National AIDS Programme)

The financing gap of services provided by NGOs was aggravated by the restructuring of the former Institute for Drug and Drug Addiction and the needle-exchange programme (NEP). Harm reduction teams reported service interruptions in needle distribution. Some projects were shut down or have been operating with minimal services. When the NEP pharmacy initiative ended, the service was allocated to the primary healthcare centers. It was criticized for not linking to people who inject drugs. Funding is restarting and grants programmes are expected to be launched in January 2014. The implementation of the NEP in the primary healthcare is still under heavy criticism from the civil society. It has to be noted that several organisations[18] are represented in the Commission monitoring this programme and these issues have been raised and discussed.

An NGO representative reported: "these measures, that led to financial cuts for civil society organizations have stopped or limited the development of responses at all levels of intervention, namely in terms of prevention, diagnostics, social and treatment support. In our case, it was particularly relevant for the development of a project on the field of prevention and early diagnosis with the migrant population, as well as a health education response, with particular focus on ARVs adherence"[19].

4.2. Budget cuts affecting people living with HIV

The severe cuts in social support measures have had an important impact on PLHIV because of the high unemployment rate (the largest study among PLHIV in Portugal reported approximately 40% unemployment in 1 064 people[20]). Apart from welfare support (minimum wage, for example, is around 485 Euros, but minimum income ensured is around 265 Euros per family, and 89 Euros per individual[21]), social support was for a large part provided by NGO's. Since the budget cuts, these are now underfunded or closing. Thus, there is a lack of support for PLHIV as is the case for most people with financial difficulties in Portugal.

Complementary diagnostics, as well as other appointments and/or treatments not directly related to the HIV infection are restricted and require co-payments. This is the case for hepatitis, though co-payment is not required for the drugs.

[18] - Grupo Português de Activistas sobre Tratamentos de *VIH*/SIDA(GAT), Agência Piaget para o Desenvolvimento (APDES) and Portuguese Drug Users Association (CASO)
[19] Interview with NGO representative – Annex A1
[20] Presentation by Pedro Silvério Marques (Ser+) – HIV Portugal 2013 – Annex B3
[21] http://observatorio-das-desigualdades.cies.iscte.pt/index.jsp?page=indicators&id=64

4.3. Investment in screening

The investment needed to tackle HIV infection and achieve earlier diagnosis, as foreseen in the national strategy, remains to be implemented. Guidelines for HIV screening in informal settings remain to be seen. A rapid testing project was only piloted two months ago in the national health system. Moreover, HIV testing is still not offered to patients in emergency units and there are no guidelines for testing according to indicator conditions.

Offering HIV screening only in health centres has potential to fail, because costly and/or result in massive amounts of test done the general population (low risk). Scaling up screening, based on the current testing model of testing in health settings, would require substantial human resources (roughly 45 minutes per each test). Moreover, many persons in key affected communities do not go to health centres. Therefore, provider-initiated blood screening[22] seems more cost-effective and offering screening outside of health services to reach out to key groups seems like a reasonable investment.

4.4. Access to treatments and stock-outs

Persons living with HIV interviewed for this paper reported the following cases[23] :

- Hospitals refusing access to people who are not from the residential area of the hospital (internal decision, not a legal barrier);
- Hospitals limiting access to doctors' appointments to people referred by general practitioners';
- Undocumented migrants facing procedural difficulties in access the national health system, even though legislation guarantees universal access;
- ARVs are being rationalized, boxes being opened and pills separated and, in some cases, there are reports of people changing antiretroviral treatment due to temporary stock outs or for economic reasons (from the hospitals' part);
- Exemption from standard health access rates and access to social support overall is more difficult for all, Portuguese citizens included.

Hospitals now manage all of their expenses and their budgets include the cost of ARVs. Thus medicines priorities may change from one hospital to another. It is suggested that this approach has probably contributed to the temporary "pop-up stock outs". Indeed, some hospitals, due to budget priorities/constraints, faced temporary stock-outs of some ARVs. This has resulted in the need for HIV patients to hospitals more often get their medication (reports

[22] Indicator conditions and prevalence
[23] Interviews with PLHIV – Annexes A5 to A9

of 2-3 times a month in some situations). This situation occurred with several drugs in different parts of the country.

In October 2013, Grupo Portugues de Activistas sobre Tratamentos de VIH/SIDA (GAT), a local organisation did a survey system for people to report experiences of stock-outs. By December, 33 cases were reported, regarding 15 hospitals all over the country (mainly in Lisbon, but extending to island of Madeira, Porto, Algarve and other regions). Most people reported that they received fewer pills and were asked to return a few days later to get more, but there were 3 reports of people who interrupted treatment. In 30 days, 11 people reported having to go only once, whereas 6 people reported having to go twice and 7 people stated more than twice.

The majority of ARVs drugs have been out of stock at some points. The most reported drug stock-outs or rationing concerned the ARVs Truvada® (14 reports) and Norvir® (13 reports), but many others were mentioned (Reyataz® – 5 reports; Prezista® – 4 reports; Atripla®, Isentress® and Retrovir® - 3 reports; Stocrin® and Kivexa® – 2 reports; Kaletra®, Trizivir® and Viramune® – 1 report).

Taking into consideration the limited financial means of many PLHIV who have to pay for the transportation to the hospitals for standard appointments and to pick up ARV medication; this current situation presents important risks to treatment adherence. The NAP Director declared that "On one hand we ask people to adhere to the treatment regimen and, on the other, we create obstacles such as having people go to the hospital three or four times per month"[24].

As reported by an NGO representative, "Despite regulated in "decision" number 2175/2013, published in the Diary of the Republic n. 26, Series II, in 06.02.2013, that hospital pharmacies cannot give medication for periods under 30 days, situations of medication being unavailable have been reported". "The fact that the hospitals are not respecting this "dispatch" is jeopardizing adherence to ARV treatment as well as the free circulation of people, creating situations of inequality in terms of access to health, well-being and professional life"[25].

4.5. Examples of initiatives taken to counter the impact of austerity

Besides the fact that treatment prices are high, Portugal is required by IMF, EC and ECB lenders to reduce the percentage of expenditure with medicines from 1.4% of the annual budget to 1.25% in 2012 and 1% in 2013. Price caps were negotiated to ensure universal access to treatment, but a pharmaceutical representative said, "the minimization of the budget impact

[24] http://www.publico.pt/sociedade/noticia/custos-dos-transportes-estao-a-impedir-doentes-com-vihsida-de-levantarem-medicacao-no-hospital-1614558

[25] Interview with NGO representative – Annex A2

on drug spending, namely ARVs has not been publically recognized, nor have its benefits been translated into a reinvestment in areas such as HIV/AIDS or Hepatitis C"[26].

In 2012 and 2013, "agreements were established between the Health Ministry and the Pharmaceutical Industry that resulted in a significant financial contribution. (…) It is also important to mention that an annual drug price revision, for hospital only drugs, was established in 2013 that has as a basis the minimal price of a group of countries"[27].

The new financial model for hospital drugs, in particular for new ARV, "should be changed (…) since these drugs, after being approved and evaluated present a price and expense cap, it is essential that that cap has an assigned budget and centralized funding"[28].

5. Recommendations to stakeholders

5.1 To address the epidemic with limited resources, Portugal needs an adequate monitoring system, with internationally comparable indicators that ensures a timely and correct assessment of the current situation. A new computerized notification system for "people in care" is being developed (SI.VIDA), but its full implementation will take time.

5.2. There needs to be meaningful representation of and regular consultations with communities, expert patients and other civil society organization to ensure that national priorities that are identified do reflect the real needs of the people they seek to address.

5.3 Consistent funding and mechanisms to ensure the sustainability of the civil society interventions. Adequate project evaluation system must be available to assess the relevance of the funded projects, and their contribution, thus allowing a common understanding of relevance and cost-efficiency of interventions.

5.4. Invest in treatment literacy, as well as initiatives that support adherence and retention in care, preferably with trained peers.

5.5. In the NAP, prioritize community-based testing guidelines for most at risk populations along with an adequate funding mechanism for community based voluntary counseling and testing and a solid evaluation and data collection mechanism. These interventions should focus

[26] Interview with pharmaceutical representative – Annex A4
[27] Interview with pharmaceutical representative – Annex A4
[28] Interview with NGO representative – Annex A2

on the most vulnerable groups as community can decisively contribute to earlier diagnosis and linkage to care of people outside the standard health response system.

5.6. Guidelines for HIV testing associated with indicator diseases being implemented in Portugal would also be important and a lobbying effort for the adoption of these guidelines could have significant results in terms in lowering the number of people undiagnosed.

5.7. The issues with stock outs must be addressed. While there is no clear "magical" solution, clear guidelines ensuring that ARVs purchase has its own budget, and is not a part of the general hospital budget (centralized financing mechanism).

5.8. As regards improving access to innovative treatments, it has been suggested to "Define a deadline for an approved drug to be effectively available at the hospital and to create a monitoring system"[17]. It would be used to assess and report on the effective time that new drugs take to reach patients.

4.9. It would also be desirable to have an integrated national guidelines mechanism for new drugs to ensure equity, quality and efficiency. At the moment; there are at least three different guidance documents for ARVs (clinical recommendations, Clinical Guidance Norms (NOC) and the National Drug Form recommendations), in addition to hospital protocols. In order to ensure

4.10 At a European level, the transition of European Medicines Agency (EMA) approved drugs into national markets could be improved and supported to facilitate access to innovative medicines.

4.11 The European Commission and member states should reflect on long term sustainability mechanisms that ensure that countries with lower GDP and/or high HIV burdens are able to provide universal access to adequate treatment.

4.12. There should be a process within the health system to enroll undocumented migrants to facilitate their access to health services.

4.13. Enabling access to complementary health services and not only HIV specific health is important for migrants and the general population.

4.14. Review a recently published manual created by the National Health Directorate in conjunction with the Central Administration of the Health System that aims to "ensure the

correct identification of non national citizens in the access to the National Health System, as well as the recognition of their respective financial responsibility"[29].

[29] http://www.acss.min-saude.pt/artigo/tabid/98/xmmid/896/xmid/6036/xmview/2/Default.aspx