EFFECTS ON THE PUBLIC SECTOR, CIVIL SOCIETY AND AFFECTED COMMUNITIES:
FINDINGS OF THE SECOND PHASE OF THE STUDY

INTRODUCTION

In Peru, the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) has funded 3 proposals (2003-2011) for work on HIV/AIDS, with a contribution of approximately US$ 77 million\(^1\). This significant investment has had a major impact on the interrelationship between those involved, the organization of the response to the epidemic, the redistribution of public resources, and the quality of care offered to people living with HIV/AIDS (PLHA).

Therefore, it is, fundamental to analyze the effects of these endeavors both in the health system as a whole and in their multiple dimensions (policy and decision making, health systems, funding, and equity), focusing on the adequate use of evidence about the status of the epidemic, the appropriateness of the interventions proposed, internal and external consistency, and the quality of indicators used.

Research in this topic is much needed not only for academic purposes but also to generate knowledge that should be used to improve international aid initiatives and recipient countries’ responses.
The study sought to assess the impact of interaction between Peruvian actors amongst themselves and with the GFATM for submission, approval, and implementation of AIDS action projects. The study had two phases.

The objectives of the first phase, previously reported\(^2\), were the following:

1. **Identify the effects that the country’s participation in the processes generated by the GFATM has had on (1) institutional entities involved in work on HIV/AIDS in Peru, and (2) the interactions between those entities in the decision-making processes in relation to HIV/AIDS.**

2. **Explore the potential effects of national interaction with the Global Fund on the structure and functioning of the Ministry of Health (MoH) divisions involved in work on HIV/AIDS, as well as on other divisions and actors in the health sector.**

3. **Understand the impact of access to these funds upon the sources and policies of financing of the national response to the AIDS epidemic.**

4. **Explore the impact of GFATM-funded activities in Peru on equity in access to project benefits and the situation of stigma and discrimination affecting PLHA and vulnerable groups.**

This policy brief focuses on the second phase of this study, aimed to further assess specific technical, political and institutional processes. The target focuses for this second phase were the following:

1. **The relevance and consistency of processes leading to formulate proposals to the GFATM, and particularly the relationship between the technical and political content of these proposals.**

2. **The sub-national (i.e. regional) response to the epidemic in Peru, including expected roles and responsibilities regarding inter-sectoral coordination (through the COREMUSAS, sub-national coordination mechanisms), and relationship with other regional plans and priorities.**

3. **A new focus on the living conditions of PLHA on 1) equity and access to health services and 2) changes or transformations experienced by PLHA’s which may have resulted from actions implemented by the Global Fund Projects.**

The main findings of the three components of this second study phase follow.

This study was funded by the Alliance for Health Policy and Systems Research. The study is also part of the Global HIV/AIDS Initiatives Network, GHIN (www.ghinet.org), a network of researchers in 22 countries that explores the effects of the three largest GHIs on health systems: the Global Fund, PEPFAR and the World Bank Global HIV/AIDS program.
I. The Formulation of HIV-related Proposals to the GFATM by The Peruvian Country Coordination Mechanism

Key Points:
- With a stable HIV epidemic concentrated on men who have sex with men (MSM), and a prevalence of 0.4% among adults\(^3\), Peru is one of the countries in Latin America with the most dynamic record of interactions with the GFATM.
- 3 out of four HIV-focused proposals submitted were funded (i.e. on the 2\(^{nd}\), 5\(^{th}\) and 6\(^{th}\) Rounds), for approximately US$ 77 million, while one submitted on the 8\(^{th}\) round was not. Additionally, three tuberculosis-oriented proposals were funded on the 2\(^{nd}\), 5\(^{th}\) and 8\(^{th}\) rounds.
- The preparation of these proposals has not occurred without criticism about their relevance or the level of effective participation of various parties\(^2\).
- Rising concerns exist over the evidence supporting these proposals, their technical relevance, and the actual lack of evidence of their impact.

Methods:
- We analyzed the contents of the official texts of the four proposals submitted to the GFATM (on rounds 2\(^{nd}\), 5\(^{th}\), 6\(^{th}\) and 8\(^{th}\), of which the last one was not successful). The Peruvian Multisectoral Strategic Plan 2007-2011 was also reviewed given its nature of a reference document for the last two proposals.

Findings:
- The discourses about the dimensions of the epidemic have changed since the first proposal was submitted, in part due to changes in the proposals format.
- Proposals describe the HIV epidemic to be mainly sexually driven (page 35, 5\(^{th}\) Round Proposal [RP]; section 4.4.2, 6\(^{th}\)RP)\(^4,5\) and concentrated in ‘vulnerable populations’. Sometimes, MSMs are presented as much more vulnerable than other groups, while in other cases the vulnerability label is indistinctively applied also to both female sex workers (FSW) and prison inmates (page 1, 2\(^{nd}\) RP)\(^6\), despite the fact that HIV prevalence information suggests a much smaller epidemic among FSW, and information of the HIV burden among prison inmates is extremely limited.
- MSM are treated as a single large group, rather than as a diverse population. Transgender persons are included as part of the MSM group, despite they are increasingly considered to be a distinct population which is far more vulnerable than most MSMs.
- There is no elaboration on epidemiological information to further characterize the present and future of HIV in Peru. What is presented is mostly a list of data pieces without a clear conclusion. In most cases, sentinel surveillance studies are used, often with insufficient clarity about estimate dates, without consistency of figures across proposals and supporting references are sometimes missing.
- Targets to measure the impact of interventions are not justified in the text (e.g. in the 2\(^{nd}\) and 5\(^{th}\) RPs the target is set for HIV prevalence among MSM to decrease to 8 %, while in the 6\(^{th}\) and 8\(^{th}\) RPs the target is set for a reduction of 50%).
- No discussion is presented on factors affecting HIV prevalence, and no modeling exercise is described. Despite the fact that antiretroviral (ARV) treatment is provided since 2004, no mention is made about the impact of ARV provision on increased survival and prevalence.
- Most of activities proposed in the proposals are vaguely described, except for the actions targeting vulnerable populations focusing on peer education and promotion, and periodic medical check-ups.
Findings (Continuation):

- Across all four proposals, the main intervention strategy with vulnerable populations is based on the peer promoter program and on access to medical care with trained staff and supplies. Changes across proposals involve mainly the scaling up of such interventions to additional geographic regions or to increase population coverage. No effort is made, however, to demonstrate the effectiveness of such interventions (particularly in the most recent proposals) and to justify their continuation.
- Prevention in the general population is focused on 3 groups considered most vulnerable: Adolescents and youth; women from Community-Based Organizations (CBOs) and vulnerable children. In the 2nd RP sex education was proposed, while the syndromic management of Sexually Transmitted Infections (STI) was proposed for the 5th and 6th RPs and both were included in the 8th RP. Again, there is no rationale provided for either the inclusion of specific groups or the selection of specific interventions.
- As related to PLHA’s care and support, the 2nd RP focused on access to ARV and support for adherence during its first phase. In the 5th RP a vague, unjustified activity to address orphans (since there were no data on them and such population was likely very small) was proposed, as well as activities oriented to offering comprehensive care to families living with HIV (again, not clearly justified in Peru’s concentrated epidemic). For prevention of mother to child transmission and the co-infection of Tuberculosis (TB) and HIV no action was proposed in the 6th RP, while in the 8th RP two important activities were incorporated.

Conclusions:

- In HIV proposals submitted from Peru to the Global Fund, the characterization of the epidemic has been very poor, often lacking a real problematization of the HIV situation. Social, economic or cultural data are used in very limited ways, so that the opportunity to contextualize and explain quantitative data is lost.
- Most of the evidence used in the 2nd, 5th, 6th RPs was generated in 2002 in absence of more recent official MoH data, so that arguing about changes or a changing context was difficult. Additionally, several descriptions were either not supported by references or supported by incomplete and non-rigorous evidence.
- In general, the approach is directed to disease burden and risk, which is very consistent with traditional public health and biomedical views of health. The most direct and best justified expression of this approach was the program to offer access to ARV to the majority of the population in need at the time (2nd RP). On risk and vulnerability, the approach that has prevailed is risk-centered, regardless of whether it was oriented to most-at-risk groups or to the general population, and it focused primarily on medical care, behavioral change and syndromic management of STIs.
- No action was proposed in order to reverse or alter the conditions generating vulnerability to HIV/AIDS among most at risk populations.
- While we can see opportunities for synergies in actions that involve scaling-up or complementarities, unfortunately most of the many proposed activities are external to each other. Many of the activities of the four proposals cannot be categorized as institutionalized.
II. HIV-related Decentralization Policies in the Context of The National Decentralization Plan

Key points:
- The Ministry of Health led a national consultation process for the formulation of a 2007–2011 Multisectoral Strategic Plan. The PEM included the regional governments as part of the regional response⁷.
- In the Peruvian Regional policy, two important mechanisms exist for the promotion of people’s participation in the process of decision making: the Concerted Regional Plans for Development (Planes de Desarrollo Regional Concertado) and Participatory Budgeting (Presupuestos Participativos)⁸–¹².
- Activities included in either one or both processes are the best indicators to show that the response to the epidemic is truly decentralized and the regions have their own response to the HIV.

Methods:
- We conducted in-depth interviews with key stakeholders of the decentralization process and of HIV programming in five sub-national settings in Peru representing contrasting contexts: Lima, Callao (Lima’s neighboring port city), Lambayeque (Northern Coast); Arequipa (Southern highlands) and Loreto (Amazonia), as well as at the national level.

Findings:
- Some studies have attempted to characterize the HIV/AIDS epidemic at the regional level. These have been conducted by NGOs or international cooperation agencies and not by regional governments themselves. However, the most important data source used in the regions is the repository of the Peruvian General Directorate of Epidemiology (Ministry of Health).
- Evidence shows that Concerted Regional Plans for Development are not considering the response to the epidemic within its priority agenda. This could indicate that efforts made by the sectors (Ministry of Health, NGOs, civil society organizations) to include the HIV/AIDS response in the Regional Plans have been insufficient. Alternatively, it could be argued that despite the efforts, HIV/AIDS in the region fails to be seen as a concern for decision makers.
- Only the Callao Region has included specific objectives and activities of medium-term to strengthen HIV intervention strategies in its Concerted Plan of Development.
- In other regions of the study, despite the fact that interviewees recognized the importance of fighting the HIV epidemic, minor progress have been made to allow this inclusion and articulation in their plans.
- There is no specific investment in HIV activities in any of the study regions. In most cases, health investment is related to improve local infrastructure and quality of health care services. Probably, people affected by HIV/AIDS will benefit indirectly.
- As part of the implementation of 6th RP’s activities, a strategy to promote more participation of regional actors was developed, but it was limited to implementation of activities without engaging in the regional management mechanisms.
- The Interviewees in Arequipa, Lima and Callao regions expressed that the PEM’s utility is limited. It does not reflect regional problems and needs that should be incorporated in the national PEM.
Findings (Continuation):

- The Lambayeque and Loreto regions have made progress towards the development of a Regional Multisectoral Strategic Plan involving many regional actors with a fundamental presence of the Regional Government. Their participation in the local COREMUSA is significant, including their assumption of leadership roles.
- Despite the importance of the COREMUSAs, they have no formal legitimacy in the regions. Actors expressed that this lack of legal support is a limitation that threatens their sustainability. Furthermore, COREMUSAs do not have access to resources to ensure their operations.

Conclusions:

- We have identified efforts of NGOs, cooperation agencies and academia to generate data about the HIV/AIDS epidemic at the regional level. However, little is known about the influence of such studies in the formulation of regional intervention strategies.
- Regional plans include no specific investments in HIV activities, and no budgetary allocation has been made for HIV/AIDS in the Participatory Budgets in the regions of the study.
- Only in Callao Region, where the epidemic is considered a health priority, HIV/AIDS is included in the regional plans and policy.
- Despite the importance of COREMUSAs, they have no legal recognition in the regions.
- The response to the epidemic, particularly the GFATM-funded projects, is poorly (or not at all) articulated with the regional management tools. Probably, the decentralization process is in a very early stage of development and actors ignore the strategic importance of this management attribute.

III. Equity and Access to Health Care and ARV Treatment

Key Points:

- Our study sought to determine the present situation of PLHA in Peru and changes in their life conditions as related to their participation in the National ARV Program³: Data on socio-demographic characteristics, health care access experiences and their perceptions around experiences of stigmatization and discrimination based on HIV status were collected and analyzed.
- The study took place in four settings: The metropolitan area of Lima (including Callao Region); Lambayeque (on the Northern Coast); Arequipa (South) and Loreto (Amazon).
- Previous studies in PLHA reached participants at health care facilities run by MoH limiting inferences only to those enlisted in the National HIV Treatment Program. This study reaches a broader and more diverse PLHA population in Peru, including people who receive care from other providers and people who are not on care.
- Free provision of HAART as well as offering of rapid diagnostic tests for HIV in pregnant women began in 2004 leading to an increase in both treatment coverage from 1,000 to over 10,000 PLHA, and HIV screening coverage in pregnant women from 20% to 65%. It is necessary to understand whether or not this new scenario has affected access as well stigma and discrimination experiences among PLHA.
Methods:

- The study used two methods to approach PLHA in five cities in Peru (i.e. Lima and Callao, Lambayeque, in the Northern Coast; Arequipa in the Southern highlands; and Loreto, in Amazonia): (a) an interviewer-assisted survey on a representative sample of PLHA reached through respondent-driven sampling (RDS); and (b) life histories on a group of PLHA of diverse gender and sexual orientation.

Findings (See also Table 1 on next page):

- 863 PLHA were interviewed in Lima, Callao, Lambayeque, Arequipa and Loreto. Most of them were young adults (mean age = 35), 60% males, 40% self-identified as non-heterosexual, and 60% had no health insurance. More than half of the participants reported that they were currently working.
- Most of the PLHA interviewed (96%) reported that they had access to HIV-related health care services. Among them, 86% were already receiving ARV treatment and 36% reported some out-of-pocket expenses for HIV-related needs within the last month. The proportion of out-of-pocket expenses is smaller in Lima among people who are treated by the MoH in relation to those treated by the Social Security Health Provider, ESSALUD.
- Factors associated to a lower perceived access to HIV-related care included transgender identity, older age and poverty in comparison with other gender identities, younger people and non-poverty strata.
- In the testimonies we find experiences of abuse, violence, discrimination and lack of basic resources, so HIV is not the worst problem in their lives. In many cases the diagnosis is seen by affected persons themselves as a life-saving resource that allows them to continue their long journey (See some testimonies below).

In their life histories, PLHA described the meanings of HAART mostly as an unexpected life-saving resource:

"I did not tell anyone. I kept locked in my room, I isolated myself. In the hospital I met guys with the same diagnosis, we agreed that HIV was not lethal and we were not going to die. They gave us hope for life. I said to myself: fight, I have to move on, I am not alone in this situation. I will inform myself and learn to use the famous HAART treatment" (PLHA, male, Lima).

The testimonies indicate that discrimination continues to be an experience for PLHA and it extends to immediate family members if their condition becomes known:

"Yes, everyone knows, my daughter....She was discriminated against, they used to yell ‘your mom, she got AIDS’, kids, neighbors, so when my dad expelled me from home people knew. My daughter has experienced this stigma and discrimination more than I did; I have not felt it so much like my daughter.” (PLHA, female, Arequipa).

PLHA prefer to hide their condition even from close acquaintances and relatives, apparently because it is possible to cover as a result of access to treatment:

"Many people are not going to expose themselves with this diagnosis, because of fear to discrimination" (PLHA, male, Lambayeque)

"Nobody knows my diagnosis: I, the doctor, the nurses, the psychologist, and friends who are following the same treatment, are the only ones who know about my diagnosis. I’d like to tell my mom but I’m a little afraid of such moment ... afraid that my mother despises me” (PLHA, female, Loreto).

The experiences of discrimination and stigma in hospitals seem to have decreased:

"I was admitted at Hospital San Jose, it is tiny but I have no complaint about the hospital. Before, the person in charge was Miss... and she was very dedicated and would visit you at home" (PLHA, male, Lima).
Lessons Learned from the Collaboration with the Global Fund for AIDS-related projects in Peru: Findings of the Second Phase of the Study.

Conclusions:
• More than 90% of the PLHA population studied in the four cities reported to be receiving HIV care. Since the data collection was not conducted in the premises of the MoH this figure is encouraging and suggests that a great proportion of PLHA has access to care.
• It is very likely that access was heightened by the ARV treatment allowing PLHAs to decide to enroll at any health facility in order to undergo regularly medical examinations and to initiate ARV when needed.
• The National ARV Program is entering its sixth year of operation. While there are some doubts around present coverage figures, this public program has fulfilled its mission to reach increasing numbers of PLHA in a sustained way.
• PLHAs continue to feel discriminated against. The experience of discrimination in health facilities appears to be diminishing and this is partly because health care providers develop rapport and insight around the different populations of PLHA. Moreover, ARV treatment turns HIV into a chronic condition and therefore minimizes its association with death. Self-stigmatization of PLHA decreases when they begin to feel that they can perform their normal activities. In contexts other than health facilities, the better PLHAs can conceal the diagnosis, the lower the experience of discrimination against themselves and their closest relatives.

Table 1: Key characteristics of 863 PLHA interviewed in 4 cities, Peru, 2008.

<table>
<thead>
<tr>
<th>Characteristic assessed</th>
<th>Proportion or summary measured</th>
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<tbody>
<tr>
<td>Head of household</td>
<td>331 (38.4%)</td>
</tr>
<tr>
<td>Currently working</td>
<td>525 (60.8%)</td>
</tr>
<tr>
<td>Total monthly income reported*</td>
<td>Mean=216 USD, Median=183 USD</td>
</tr>
<tr>
<td>Classified in Poverty stratum**</td>
<td>189 (21.9%)</td>
</tr>
<tr>
<td>Access to HIV care</td>
<td>832 (96.4%)</td>
</tr>
<tr>
<td>Receiving HAART***</td>
<td>703 (84.7%)</td>
</tr>
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</table>

*Estimate based on interviewees’ reported expenses, **According to Ministry of Economy’s algorithms, ***Among those reporting access to any HIV care service.
RECOMMENDATIONS FOR POLICY MAKERS:

I. At this point of the response to the epidemic, and given recent sustainability concerns, funding should prioritize sound proposals based on a solid analysis of recent evidence and reflecting consistency between key drivers identified and proposed responses. The political legitimacy of the proposals should not be established at the expense of technical quality.

II. Solid evaluation designs for proposals to be approved are essential. Indicators should be carefully chosen and should ideally come from information systems whose continuity and reliability is ensured. Based on modeling exercises, targets should be set, to the extent possible, to propose reasonable, realistic change that should nevertheless justify the intervention.

III. The use of state-of-the-art, evidence-based intervention strategies should be promoted in proposals, according to epidemic profiles and cultural context.

IV. Special efforts must be made to go from rhetoric to practice and effectively link HIV-specific processes with national sectoral and multisectoral processes, particularly at the sub-national level, to avoid the risk of duplicity, inefficiency, and lack of consistency and sustainability.

V. Program managers must continue efforts to ensure that the benefits of funding reach all those for which support was planned, to avoid that conditions generating greater exclusion (e.g. transgender identity, poverty) self-perpetuate and constitute a barrier for equity.

VI. While a decrease is being reported in stigma and discrimination, reflecting the normalization of HIV, efforts must be made to understand persistent barriers in certain contexts, and to develop more effective ways to counter them.

RESEARCH TEAM:

Carlos F. Cáceres (Principal Investigator)
Clara Sandoval and Rocío Valverde (Component I)
Roberto López, Alejandro Chirinos, Clara Sandoval and José Pajuelo (Component II)
Alfonso Silva-Santisteban, Eddy R. Segura, Rocío Valverde and J. Maziel Girón (Component III)
The Unit of Health, Sexuality and Human Development (USSDH) is based at the School of Public Health and Administration “Carlos Vidal Layseca” at Cayetano Heredia University

The Institute of Studies in Health, Sexuality and Human Development (IESSDEH) is a Peruvian civil society institution, constituted in 2007 to promote work for, with and from the community. The IESSDEH shares goals and resources with the USSDH. IESSDEH and USSDH/UPCH have signed a cooperative agreement and work closely together.

Conformed by a multidisciplinary and diverse technical team, the USSDH seeks to generate relevant knowledge and innovative strategies oriented to impact public and social policies with emphasis on health, sexuality and human rights, framed by the principles of respect for diversity and social justice conducive to sustainable human development.

We work collaboratively with a number of social actors, national and international institutions, as well as communities most vulnerable to, or affected by HIV and other barriers to sexual health and rights, in social actions oriented to improve their access. We are committed to confronting all existing forms of exclusion and discrimination, and to building an equitable and inclusive society.

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Av. Armendariz 445, Miraflores, Lima 18, Peru
Phone + 51 1 203 3300 – Fax + 51 1 203 3301
www. iessdeh.org
For further information, please contact Clara Sandoval (clara.sandoval@upch.pe)

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9. Congreso de la República: Ley Orgánica de Gobiernos Regionales. Ley 27902 and Ley 27867
10. Congreso de la República: Ley Marco del Presupuesto Participativo, Ley N° 28056

Notes
a. Enrollment in the National ARV Program is defined as the condition of a PLHA who is integrated into the system either for clinical monitoring without requiring antiretroviral treatment yet or receiving HAART treatment.