

# **Meeting Report: National Stakeholder Meeting on Implementation of HIV test in Primary Care & Linkage to Care in Portugal**

**September 2017**

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This meeting was commissioned by the OptTEST by HiE project, coordinated by PHE, UK, and arranged by GAT, Portugal.

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## Introduction

In June 2017, a two day' stakeholders meeting, coordinated by GAT under the EU co-funded OptTEST (Optimising Testing and Linkage to Care for HIV in Europe) project, was organized in Lisbon in order to reflect and discuss:

- a) Knowledge about HIV and implementation of HIV testing in primary health care with the presentation of the results of the "RESPECT" study conducted by the Anti-Discrimination Centre<sup>1</sup>;
- b) Linkage to care of people with a reactive HIV test or diagnostic: challenges and facilitators for the improvement of linkage to care, with special focus on key populations;

The main objective of the meeting was to outline, with the input of multiple actors related to public health sector and non-governmental organisations (NGOs)<sup>2</sup>, the barriers and possible solutions to implement rapid HIV tests at primary healthcare settings and how to scale-up linkage to care and, in a future discussion, retention of patients in care.

Overall, HIV screening is well recognized as fundamental in the fight against HIV/AIDS, but there is a need for screening offered to reflect the epidemic context. In Portugal, 1,220 new HIV diagnosis were reported in 2014<sup>3</sup>, more than 50% of which were estimated as late diagnoses, highlighting the persistence of effective barriers to testing<sup>4</sup>. The most prominent self-reported transmission route remains heterosexual contact, accounting for 61% of the notifications in 2014. Sex between men, which is the main transmission path in the majority of other EU/EEA countries, is reported as the source of infection for 31% of new diagnoses in Portugal. In recent decades, there has also been a consistent increase, both in the absolute numbers and relative contribution of sex between men for new HIV reported cases in Portugal.

It is estimated that sharing of injection material - typically relevant for concentrated epidemics - is responsible for less than 5% of the new cases in our country.

With regard to geographic origin, nearly 20% of individuals with new diagnoses were born outside of Portugal, and three quarters of these in sub-Saharan African countries. It is estimated that over 80% of the newly diagnosed individuals in 2014 lived in coastal districts, mainly in the larger urban areas.

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<sup>1</sup> RESPECT's final results will be available mid-2018, and will include the data presented on this meeting, as well as additional information, and a post-intervention assessment.

<sup>2</sup> Agenda and participants list available as Annexes 1 and 2, respectively

<sup>3</sup> Ministério da Saúde. Direção-Geral da Saúde: Portugal - Infeção por VIH, SIDA e Tuberculose em números - 2015. 2015

<sup>4</sup> Infeção VIH/SIDA: a situação em Portugal a 31 de Dezembro de 2014. Departamento de Doenças Infecciosas. Unidade de Referência e Vigilância Epidemiológica. Núcleo de Vigilância Laboratorial de Doenças Infecciosas; colab. Programa Nacional para a infeção VIH/SIDA: Instituto Nacional de Saúde Doutor Ricardo Jorge (INSA, IP); 2015.

This portrait of the Portuguese epidemic highlights vulnerable population groups. This vulnerability concerns not only the risk of infection, but also access to tests, further reinforcing the importance of the screening offer among the most affected groups - such as men that have sex with men (MSM), sex workers (SW), migrants and injection-drugs users (IDU) - for which some prevalence estimates reach 10%, and adequate linkage to care pathways which respond to the needs of all population groups.

## Day 1: HIV knowledge and HIV testing in Primary Health Care

### 1.1 Knowledge about HIV and implementation of HIV testing in primary care

The Anti-Discrimination Centre presented the RESPECT study (Annex 3), a replication/adaptation of a project with the same name developed in Ukraine after the Stigma Index Study<sup>5</sup>. The RESPECT study aimed to identify and assess the barriers and obstacles associated with stigma and discrimination against HIV-positive people, and to outline and implement strategies to overcome the identified barriers.

The study was conducted in 2016, among three ACES (Groups of Health Centres operating in close territorial areas) in the Greater Lisbon area, with a total of 167 health professionals participating (84% females and 60% more than 40 years old).

Approximately 30% of respondents did not know that HIV couldn't be transmitted through breast milk; more than half assumed that HIV could be transmitted through saliva (60%), spit (57%), vomiting (55%), urine or runny nose (both with 49%). The doctors gave more correct answers in the items breast milk, faeces, saliva and amniotic fluid than nurses.

Three-quarters (75%) of respondents believed that there is a risk of HIV transmission by kissing in the mouth a person living with HIV, 36% sharing linen and bathroom linen, 25% sharing cutlery, 21% through a mosquito bite and 8% touching the skin of a person with HIV.

The nurses overestimated the risk of sharing bedding and bathroom linen and sharing cutlery more than doctors and underestimated the risk of needle-stick injury with an unsterilized needle (more than 8% report that it is a risk-free situation).

Almost 50% of the health professionals who responded to the survey felt there is a high or medium risk of HIV transmission in their professional activity. Some of the situations where perceived risk were reported are summarized in the table below.

<b>Activity</b>	<b>% of respondents who reported perceived risk of HIV infection</b>
Providing first aid to someone with infection	77%
Gynaecological examination	38%
Personal hygiene	20%
Contact with saliva	45%
Contact with sweat	18%
Contact with person living with HIV	10%
Sharing a bathroom	26%

Additionally, 40% of respondents said they always wear gloves when working with HIV patients, and 9% always wear a mask (a trend that is more pronounced in

<sup>5</sup> <http://www.stigmaindex.org/portugal>

nurses than in doctors). In the "Other" response: Most refer to gloves when exposed to biological fluids.

Only 45% of the health professional who responded to the survey had knowledge of standards set by the National Health Directorate in December 2014 concerning the guidelines for offer of an HIV test. Awareness was lacking more among nurses.

It was noted that 16% of physicians and 15% of nurses report that the behaviour of employees is different among people living with HIV, with 25 workers reporting that when dealing with an HIV-positive patient, health professionals take increased precautions in the provision of medical care

Only 26% of respondents report that there is a policy defined in their establishment to preserve the confidentiality of the diagnosis of users.

Primary healthcare services provide a wide array of health services to a vast number of people. It was clearly stated that it is very difficult to keep up with all guidelines and regulations, and implement high quality responses in all areas. Thus, the use of rapid testing in primary healthcare (PHC) will require continuous investment, including training, technical support and monitoring, as well as positive consequences for the healthcare unit.

Alternatives such as indicator condition testing, taking into consideration the work done in OptTEST presented by Rossi Lugo<sup>6</sup>, and opt-out testing strategies associated with standard blood tests prescribed by primary healthcare doctors were discussed, and could be cost-effective in some units, depending on local epidemiology.

Practical implementation of rapid testing services in healthcare centres carries several constraints in terms of human resource time allocation. Adding HIV to the already prescribed blood tests could achieve the same goal and alleviate the burden. Rapid testing makes more sense in PHC, which have outreach activities, or for particular situations where a result is required more urgently.

Additional points were discussed and are summarized as action points or recommendations in the following section.

## 1.2 Possible solutions and next steps

Testing in primary healthcare is an important approach in increasing early diagnosis of HIV. However, the RESPECT study indicates important gaps in terms of basic knowledge regarding HIV infection, and the situation is most likely similar in other healthcare centres.

Is it thus paramount that a **training package** is implemented and its results monitored by official structures, targeting PHC professionals both involved and not involved in the testing activities. The training package should incorporate

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<sup>6</sup> Annex 4

epidemiological data of the health area of each ACES (Health Centre Group) to help tailor the testing strategy.

This training package should **include** not only functional information on **routes of transmission**, but also practical information on **testing offer (strategies on how to propose an HIV test were mentioned) and procedures (including counselling associated with both positive and negative results)**, and integrate a **module on stigma and discrimination towards PLHIV and key affected groups**. Including issues related to **data protection and confidentiality** should also be considered.

Within the framework of the RESPECT study itself, an action-research project, the development of pilot interventions is currently underway in 3 ACES in Cascais (these actions intertwine with those of the Fast Track Cities Cascais). A new implementation of the questionnaire is planned for May/June 2018 to observe the impact of the interventions. Then, it will be up to the Ministry of Health to replicate the interventions that have proven effective.

In the meantime, the Antidiscrimination Center (CAD) continues to deliver training to healthcare professionals on issues related to HIV, stigma and discrimination, and has increased the focus on HIV testing offer in primary care, as well as associated counselling.

A future partnership with official structures may allow for the scale-up of these trainings sessions and more technical training related to testing may also be added through the Community Based Screening Network<sup>7</sup>. Both these projects will also help create a network of community based organizations to contribute in the linkage to care process and system navigation, in partnerships with PHC.

**Reinforcing the existing recommendations regarding testing offer, both related to indicator conditions, and to key groups** should also be in the priority list. Knowledge gaps from health professionals regarding who to offer HIV tests to were reported, since guidelines and recommendations are high in number, and it is impossible to keep them all in mind.

At a practical level in the healthcare centres, the **availability of rapid tests** in all centers must be guaranteed. **Human resources** at a central level (either regionally, nationally or both) to help structure implementation processes, provide support and monitor progress are extremely necessary. The data collection process associated with rapid test could also benefit from a revision and upgrade.

It is necessary that before the implementation of such programs, the **data collection system, testing and referral procedures are clear** for every person involved, with very clear indications and pathways, and that evaluation can be done also through cost-effectiveness indicators.

A minority of primary healthcare settings (Specific Family Healthcare Units) are being **payed to perform HIV paid tests**. Expanding the payment system, at a minimum, to centres located in areas where there is a high prevalence of HIV

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<sup>7</sup> <http://www.redederastreio.pt/>

infection could contribute to an improvement in terms of testing uptake. Financial incentive programs directed at management of diabetics and other pathologies are already in place, but there is still no program for HIV.

An **improved referral protocol** either ensuring that healthcare staff or a partner organization can assist people with reactive result in the referral process, and help navigate the hospital system, should also be considered.

Increased **public awareness**, either nationally or locally in higher prevalence contexts would also be desirable. The last (and first for MSM) campaign for HIV was in 2008, directed at the MSM population. Increased awareness could result in greater test seeking behaviour, as well as in a reduction of stigma associated with regular HIV testing.

## Day 2 - Linkage to care

### 2.1 Current perspectives on data collection and barriers to linkage to care among key groups

The meeting started with the presentation of OptTEST's findings on linkage to care at a European level, as well as available data for Portugal, by Sara Croxford (Public Health England, UK)<sup>8</sup>, followed by presentations of the national picture, by Isabel Aldir (Director of the National HIV, Viral Hepatitis and Tuberculosis Program), and on the current state and future challenges of the national HIV ambulatory treatment program by Sofia Mariz, from ACSS (Administração Central do Sistema de Saúde)<sup>9</sup>.

These presentations set the tone for an in-depth discussion on linkage to care definitions and the national data systems.

There was consensus that Portugal lacks relevant data to inform the linkage to care indicator in the continuum of care, and that important caveats of Portuguese data must be considered when interpreting national estimates of linkage to care using the OptTEST definition. In OptTEST, linkage to care is defined as the time between the first screening or lab test, and the first doctor's appointment with a confirmatory test already performed (proxies for clinic attendance can include first CD4, first viral load or treatment initiation).

Information systems currently do not allow for this diagnosis and care information be linked, which creates a gap in terms of timely data access (and subsequent analysis).

Two main points were discussed: the SI-VIDA information system, and information systems' integration and interoperability.

The SI-VIDA<sup>10</sup> (National information system for following HIV+ patients at a central level) was implemented in 2007 with many difficulties in terms of its implementation and the data generated from the system is only now starting to be analysed. The system also has some limitations in terms of being able to provide up-to-date information, possibly due to limited resources to analyse the available information. The information regarding 2007 was only available in 2013 to INSA (National Public Health Institute in charge of surveillance).

Some of the difficulties in the implementation were due by the fact that the SI-VIDA system is independent from the clinical data information system. This means that the doctor needs to fill the patient information on two separated systems. A similar situation exists for clinical data and case report data, which increases notification related issues, and creates unnecessary effort for medical teams and the system as a whole.

Division of information systems is not helpful for an understanding of the national situations, and efforts should be undertaken to integrate the current systems into a

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<sup>8</sup> Annex 5

<sup>9</sup> Annex 6

<sup>10</sup> <http://spms.min-saude.pt/product/sivida/>

more efficient and user friendly platform, in order to reduce waste and eliminate duplicate data collection and human resource burden.

Another important point mentioned was that information systems' users should receive feedback from the systems they feed data into, as well as have a clear data request protocol.

Although these two points should be valid in general (*ie*, society should have data reports from the public information systems as well as have a clear pathway to request non-personal data from public databases, for research purposes), for system users (doctors), being able to both generate evidence and receive information on the performance of the system overall and his or her unit in particular could motivate the systematic use of the information systems.

## **2.2 Administrative and financial barriers for an effective linkage to care of key groups**

The next presentation by João Brito<sup>11</sup> introduced a discussion on both regulatory and practical barriers related to linkage to care of key groups in Portugal.

Although generally the legal and regulatory framework of the country is quite favorable in terms of access to health, some practical barriers still remain. Some of the main issues identified include the fact that the knowledge in terms of procedures and mechanisms to access the national health service (NHS), as well as applicable fees and exemptions are not homogeneous, and therefore administrative barriers in linkage to care continue to exist, mostly motivated by the lack of knowledge of the current legal and regulatory framework.

Ensuring all personnel are aware of procedures and that practical ways of applying these procedures and regulations, would minimize administrative barriers in access to undocumented migrants. This could be achieved through dissemination of the current guidelines or additional training when necessary. Clear information on exemption of NHS fees should also be made available, and the pathways to obtain it would, ideally, be available in all hospitals policy documentation.

Although legally foreseen, implementation of a referral mechanism from Civil Society Organizations (CSO) to the NHS still requires a doctor to sign a referral form, even if the doctor does not see the person with the reactive result. With de-medicalized testing in the country being responsible for more and more HIV tests and diagnoses every year, referral pathways from civil society are increasingly important in order to ensure that people are swiftly and easily connected to the NHS.

Universal access to healthcare system for anyone being tested in the country, within 24 hours, would be a desirable (and feasible) scenario in Portugal. For those who live in Portugal and do not have a healthcare number or a valid residence permit, the linkage process can be very lengthy and complex, including multiple changes of periodic health system numbers, circulating through a series of public services which

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<sup>11</sup> Annex 7

are not always well connected and fluid to navigate, and for many people (even those with documentation) this process can work as a deterrent and ultimately an unsurmountable barrier to access health services.

### 2.3 Possible solutions and next steps

Closely **monitoring the implementation of SI-VIDA and analysing** its information is critical in order to concretely understand adherence and retention in care, especially in key groups, and to develop intervention strategies where necessary, both geographically and group specific. SI-VIDA should be capable of integrating data from viral hepatitis and STIs, as well as ideally TB.

Regarding data integration, a meeting between GAT and the National AIDS Program will be scheduled in September/October to further explore possibilities of **linking screening and testing data to clinical data**, in order to better understand the continuum of care, and have a more in-depth view of people lost to follow up (LTFU).

Advocacy efforts towards **integration and interoperability of information systems** will also be a priority in the agenda, along with **protocols for access to anonymous data from third parties**, to allow for independent data analysis and widen scientific use of available information.

**Implementation of the “Freedom of Choice” regulation<sup>12</sup>** will also continue to be monitored, alongside the real-life implementation of the universal access to healthcare law.

Models which allow for the **unobstructed referral of people from accredited NGO’s** will be looked at and advocated for as a means to reduce LTFU from testing to specialized medical care.

Easy, **fluid referral pathways**, well known to all public institutions and community actors who work on the field could greatly contribute to improve linkage to care processes in several key groups, particularly migrants and people who use drugs, and will be advocated for, along with monitoring and improvement of the implementation of access to health regulations.

On the topic of **service integration, complimentary support networks** should be in place locally to ensure that people have access to social and, when necessary, financial support, in an effort to maximize linkage and retention in care. People in difficult social and economic situations tend to prioritize more immediate needs, and many practical issues stand in the way of linkage/retention, including transportation and food money, user fees, disorganized lifestyles, unsafe housing, stigma and discrimination, among many others. Health should not be seen as a one dimensional issue.

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<sup>12</sup> Legal norm (Despacho) granting people the freedom to choose the structure in the Health System that will treat them (Hospital for example), regardless of the official address of the person, as Portugal’s Health System works, by default, by influence areas. (Despacho 5911-B/2016, published on May 3<sup>rd</sup> 2016).

**Investing in linkage and retention support services**, both within and complimentary to the NHS appears as a possibility that could contribute to improve several of the issues identified. Trained people could simultaneously assist people navigating the several systems and regulations, and act as monitoring agents of the system, reporting to relevant agencies when necessary. The Antidiscrimination Centre will also continue to actively monitor and support access related issues, and report on persisting barriers.

## Final notes

The present version of the report will be used as an advocacy tool, through a series of feedback loops with participants and, upon agreement, its final version will serve the same purpose with other relevant stakeholders.

Some developments occurred since the meeting were held, with relevance to the topics discussed in the meeting.

In early September, GAT published a public position advocating for a new payment model for anti-retrovirals (ARVs) in Portugal, of centralized payment with an expense cap, which would remove the financial burden of paying for ARVs from the hospital, which would further incentivize hospitals to receive and maintain HIV+ patients without a negative impact to other hospital areas. The information gathered in this meeting contributed to inform GAT's position on the matter.

The meeting also created inter-stakeholder dialogue, which emerged as a necessity in the meeting itself, since different stakeholders had different information on the same matters. Greater articulation between public actors on its own may lead to better informed decisions and facilitate finding solutions at an institutional level.

A lengthy discussion on information systems also contributed to identify existing barriers and possible solutions or ways forward in terms of improving national data integration. Challenges of interoperability remain, and this meeting helped push that issue into the institutional agenda.

In terms of PHC, and as mentioned, Ser+ and GAT will continue to advocate, and deliver when possible, for the training of PHC personnel, and for the implementation of adjusted testing strategies in each PHC. Indicator condition testing will be one of the priorities in the agenda, and the clinical norm is already published.

Within the *Fast Track Cities* consortiums, further possibilities of implementation and/or testing scale up in primary care will be explore

## **ANNEX 1 – Meeting agenda**

**5th of June 2017** - Knowledge about HIV and implementation of HIV test in Primary Care

14:00 Introduction

14:15 Session objectives - Daniel Simões

14:45 Presentation of the intermediate results of the study RESPECT Portugal - Ana Duarte

15:15 Spanish case: obstacles to generalization of HIV testing in Primary care; sharing of technical, administrative or legal solutions - Rossie Lugo (CEEISCAT)

15:30 Coffee-break

16:00 Roundtable discussion - consensualizing, selecting and/or approving most relevant solutions and/or identification of ways to remove existing barriers

**6th of June 2017** - Linkage to care: Current perspectives on data collection, barriers to linkage to care and retention with focus on key groups

10:00 Introduction and session objectives - Daniel Simões

10:30 Perspectives and current discussion on Linkage to care data - Sara Croxford (Public Health England)

11:00 The Portuguese case: Current status and future challenge - Sofia Mariz (ACSS) and Isabel Aldir (PNVIH)

11:30 Coffee-break

11:45 Roundtable discussion - Challenges and facilitators for the improvement of linkage to care data and future steps

13:00 Lunch break

14:30 Introduction and session objectives - Daniel Simões

14:45 Administrative and financial barriers for an effective linkage to care of key groups - João Brito (GAT)

15:00 Coffee-break

15:15 Roundtable discussion - Opportunities for the improvement of linkage to care processes among key groups

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## Presentations:

**ANNEX 3 – Respect Pt Presentation and results**

**ANNEX 4 – Indicator condition testing Opt-TEST**

**ANNEX 5 – OptTEST - linkage to care**

**ANNEX 6 – Portuguese case: Current state and future challenges - HIV**

**ANNEX 7 – Barriers to more effective linkage to care**

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