



Graduate School of Development Studies

**Citizen Participation in HIV/AIDS Policies:
A case study of the Global Fund in Peru.**

A Research Paper presented by:

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(Peru)

in partial fulfillment of the requirements for obtaining the degree of
MASTERS OF ARTS IN DEVELOPMENT STUDIES

Specialisation:

**Development Research
(DRES)**

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The Hague, The Netherlands
September, 2008

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List of Acronyms

AIDS: Acquired Immunodeficiency Syndrome
ARV: Antiretroviral
CCM: Country Coordinating Mechanism
CONAMUSA: Coordinadora Nacional Multisectorial en Salud (Multi-sectorial National Coordinator on Health)
COREMUSA: Coordinadora Regional Multisectorial en Salud (Multi-sectorial Regional Coordinator on Health)
GAM: Grupo de Ayuda Mutua (support group)
GF: Global Fund to Fight AIDS, Tuberculosis and Malaria
GIPA: The Greater Involvement of People Living with HIV
HIV: Human Immunodeficiency Virus
MSM: Men who have sex with men
PDL: Persons deprived of liberty
PEM: Multi-sectorial Strategic Plan 2007-2011 for the Prevention and Control of STI and HIV/AIDS in Peru.
PLHA: People living with HIV AIDS
PRA: Participatory Rural Appraisal
STI: Sexually Transmitted Infection
SW: Sex worker
HAART: Highly Active Antiretroviral Treatment.
TB: Tuberculosis
UN: United Nations
UNGASS: United Nations General Assembly Special Session
UPCH: Universidad Peruana Cayetano Heredia

Abstract

This paper explores the experience of people living with HIV/AIDS participating in CONAMUSA, an organism that works with the Global Fund to Fight AIDS, Tuberculosis and Malaria in Peru. CONAMUSA is a multi-sectorial space that is also shared by diverse actors such as the Health Department and NGOs. The political stories of these leaders are marked by stigma and urgency. Both contribute to a particular form of political action: necessity participation. A second element in the paper is the role of support groups as possibilities for political awareness.

Relevance to Development Studies

This research is an attempt to explore the experiences of people living with HIV/AIDS. Their particular condition implies challenges for their political participation. The lessons that can be drawn from this experience can be transferred to other efforts of civil society and can challenge assumptions on citizenship and political action.

Keywords

HIV AIDS PARTICIPATION

Acknowledgments

This research wouldn't have been possible without the invaluable collaboration of the courageous activists who took part in the fieldwork. I feel particularly grateful to Edward Armas who was not only the workshops' facilitator but who also helped me to keep a reflective attitude during this process. I would also like to express my gratitude to John Cameron, Rosalba Icaza and Manine Arends for their guidance through this academic (and emotional) journey. Last but not least, I would like to thank the HIVOS-ISS Civil Society Building Knowledge Programme, which made possible this research.

Chapter 1

Introduction

This research is intended to develop a deeper understanding of the dynamics of citizenship by the PLHA participation, in the decisions of CONAMUSA (the civil society space for HIV-AIDS in Peru) that affect public policies in health. Does participation in CONAMUSA required by the donor (The Global Fund), engage PLHA as full citizens?

1.1.- Background

On the Global Fund

The Global Fund to Fight AIDS, Tuberculosis and Malaria, is a joint effort by different multilateral and bilateral donors that came together to fight against the three most devastating diseases that kill over 6 million people every year.

Public health experts have identified a number of highly effective interventions to prevent and treat AIDS, TB and malaria. However, these interventions have to be done globally to have a significant impact. For this, a significant increase of resources was required. Leaders of the G8 countries acknowledged this need for resources in their 2000 meeting in Okinawa, Japan. African leaders at a summit held in Abuja, Nigeria in April 2001, reinforced this. The United Nations Secretary General Kofi Annan called for the creation of a global fund to channel additional resources. A UN General Assembly in June 2001 concluded with a commitment (endorsed by the G8 countries) to create such a fund. Created in 2002, a Secretariat was established adopting the legal form of a foundation based in Switzerland (The Global Fund).

The GF has committed US\$ 10.1 billion in 136 countries to support aggressive interventions(The Global Fund). As a partnership between governments, civil society, the private sector and affected communities, the GF represents an innovative approach to international health financing.

The operation of the GF is different than other institutions (like WHO, the World Bank or UNAIDS) that oversee implementation of programmes with a large number of staff. The GF doesn't implement programmes, as it relies on Country Coordinating Mechanisms (local stakeholders that are formed by civil society organizations, the representatives of relevant State Ministries or NGOs). Working in this way, the GF avoids bureaucracy and unnecessary money spent.

On CONAMUSA

The Global Fund chose Peru as one country to help against HIV-AIDS, TB and Malaria. CONAMUSA as a multi-sectorial space appeared for the presence

of the GF. CARE PERU is the administrator of the fund, and CONAMUSA is the institution responsible for elaborating proposals to achieve these objectives and supervise activities done by the GF.

CONAMUSA - Coordinadora Nacional Multisectorial en Salud (Multi-sectorial National Coordinator on Health) aims for an equitable action in health services, using an integrated approach.

CONAMUSA is an organism of coordination constituted by representatives of the government, bilateral and multilateral international cooperation agencies, civil society and organizations of people directly affected by HIV/AIDS, Tuberculosis and Malaria in the country. In formal terms, CONAMUSA tries to build consensus, develop shared messages and concepts among all the sectors, closing the gap among public and private spheres, complementing the government work on prevention of HIV/AIDS, TB and Malaria.

The functions of CONAMUSA (Conamusa) are:

- To coordinate the presentation of technical proposals of Peru to the Global Fund and other donors.
- To contribute with the evaluation and follow-up of the activities approved in the programmes and projects of the Global Fund and others.
- To promote approaches to assistance programmes for development and health, ensuring linkages and consistence of multi-sectorial programmes.
- To promote citizens' democratic participation in a multi-sectorial way, with emphasis in the strengthening of organizations and groups directly affected.
- To elaborate and approve plans and programmes to reduce the number of cases and impact of HIV/AIDS, TB, Malaria, and their social consequences.
- To promote information mechanisms as web page resources.

However, there is little information on the quality of participation of civil society actors in this space and the results of this participation in HIV/AIDS policies. Who are participating? Who are not participating? With which purpose? These are questions that remain without answer.

On the other hand, the GF works with similar civil society spaces in other countries. Then, it is important to problematise and reflect on the consequences of this model and the effects of this participation in policies.

Currently there are 4 main platforms (that group other organizations) that participate in CONAMUSA. There are also many organizations that consider themselves as "independents", they are not affiliated to any platform and their

level of involvement in the decision making processes around the representatives of PLHA is lower.

1.2.- Relevance and Justification

According to UNAIDS, there are 93,000 PLHA in Peru. From them, around 52% receive ARV treatment (Unaid). However, there are many inequalities in the access to this treatment. Approximately 20% of infected people in Lima (the capital) don't receive treatment. This amount grows to 70% in provinces.

Is citizen participation affecting the access to the treatment? There are multiple discourses on participation, health and HIV/AIDS. Citizen participation is a trendy phrase among donors, NGOs, academic institutions and policy makers.

In an international level, there is a growing concern on the participation of PLHA. This concern is shared not only among international organisms but also by governments and civil society groups. This enabled the emergence of the GIPA Principle as an international advocacy tool for the PLHA rights of self-determination and participation in decision-making processes that affect them. GIPA permits to think on different modalities of involvement of PLHA, dimensions and levels. Also, it implies actions from governments, PLHA organizations, civil society and international partners. It was formalized at the 1994 Paris AIDS Summit (42 countries agreed on the Principle) and later, in 2001 by 189 UN member countries. The 2006 Political Declaration on HIV/AIDS unanimously adopted by 192 Member States at the 2006 High Level Meeting on AIDS also advocated this Principle (Unaid 2007).

Behind these discourses, however, there is a multiplicity of meanings that correspond to different epistemological stances. These discourses make possible to maintain and recreate (or transform) practices. It is important to problematize and analyze the different meanings and discourses behind the actual practices in CONAMUSA.

With this, it will be possible to obtain an explanation on how policies on HIV are affected by civil society in the context of a mainstream development intervention (the GF). At the same time, it will be possible to reflect on the citizen participation model of the GF and to draw lessons for a better performance of civil society action in health.

1.3.- Research Questions

The main research question that will be developed here is:

- What are the challenges and possibilities of participation as full citizens of PLHA under the Global Fund scheme in the Peruvian case?

The answer will rely on three sub-questions:

- Why some PLHA and known to CONAMUSA do not participate in fora offered by this institution?
- What are the forms of participation of PLHA in fora offered by CONAMUSA?
- What are the challenges that PLHA raise to the theories of citizen participation?

1.4.- METHODOLOGY

The methodology will rely on metaphor analysis and the use of focus groups. I will introduce now these elements.

Why metaphors?

Far away from being just an ornamental device, metaphors are a key element to shape reality and negotiate power and politics. They can express values and ideologies that spread out through language.

Metaphor comes from the Greek word *metapherein*, that means “to transfer” (Collins English Dictionary and Thesaurus 1993). Dvora Yanow defines metaphors as:

“... the juxtaposition of two superficially unlike elements in a single context, where the separately understood meanings of both interact to create a new perception of each, and especially of the focus of the metaphor” (1992: 91).

But metaphors are not innocent. Their use in informal conversations, homes, media, school, the street or the workplace affect the public arena in a constant process of meanings negotiations in a day by day basis. That process shapes reality not only because of the meanings contained in the metaphors, but also, as Yanow says, because they suggest possible action in response to the situation described by the metaphor(1992).

But even more, metaphors can “frame” reality. Like with paintings, frames direct the attention to certain (framed) elements, while diverge the attention from those not framed. According to Yanow (1992), by highlighting some aspects and obscuring others, they organize perceptions of reality and suggest appropriate actions. Among these actions, it can influence policy decisions. Donald Miller says that “in the domain of social policy, it directs us to the problem-setting end of the task, which then largely determines the solution to be sought”(1985: 191).

For this reason it is important to be aware about the metaphors in policy making, as they frame the ways in which a problem is addressed and the solutions are sought.

In the particular case of HIV/AIDS, metaphors can be useful to analyze policy texts, debates and experiences, in a topic in which language is particularly important to name, include, discriminate, invisibilize, visibilize or create categories. All this is reflected in the design and implementation of policies. This particular universe of meanings is also used in everyday life by activists to give sense to their experience. Being aware of them may help to see the “blind aspects” that are usually overlooked.

AIDS as metaphor

Susan Sontag, in “Illness as Metaphor”, reflects on the narratives around health and society. According to her: “My point is that illness is not a metaphor, and that the most truthful way of regarding illness – and the healthiest way of being ill – is one [...] most resistant to, metaphoric thinking” (1978: 3).

Her work considers mainly TB and cancer as representative illnesses that carry strong metaphors in society. From the romantic views of TB in XIX Century to the fateful idea of cancer in XX Century, those diseases are surrounded by social constructions, beliefs that may entail blaming the patient, elaborate interpretations and explanations in psychology that could lead to a social prison for patients.

In the same way, there are metaphors around HIV/AIDS that transform a mere disease (yes, a mere disease) into a cultural product plenty of meanings, of metaphors. In “AIDS and its metaphors”, Sontag reflects on the use of HIV/AIDS as symbol of latency, divine punishment, poverty, change (mutation), invasion, or in the construction of the computer viruses’ notion. One of the most harmful metaphors regarding AIDS and illness in general, is the military metaphor as it shapes the way how a disease is understood. According to Sontag:

“The metaphor implements the way particularly dreaded diseases are envisaged as an alien “other”, as enemies are in modern war; and the move from the demonization of the illness to the attribution of fault to the patient is an inevitable one, no matter if patients are thought of as victims. Victims suggest innocence. And innocence, by the inexorable logic that governs all relational terms, suggests guilt.”(1991: 97)

In the case of HIV/AIDS, this guilt is accentuated through the metaphors, maintained not only in everyday language, but also through scientific language. This guilt, travels through these metaphors, and affect policies, having real consequences. According to Sontag:

“Why me? The cancer patient exclaims bitterly. With AIDS, the shame is linked to an imputation of guilt, and the scandal is not at all obscure. Few wonder, Why me? (...)to get AIDS is precisely to be revealed, in the majority of cases so far, as a member of a certain “risk group”, a community of pariahs. The illness flushes out an identity that might

have remained hidden from neighbors, jobmates, family, friends.”(1991: 110).

Risk groups are formed by risky people. Risky for the “general public” (a construct that may appeal to white, middle class and heterosexual men). Under the war metaphor, risk groups may be understood as dangerous Troy horses. The strategy then consists in identifying and separating them.

It is understandable that HIV/AIDS metaphors can discourage people to have safer sex, to have opportune diagnosis and treatment, to participate in support groups or in activism. Therefore, metaphors may kill.

If HIV/AIDS doesn't have a moral meaning, if it is a natural fact, it is important to expose and criticize those metaphors to achieve liberation (Sontag 1991). It is not possible to avoid metaphors, but making them explicit is a useful tool to analyze discourses, practices and policies.

Why focus groups?

Focus groups allowed to gathering information in a collective basis. Groups' dynamics can provide information on interaction and dialogue among participants and the richness of collective reflection. Indeed, many advantages made focus groups suitable for the research topic and fieldwork.

One of those advantages is to provide a safer space for informants. The theory of focus groups is grounded in the idea that people tend to feel more comfortable among peers. This comfort is related to the focus group environment, a closer one to a natural context. This comfort leads to a safer feeling that encourages the exchange of concepts, ideas and feelings among participants. In the particular case of PLHA this element is crucial. As Laws (2007: 298) mentions:

“Being in a group with others “like you” can give people confidence to speak about their experiences in a way which may not occur in one-to-one interviews, especially, perhaps, when the subject under discussion is in some way stigmatizing”.

A second advantage of using focus groups is the diversity of ideas and language that can allow encourage. This element is particularly important in the case of looking for not only similarities, but also differences. As Krueger (2000: 24) mentions:

“Focus group interviews should be used (among other reasons) when the researcher is looking for a range of ideas or feelings, different perspectives among groups of people, uncover factors that influence opinions, behavior or motivation, when it is important to identify ideas that emerge from the group and when there is high value on capturing comments or language used by the target audience.”

In the case of the different groups that I worked with, the usage of language was important to discover practices and relationships. As Stewart and Shamdasani (1990) mention, the opportunity for focus group participants to express opinions and ideas in their own words is a particularly attractive feature.

In addition to this, it is also claimed that focus groups can help to reduce the power of the researcher, with participants feeling some “strength in numbers”, and having greater control of the process (Laws 2007).

The focus groups used participatory techniques and they were complemented by individual semi-structured interviews, when the particular characteristics of the informants entailed difficulties in focus groups. The techniques are explained in Annex A. Photos of the first one (Rivers of Participation) can be found in Annex B. Photos of the second technique (Choosing Images) are in Annex C and D, and its results table in Annex E. Annex F is the detailed programme of the focus groups. The interview guide can be found in Annex G.

1.5.- Information Sources

Primary Data

The field work phase to gather primary data in Lima, Peru, was developed between July 14th and August 26th 2008. 5 focus groups were organized with the collaboration of HIV/AIDS community groups’ leaders. In addition to informal meetings and conversations, 14 interviews were done, from which 8 were selected for the final report according to their relevance for the objectives of the research. I gathered information from different actors (PLHA, NGOs, the Ministry of Health and other related state and academic actors) that participate in CONAMUSA to triangulate the information, looking not only for similarities but also for differences. In addition to this, there was a ninth interview (in Amsterdam, The Netherlands) with a key informant related to the Global Fund Board. The detailed list of the focus groups and interviews can be found in Annex H. The quotation will use the codes assigned to them in this Annex.

Secondary Data

In addition to specialized bibliography referred before, I did a review on grey literature, institutional reports and other case studies already published on similar topics. Web resources and electronic material were also consulted.

1.6.- Ethical Dimensions

This research took into account the special situation of working with PLHA. Three notions were pivotal:

Confidentiality

The special condition of PLHA implied a responsibility on confidentiality on the informants' identities and any other information that could have led to reveal the HIV condition of the participants. For this reason, during the focus groups with PLHA, there weren't photos of participants.

An exception was done in the case of the interviewees (activists with a wide experience in media and civil society work), as they specifically asked to be mentioned with their names and institutions.

Informed consent

As Bulmer (2001: 49) says:

“Informed consent is generally taken to mean that those who are researched should have the right to know that they are being researched, and that in some sense they should have actively given their consent”.

For this purpose, a summary document on the research was spread out. In addition to this, at the beginning of every interview or focus group, a brief explanation on the research was provided, giving the opportunity to the informants to ask questions and doubts.

The focus groups represented an advantage for informed consent, as the invitation implied information, and the possibility to reflect and take a decision on the assistance.

Trust

According to Ryen (2007: 223):

“Fieldwork is an arena where trust, empathy, rapport and ethics are closely linked. A deep and intense field relation is built on shared understanding, also referring to the researcher's self-presentation through ongoing internal dialogue”.

In a context in which there is usually, power relationships among researcher and participants, it was important to have a transparent self-presentation that helped to develop confidence. Developing trust was a mutually beneficial and on-going process during all the research and it implied resources, time and effort to build it through numerous informal meetings, introductions, conversations, and also sharing knowledge and information resources with the different informants. Part of this is the participants' experience with participatory methodological tools, which can be replicated in their own groups, to generate consensus and facilitate dialogue.

For what is this research? The purpose of this research is multiple. For understanding participants concerns and needs, for program development, for decision making or for policy making and testing (Krueger 2000). Also, a research on citizen participation is useful to reframe PLHA not as patients, nor victims, nor risk groups, but as citizens.

For whom is this research? This research is intended to be useful for PLHA in their claims for rights but also for policy makers and donors that would like to improve or innovate forms of aid on HIV/AIDS.

Chapter 2

Theoretical Frame

This section has the intention of developing an epistemological reflection on an initial theoretical framework on the research paper.

For this purpose, I will explore some initial notions of citizen participation in health to map the epistemological stance of my theoretical framework.

There are multiple discourses on participation in health. Citizen participation is a trendy word among donors, NGOs, academic institution and policy makers. Behind discourses and practices, however, there is a multiplicity of meanings that correspond to different epistemological stances that is necessary to distinguish.

On the other hand, health and development have a relationship that could be framed under different practices, discourses and paradigms. I will focus on health not only in its biomedical condition but also in its social and political dimension related to the access to the services.

It is important to mention that the epistemological stances that will be exposed on participation in health are in a constant relation of influence, dialogue, debate and building.

The notions of participation in specialized bibliography, policy documents or reports, can be varied and wide. NGOs, governments, multilateral institutions and government aid agencies use similar words to refer different practices in the ground. There are no pure categories around the idea of participation. However some paradigms could be identified around researchers with different epistemological stances.

2.1.- Cornwall's Spaces and Power

In her works on "Making spaces, changing places" (Cornwall 2002) and "Spaces for Transformation?" (Cornwall 2004), Cornwall has reflected on participation, power and spaces. Departing from the works of Henri Lefebvre, Michel Foucault and Pierre Bourdieu, among others, Cornwall reflects on participatory spaces' architecture (and the power structures related to them) taking into account the plethora of metaphors related to space that can be found in political discourses (e.g. political arenas, widening participation, policy space or displacement).

Cornwall uses space as an entry point to theorize on power and participation as space can be a useful device to unveil power practices. Space is an entry point to analyse participation:

“...the concept of space, and of participation as a spatial practice, is a particularly useful frame. Talking in terms of spaces for participation conveys the situated nature of participation, the bounded yet permeable arenas in which participation is invited, and the domains from within which new intermediary institutions and new opportunities for citizen involvement have been fashioned. It also allows us to think about the ways in which particular sites come to be populated, appropriated or designated by particular actors for particular kinds of purposes” (Cornwall 2004: 75).

Participation spaces are not neutral as they gather people with different backgrounds of meanings and power. These spaces are the settings where power is excerpted. To distinguish them, Cornwall introduces the notion of “invited spaces”:

“...these institutions tend to be artifacts of external intervention. Distinguished from “popular spaces”, those arenas in which people join together, often with others like them, in collective action, self-help initiatives or everyday sociality, “invited spaces” bring together, almost by definition, a very heterogenous set of actors among whom there might be expected to be significant differences in status” (2004: 76).

Invited spaces and popular spaces can influence each other in multiple manners, and the boundaries among them can turn blurred. People that participate in one space can transit easily to other spaces, assuming different identities and roles (and with different degrees of power). Indeed, invited and popular spaces are not separable as one influence in the other in a constant process of power reconfiguration.

If power holders can create participatory spaces and invite different groups of society to participate, “invited spaces” can express already existing power relationships (the decision who is invited or not is political). However, “popular spaces” can reproduce inequalities as well.

In any of both spaces, there are shifts of strategies and discourses in a process of constant negotiation of power. Due to this, the future of it is not predictable, not even in invited spaces:

“Discourses of participation might be viewed, following Foucault, less as a singular, coherent, set of ideas or prescriptions, but as a configuration of strategies and practices on constantly shifting ground. (...) Spaces produced by hegemonic authorities can be filled with those with alternative visions, whose involvement transforms their possibilities. Spaces created with one purpose in mind may be used by those who engage in them for something quite different.” (Cornwall 2004: 81)

Cornwall suggests that this uncertainty creates opportunities for transformation in invited spaces. For this, it’s important to have “sites of

radical possibility”, independent groups that could create opportunities for marginalized actors to gain capabilities and organize an agenda.

2.2.- White’s forms of participation

Sarah White states that not every kind of participation is positive. Under certain forms, participation can even perpetuate unequal relationships and injustice. However, if the conditions are available, participation can also create capacity in people to claim for their rights. White distinguishes 4 kinds of participation (White 2002):

1. Nominal Participation: Referred to the mere presence of people (without voice) in participatory spaces.
2. Instrumental Participation: People are used as instruments to execute decisions taken by others. In this level people have no voice, but they participate building bridges, schools or health centers, in a basis of communitarian work with no power in the decision making process.
3. Representative Participation: People have a voice and they have power in the decision making process.
4. Transformative Participation: People not only have a voice in the decision making process but participation is evaluated in terms of processes (capabilities developed in people) and not only in terms of results.

This classification establishes a hierarchy of values in which process is more important than the results. Therefore, it is a refusal of the search of efficiency usually related to market-oriented and logical positivist approaches.

Internal transformation is difficult to measure. There is no emphasis in the *positum*, or in a sensible experience. Can empowerment be observed, counted, measured? Positivists demand to observe effects, consequences, results. A more process-oriented scope assumes that there is a knowable reality but at the same time, it assumes that senses can mislead us. This kind of approach has to deal with a key question in development: if internal processes of generation of capacities are not visible, how to measure change?

Other value in the classification of White is the empowerment of people related to the idea of generation of citizenship and deliberative democracy. The idea of dialogue and public sphere may correspond to a Habermas’ idea of consensus (1989).

2.3.- Tanaka’s complexity levels

In Peru, Martin Tanaka (2001) developed a model for participation analysis taking into account the context in which it is produced:

“It is not possible to think on participation in abstract, outside the scope of the conditions in which it is produced. Not to consider the

differences that these contexts determine conduces to think on inapplicable, or even worse, counterproductive models”(2001: 10).

He did research on participation in three kinds of communities: high complexity (highly heterogenous urban areas with access to basic public goods and leaders that assume the costs of collective action), intermediate complexity (with a relaxed communal identity, more integrated to urban areas, not much demand for public goods, with interest groups and highly qualified social leaders) and low complexity (small rural populations, isolated, in extreme poverty and strong communal identity, mobilized to have essential public goods as they lack basic public services like water or electricity). According to his findings, participation in low complexity communities was very high because people had to organize and participate to survive and to satisfy basic needs. In intermediate complexity communities, this participation was decreasing as it was not necessary to satisfy basic needs. In high complexity communities, full participation was more difficult, because in larger cities, political relationships among people and groups are mediated by representation agents and people tended to participate less.

2.4.- Development and health: Access and citizenship

The way of positioning health in development is not a consensual space. There are some approaches that link development with the development of science, discovery of new medicines and treatments. There is a second approach that is more related to social exclusion in the access to those treatments, access to a doctor, medical services, medicines, etc. (due to racism, classism, gender exclusion, poverty, etc). A third approach questions the power element in the doctor-patient relationship that health science entails through elements such as the examination, the power symbols of medical science and the medical guild. This research will take into account elements of the second and third approaches.

One particular entry point to the health-development relationship is related to the access to the health services. Under this scope, development has not only to deal with science progress, this is not enough. Science outcomes have to be also accessible to the people that face barriers of exclusion in society. There is a level of objectivity (naming, counting) to monitor the access. But at the same time, there is recognition of unequal relationships in society that is important to face.

Usually, the access discourse is related with citizenship approaches (many of them related with the perspectives of Cornwall, Chambers and White already described). Citizen participation in the process of knowledge building can be related to a constructionist paradigm. As Marks (2005: 96) mentions:

“Many in the public health field attach primary importance to eliminating social disparities and inequalities in access to health, the moral justification of which is often expressed in terms of social justice. Human rights sometimes become a surrogate for social justice, the

assumption being that what contributes to social justice in the context of development is also a contribution to human rights”.

The discourse on rights and citizenship have a clear correlation with the ideas on equal access to health. The framework on citizen participation is part of this approach.

2.5.- The Strategy

This is the strategy to address the research question. I will use two wide notions: space and time in participation.

I realized that the group of topics related with two research sub-question corresponded easily either to space or time approaches. Therefore, I appealed to these notions for clarity and organization purposes. However, I am aware that all the topics are related in one way or another to all the sub-questions, to space and time.

To start, I will address sub-question 1 (referred to the limitations to participate), working with elements related with the notion of time in participation (Chapter 3).

Then, I will address sub-question 2 (forms of participation), working with elements related with the notion of space in participation (Chapter 4).

Finally, I will discuss in a conclusive section (Chapter 5) on the theoretical challenges (sub-question 3). This conclusive chapter will allow integrate previous reflections and examine cross-cutting topics.

Chapter 3

Participation and Time: Facing Limitations

“You feel grateful for every day you have. Before, on the contrary, you used to wake up and say, damn, it has dawned, I have things to do. But now you say, oh great, I woke up well, I am fine” (FG5, 14/08/2008)

On Time

We are made of time. The human experience consists on it. Time to live, time to be and act with others. Time for work, for activism, for leisure, for family. Decisions about time shape our world and define who we are.

In participation theories, time has been usually framed as a cost. However, time, as an essential element that shapes people’s lives, is much more than a cost as it determines people’s decisions about their participation and how participation is experienced by them.

In the case of the informants discourses, the references to time and its value are numerous. The metaphors that refer to time are constant and varied. If time is important for everybody, there is a deeper awareness of it in issues (and people) related to HIV/AIDS. One of the reasons is that social constructions about HIV are related to death, and death reminds society about the limits of human experience, the limits of life.

The value of time in HIV/AIDS is particular, and this perception affects participation. The following sections will explore the time dimensions of participation in the CONAMUSA experience, through stories of involved people in this process.

On this chapter

Following a reflection on time, this chapter will be focused on the constraints to participate: the initial process, the decision to participate or not, its motivations and the internal process that activists have had to gone through.

This section will start showing the results of the rivers of participation in the focus groups (an exercise that allowed rescue memories, past times), and then it will move to address two key elements that were identified: stigma and the effect of free HAART in politics.

Finally, there will be a reflection on a type of participation that I identified and in which time is a crucial element. I decided to call it “necessity participation”.

3.1.- Navigating through Participation Rivers

The rivers were a fascinating opportunity to know about the experiences of PLHA in the platforms involved in the deliberative processes around CONAMUSA.

The rivers, with its waterfalls, eddies, rapids, backwaters, lakes, tributaries and branches, showed life stories of political awareness and action. Every story is unique as every experience of participation too. Time was used differently in each case. However HIV/AIDS was a common element that gave this time a new sense (not only scarcity but also transcendence). Some key moments were identified.

To know about **life before the diagnosis** was important to reflect on the previous political story of people who are participating now in activism. Different kinds of responses were given.

Some people referred the importance of sport activities, church groups, workplace, communities, the school, university groups and dance and art groups (FG4 04/08/2008, FG5 14/08/2008). There were also references to the importance of family values in the development of social interests and activism portraying trees as symbols of family, freedom and protection (FG4 04/08/2008, FG2 22/07/2008). When the focus group was conformed only by women, in addition to the ones already mentioned, other experiences of participation appeared, like Soup Kitchens (comedores populares) and programmes for poor children’s breakfast (Programa Vaso de Leche) (FG5 14/08/2008).

Before the diagnosis, many other obstacles to their participation were referred in their lives, usually portrayed as “stones”, like: parents’ divorce, family conformation, teenagers’ issues, love problems, sexual identity.

In the case of women, particular difficulties were referred such as gender discrimination at the placework, issues related to be single mothers and the lack of awareness regarding HIV/AIDS due to a religious background that consider heterosexual women as not linked to this issue (FG5 14/08/2008).

In general, while some people had strong political stories of participation (in political parties, in neighborhood organizations, etc.) linked with many other personal experiences before the diagnosis, other people referred that getting HIV AIDS changed their political life completely, moving from stagnation to an activism that never planed nor had in their previous life.

The diagnosis was referred as a crucial moment in all the focus groups that changed not only their lives but also their stories of participation.

Recurrent metaphors refer the diagnosis as: a cut in the life, an interrogation mark, as darkness (FG4 04/08/2008). Others mentioned waterfalls and foggy vision as they didn't know what was waiting for them (FG5 14/08/2008), or just a detour (FG3 25/07/2008). A fall, storms and "the harvest of what we sowed" depicted feelings of anger, depression, sadness and suicide thoughts (FG1 18/7/2008).

The hardest experiences were referred by people living in the provinces, referring to have "hit bottom" because medicines are expensive and their sexual orientation may have created new barriers. HIV itself was a factor for discrimination in smaller cities that increased loneliness feelings. Participants told stories of "well known persons" that lost many friends due to their discrimination. At the same time, information was a key element that helped to face that situation (FG1 18/7/2008).

During the diagnosis time, it is usual that the river decreases its flow (thinner courses) as participation decreases and isolation feelings appear. At the same time resilience appears with religion ("my body was sick, not my soul") (FG3 25/07/2008), or change commitments ("despite everything you can change") (FG4 04/08/2008).

The family appears as part of life plans that now seem frustrated ("life has finished, I won't have a family") (FG4 04/08/2008) or as a reality that unexpectedly is a source of love and support despite their conservatism (FG4 04/08/2008). In other cases family can be a "refugee" that however, can isolate from other spaces, avoiding to face the situation (FG5 14/08/2008). But it can also be a motive to face it ("I suffered a relapse but I got better for my children") (FG5 14/08/2008).

It is important to mention that women referred the lost of their husbands, partners or children and the diagnosis moment was linked with those events ("I didn't care. More important was the diagnosis of my child and also my husband") (FG5 14/08/2008). These losses were referred in different ways, like muddy waters in the river (FG2 22/07/2008).

The involvement in activism and in CONAMUSA related spaces was linked to the GAMs ¹(I will go back to this point in the next chapter). Get involved in activism beyond GAMs is a major step. Find (or create) an organization allowed to get help to face difficulties and raise expectations (FG4 04/08/2008). This fact is referred as "rivers growing", a dream that came true or build a process where there was no clarity ("I found light") (FG4 04/08/2008).

¹ GAM stands for "Grupo de Ayuda Mutua" (Support Group). In this research I will use the Spanish acronym as it is widely used by PLHA and people working on HIV/AIDS issues. Its presence in everyday language gave me the impression that GAM as a concept is much more than a simple longer name substitution.

Some of the drawings depict planes and suns (trips abroad, training, new possibilities, see with clarity), but also little shanty town houses (work in human settlements giving information) (FG4 04/08/2008). One participant described his beginnings as an activist as a bird in a nest that wanted to fly quickly but that had to learn to walk first (FG1 18/7/2008).

Along these stories, stones and rocks symbolized difficulties along the road (FG5 14/08/2008, FG2 22/07/2008). In some cases, their hardness during activism was balanced with new opportunities (FG2 22/07/2008).

The participation experience also created capabilities in terms of social abilities in a space that not only gave emotional support but that allowed to discuss political issues (FG3 25/07/2008). Positive changes in life attributed to information access have been constantly mentioned (FG4 04/08/2008). At the same time, awareness of capabilities that activists already had, was something that happened during their involvement in different groups (FG4 04/08/2008).

CONAMUSA was referred in different ways, but many times as a difficult space where activists have to deal with many things, many tensions (turbulence) that also helped them to strengthen their river (experience) (FG2 22/07/2008). Also, CONAMUSA's role on free HAART was seen as a light, a sun (FG1 18/7/2008).

The activists have represented their current moment (a quiet period) with fishes, blue colors, tree fruits and family (FG1 18/7/2008, FG5 14/08/2008, FG2 22/07/2008). Roses represent people alive in some cases, and eddies represent organizations working and interrelating with other organizations under a shining sun (FG1 18/7/2008).

This “normalization” of HIV in everyday life is expressed by an activist: “My house is full of pills and brochures, HIV is natural at home” (FG4 04/08/2008). However, people refer also the need of constant support to deal with the hardness of their activists roles (FG1 18/7/2008).

Some people renamed their river of participation as the river of the reinitiation in life as HIV positive (FG4, 4/8/2008).

3.2.- Stigmas

Many times there have been references to the word stigma as discrimination in the focus groups, in the interviews (in English and Spanish), in official documents and in specialized literature. Different activists have referred the stigma as an obstacle to get involved politically in a participatory space.

Stigma (plural, *stigmata*) is a Greek word that in its origins referred to a kind of tattoo mark that was cut or burned into the skin of criminals, slaves, or traitors in order to visibly identify them as blemished or morally polluted

persons. These individuals were to be avoided or shunned, particularly in public places. The word was later applied to other personal attributes that are considered shameful or discrediting (Healthline Networks Inc.). Also, *Stigmata* are the marks that appear on the hands and feet of some holy people, and which look like the wounds made by nails on the body of Christ (Longman 2003).

Many characteristics of the original senses of this word may be applying to the particular discrimination of the activists. Discrimination is the result of prejudices regarding PLHAs that create stereotypes. The holder of stigmas is a deviant of a social norm. Therefore HIV is not just a medical fact. Stigma creates a perverse symbolic social epidemic that is much easier to spread out, plenty of fear, symbols, guilt, condemns, in which its meanings have not only semantic effects in activists' world, but they have also a direct influence in the difficulty to organize people, participate and claim rights.

One of the strongest beliefs is that PLHA “are going to die” (this element was a recurrent challenge for the activists in all the focus groups). To participate have implied first, to face and deconstruct this stigma, to have hope to interact with others and to have life perspectives in which political action can have sense. Otherwise, the inevitability of death leads to abandon any hope not only to participate, but to live.

However it was not possible to eliminate all the stigmas. To reveal a personal health condition in a public arena brought labeling, categorizations and judgments on the activists. As one of them mentioned, “the activism was paid with our face. Nobody would have liked to be known revealing publicly your diagnosis. We had to pay that price given the necessity to participate” (FG2 22/07/2008).

Stigma is related to language, and the battles for language are part of the activists agenda. The battlefield is usually the media but also in the everyday life. The terms “sidoso” (a pejorative term to refer a PLHV), “peste rosa” (the pink pest, alluding to gay people) or “seropositivo” (“HIV positive” as a noun, using a diagnosis result to label a person in his/her everyday life).

These words are part of language and meaning wars in which metaphors are not an inoffensive issue as their impact in participation and policies are tangible.

3.3.- Other constraints to participate

Other constraints to participate could be mentioned. The first one is resources. To participate implies to allocate time and money in the different volunteer activities (Van Rooijen 11/07/2008). PLHA many times don't have regular incomes and to participate implies to attend to meetings and dress up adequately. In the case of women, they refer also lack of time for housekeeping activities and lack of support to leave their children (FG4 04/08/2008). People

with more money are more liable to participate, however they also have to face the same stigma related to HIV as all (Van Rooijen 11/07/2008).

A second constrain is the current post-HAART moment, with fewer people in GAMs and more people reinserted in their jobs and families. Being a leader means visibility and many people are not prepared for that. Activism nowadays is based on will (FG4 04/08/2008).

A third constrain is conflict: participation may imply confrontation and the possibility of exclusion of independent groups (Chujutalli 01/08/2008). Also, the previous conflicts were considered as causes of emotional stress in activists and the movement's disarticulation (Cruz 22/07/2008).

A fourth constrain is the lack of information in both sides: the ones who are participating in independent groups (Chujutalli 01/08/2008) and platforms. Availability of information is crucial to involve people in activism. With information, people can defend their rights (Stucchi 23/07/2008, FG2 22/07/2008).

Other constrains may be personal circumstances (courage, personal stories of activists), and the civil society history in a specific context (Van Rooijen 11/07/2008). Also, the lack of operative support to spaces like CONAMUSA, is expressed in the lack of transport reimbursements for representatives (it should be recognized for activists in Lima and in the regions), and in the insufficient operative staff (nobody in the past, but 3 nowadays) (Cabello 31/07/2008). Finally, international processes, like those related to UNGASS² have not been spread out extensively with communities as it has happened among NGOs (Cabello 31/07/2008).

3.4.- Antiretrovirals and Politics

Another element that influenced the experience of PLHA participation is the universal access to HAART in Peru since May 2004. The impact of this policy in the PLHA activism and participation was notorious. According to different interviews and focus groups, two periods can be distinguished: before and after HAART.

CONAMUSA was created in May 2002. The implementation of the GF Second Round projects started in 2003, and CONAMUSA was recognized by a Presidential Decree on 23 May 2004.

² In 2001, the Declaration of Commitment on HIV/AIDS was adopted by the United Nations General Assembly Special Session (UNGASS). It was the first global commitment to fight against HIV/AIDS. By committing to the Declaration countries agreed to time-bound commitments and a regular process to review their progress in meeting those commitments.

During the Pre-HAART time, the activism was experienced in a much different way. Many informants have constantly referred that before HAART there was just “more activism” (FG1 18/7/2008). Even before the Global Fund presence, that period is remembered as the “heroic times”: “Before HAART, before that the first project of the GF was approved, many comrades died, we fought, we went to the streets, we were more activists” (FG1 18/7/2008).

In that time, The Union for Life (El Colectivo por la Vida) appeared. Many informants have consistently referred this as their most successful experience of participation (Cruz 22/07/2008, Cisneros 21/07/2008). The objective of the Union was clear: to get free access to treatment for PLHA. The clarity of the objective and the possibility to gather efforts around a single agenda (free access to treatment) were some factors of the success. The Union did different activities to excerpt pressure in the State through legal and social action. In addition to this, there was a coincidence with the beginning of Global Fund presence in Peru (Cruz 22/07/2008).

The Global Fund created the possibility, with CONAMUSA, to engage the Peruvian State in the HAART policy, covering the first year (2004) of the treatment and transferring completely that responsibility to the Peruvian State in the third year.

The impact of this was enormous in activists’ health and political action. For the PLHA community it was a long waited conquer. As one informant said:

“The situation before HAART and after HAART is like, before Jesus Christ and after Jesus Christ. In the past, the ones without money to buy HAART died, the ones that came with a CD4 count lower than 100 came with their sentence, the ones with money bought HAART. In my case I made even the impossible to buy the HAART” (FG3 25/07/2008).

The use of religious metaphors is not infrequent in activists’ discourses nor in institutional settings in which attributing ARVs a “Lazarus Effect” is part of the common HIV/AIDS language³. The religious metaphors imply a depiction of ARVs as something much more than just medicine.

Steven Robins has reflected extensively on the different effects of framing ARVs under a mundane medicalised approach or charged with an aura of quasi-religious miracle. A research comparing the UK (where HIV may be considered a chronic illness like diabetes) and South Africa (where the narratives of Lazarus effect and “God’s gift of life” are strong) led, among other reasons, to different consequences in activism. While in the UK, a biomedical approach favored individual treatment and the de-politicization of

³ See for example the document “Partners in Impact” (The Global Fund 2007: 63).

the HIV/AIDS movement, a more collective response and a different frame of ARV treatment in South Africa, allowed the movement continuation after the HAART distribution (Robins 2005).

In the Peruvian case, many informants referred that once HAART arrived, the activists went away (Stucchi 23/07/2008). The possibility to have access to medicines allowed to finish a “necessity” period in activism. Once the necessity was covered, the motivations for activism were focused on new agendas: prevention, timely distribution of ARV in the regions, the costs of diagnosis, exams and treatment for opportunistic diseases (that was not covered by HAART), etc. This change of agendas had as a correlation a change in the activists and a clear decrease in the new activists involved. New patients had more possibilities to have access to medicines, be reinserted at their workplaces or to deal with the disease in their families’ environment, without having had to be involved in activism or assumed the costs of appearing in the media. They had more choices.

“AIDS treatment killed activism” is Robins’ revealing quote of a UK activist (2005: 12). In this case, the movement in the UK couldn’t move beyond a personal agenda. According to Robins, the medicalized approach to HIV/AIDS treatment focused on isolated rational individuals that had to act “responsibly” (leaving behind more “holistic” therapies). It could be argued that the South African movement remained very active, as there were many important problems even after the HAART distribution. However, in the UK there was also a pending agenda. The adherence to the treatment was one of them. People with adherence problems may create resistance to ARV medicines. They didn’t have the chance to act politically but on the contrary, they were regarded as “dysfunctional” and sent to psychological services (Robins 2005).

This has happened in Peru to a certain extent. HAART has weakened activism and has framed HIV/AIDS under a stronger biomedical approach. Despite religious references to ARV, Peru doesn’t have the strong South African narratives described by Robins on the missionary (quasi-religious) activists’ role.

It is fair to say that other factors also influenced in this change in activism in Peru. Indeed, the new post-HAART moment coincided with the formalization of CONAMUSA’s legal framework and the GF projects’ implementation in which activists were actively involved.

This ARV effect in activism challenges the notions of “therapeutic citizenship” that Nguyen has argued. According to him, therapeutic citizens would be produced by humanitarian/development practices and techniques (Nguyen 2005), creating a particular kind of citizenship:

“Therapeutic citizenship broadens “biological” notions of citizenship, whereby a biological construct – such as being HIV positive- is used to ascribe an essentialized identity, as in earlier forms of eugenics and

racial ordering. Therapeutic citizenship is a biopolitical citizenship, a system of claims and ethical projects that arise out of the conjugation of techniques used to govern populations and manage individual bodies”(2005: 126).

The emergence of new identities (as HIV activists) may be facilitated by international policies on HIV/AIDS, however, only considering them is limiting. Activism is also influenced by many other multiple actors, cultures, experiences, collective and personal narratives, and local-non-HIV/AIDS-policies.

Following a “therapeutic citizenship” logic, Nguyen claims that drug availability will have a multiplier effect on HIV people’s voices (2005). The contrary has happened in many parts of the world (as in Peru or in the UK). Nguyen’s frame fails to explain the ARV contingent effect in activism. This effect can be variable as activists identities can be fluid (and not essentialized as he argues). After ARV some PLHA decided to leave activism and to go back to their previous lives (and identities), while others gained skills to be involved in other political agendas (LGBT, feminist, etc.) and identities (as consultant, successful professional, political representative, etc).

The ARV effect on activism shows that citizenship identities around HIV/AIDS can be fluid and difficult to predict (and therefore to plan) by international AIDS policies.

It also shows the importance of time in political identities. It is interesting to notice that the different perception of time that ARV brought into activists lives (HIV/AIDS is not a death sentence any more), changed the political landscape in activism. With “more time”, activists had the opportunity to choose other political identities.

3.5.- Necessity as a Catalyst for Participation

Given all these constraints, why do PLHA participate? A first level of answers may rely on good will, a special interest on humanitarian or social issues or because they feel that there are many things that they can do for others (FG3 25/07/2008, FG2 22/07/2008).

However, many reflections during the focus groups or interviews suggested the idea of necessity as a deeper level of motivation:

“How do you create an activist? First, as there were no medicines nor nothing that could save you, people with HIV started to get together in groups (you couldn’t talk at home). They started to create GAMs and that was a support. With time, some people decided to change, and stopped just hugging each other and started to demand rights. That is why necessity made us activists” (FG2 22/07/2008).

Even more, as the context of participation was necessity, the activists lacked free choices to define the conditions and forms of their participation. This “necessity participation” (I will go back to this concept in the fifth chapter) challenges the common notions of what a good citizen is supposed to do. In the case of HIV, to participate was not in any activist’s plans. As somebody mentioned:

“Here the State invisibilized the issue, then there was the necessity that us, the activists had to pay for that. It was like paying something to visibilize the problem of HIV AIDS, but with your face. Many of us had to appear in the media, but nobody would have liked to be known making public your diagnosis (...) Now it is different, nobody has the idea of becoming an activist, because if I receive my diagnosis and I have the medicine, then I do my normal life, I study my master, etc. They made us activists by force” (FG2 22/07/2008).

Participation has costs, but in the case of PLHA, the cost can be very high. Activists had to “pay” (a cost, something from them given to others) with their “face” (revealing their diagnosis publicly). Nobody planned as a life project to become an “HIV activist” having their own diagnosis as a political tool of identity. The disclosure of their condition exposed them to something more than discrimination: stigma. The mark therefore, can work to isolate, like in the ancient agora, through the media. The consequence is a perverse dilemma: PLHA are discriminated because the opportunities to participate (get information, claim rights) are few; but at the same time, if they participate, they are exposed to deeper levels of stigma and exclusion, putting at risk their health and lives. However, not participating implied also risk for their lives: “if I don’t fight, if I don’t do a sit-in, a march, advocacy then my life is in danger, I had to participate” (FG3 25/07/2008).

Another element to consider is that necessity is time. Before HAART the diagnosis meant a death sentence, a race against time. The political action was marked by this element. Urgency, desperation, necessity, lack of time. After HAART there is a change in the level of necessity and an evident change in the level of activism. With HAART there is time. Even more important: the *perception* of time is different. This new way to perceive, to frame, to consider time (and therefore life) affected participation as it has been argued before. As one activist said: “nine years, ten years ago, when I was diagnosed, everybody identified: HIV means death, with HIV you won’t be here tomorrow...”(FG4 04/08/2008).

Chapter 4

Participation and Space: A Geography of Activism

“(With the GAMs) the idea is to give an emotional space to the people” (FG4 04/08/2008)

This chapter will start showing the results of the “Choosing Images” technique used in the focus groups. This information will be used to analyze the features of the CONAMUSA space, through its participation forms using Sarah White’s approach and the GIPA Principle. After this, I will address three topics that have spatial connotations: the mutisectorial character of the CONAMUSA model (an invited space), the activist-consultant dilemma and the mutual support groups (a key element for the activism).

At the same time, the theoretical frame on spaces and participation already described in section 2.2 will be particularly useful.

4.1.- Predominant Forms of participation in CONAMUSA

For this section, I will use the results table (see Annex E) of the images chosen by interviewees and participants in the focus groups. The most highly ranked images and the ones created by the participants were prioritized. The informants had a group of 11 images to choose (See Annex C). It is important to consider that the same figure can belong to different forms of participation, as what it’s relevant is the interpretation that the informants gave to them.

Elements of nominal participation

Not many highly ranked elements of nominal participation were found. However, figure 1 was chosen in the Callao Platform focus group (“we are silent, overwhelmed, they don’t take us into account”) and by the INPACVIH representative (“If I go, I prefer to be silent, if you express an opinion, you are not taken into account”) to depict exclusion and silence.

Elements of instrumental participation

References to instrumental participation can be related to the excess of work depicted in figure 2: “the human resources team is like the bike, so small compared to the load that it has to carry” (Centurión 20/08/2008). The metaphor of the bicycle implies to carry and move, to achieve a destination, a goal. This process can be a burden.

Another instrumental element (FG3 25/07/2008, FG5 14/08/2008) is related to the possibilities of manipulation of the representatives (figure 3) by other actors in CONAMUSA due to different knowledge: “you have to know a lot on the topic, you know that there is a level plenty of technicians, professionals” (FG3 25/07/2008). CONAMUSA is a space of knowledge and information, this is an opportunity but also it can intimidate.

In the instrumental narratives of the communities’ platforms, NGOs appear as power holders. This has to be understood in a wider landscape of negative perceptions about NGOs in the country. Some referred the “unity and power that they have to get the “objectives” [projects] of CONAMUSA and manipulate” (figure 6) (FG4 04/08/2008). Similarly, other group used the jocker to create a figure that would depict NGOs as the only ones with benefits (“the most favoured with CONAMUSA is a group of NGOs [...] that are in all the objectives of the Global Fund, they execute everything...”) (FG3 25/07/2008).

The unity of different groups (from the old days of Colectivo por la Vida) was something lost in this space due to the new work in consortiums and rivalries (figure 6) (Chujutalli 01/08/2008). A jocker was used to depict some actors in CONAMUSA as: “a little dog that barks only when he is interested on barking, the rest is observing as a comfortable witness” (Cáceres 16/07/2008).

Other instrumental features are related to the lack of communication canals between the representatives and the communities, which makes difficult for the representatives to choose the path to take (figure 9) (FG1 18/7/2008). This was reinforced by other group that said that the representatives lack a guide to proceed (FG2 22/07/2008). The PROSA representative chose also that figure (“they don’t know where they go regarding CONAMUSA, I feel that CONAMUSA is an initial process, it’s structure has to be reconsidered”) (Cruz 22/07/2008). The lack of clarity in this space’s rules (on accountability, election of representatives, etc.), affects the process of representation. In that sense, the participation remains in an instrumental level.

Elements of representative participation

Elements of representative participation were suggested mainly by Peruanos Positivos (as the two PLHA representatives in CONAMUSA are from this platform). PLHA participation was referred as independent: “We don’t let anybody manage us anymore, we know how to claim” (comment on figure 3) (FG1 18/7/2008). This group also said: “we have a participation in which you can hear these voices and the existing problems, you can hear them”(figure 6) (FG1 18/7/2008).

Peter Van Rooijen chose the same figure (6) to describe the experience of the PLHA delegation in the board of the GF, giving a similar meaning: “this delegation is seen as the voice of the people with the diseases, and it is seen, perceived and experienced as a force” (Van Rooijen 11/07/2008).

This figure was also interpreted as the quest for synergies, joint efforts from different sectors (not always with similar thoughts) while the fist (the force) would be a concrete result of that participation: the PEM (Cabello 31/07/2008)⁴.

It is interesting the use of metaphors such as “voice”, “to hear”, and “force”. In these cases, representation is portrayed as something tangible that has to be noticed, perceived. Tangible results are the best way to corroborate this presence. However, Van Rooijen mentions that this visible representation implies a hidden constituency (as it appears in figure 6) (Van Rooijen 11/07/2008). In spatial terms, being heard (noticed) implies physical proximity in CONAMUSA space (something easier for people in Lima than in the regions), been hidden implies distance, disguise, stigma.

Other group chose the joker to depict the challenges of the PLHA representatives when they have to face power inequalities and act as: “a balance or something that tries to regularize this” (FG5 14/08/2008). Despite its limitations and unclear rules, there is a representation system that makes that many PLHA activists had this as a goal, claiming different kinds of criteria that could entitle them as legitimate representatives. As an activist said: “our mission as Alianza is to be part of CONAMUSA; representatives of PLHA as we have the highest amount of users” (figure 10) (FG3 25/07/2008).

Elements of transformative participation

Transformative participation can be traced in different themes. One of them is the sustainability of the process, framed by some informants as a sensation of hope or being part of something new and different. For José Luis Sebastián, there is hope (figure 8) in CONAMUSA as “in our country there is a disposition to (...) sow something new” (Sebastián 15/08/2008). The little plant figure was also used to describe an incipient process in a global level (“we are still young, vulnerable, we need to grow, communities and civil society”) (Van Rooijen 11/07/2008) and in the national level (“the plant, something is blooming, and it will be a tree later, the multi-sectorial process is still incipient, the big tree for me is the sustainability of this process”) (Cabello 31/07/2008). Others used the joker to depict the mobilization of PLHA in their own communities in a much deeper level than in the rest of civil society (Sebastián 15/08/2008). These metaphors reflect the perception of development of political skills and abilities for a multi-sectorial space (a requirement for sustainability).

Other element of transformative participation is related to learning processes. José Luis Sebastián thought in “group work” when he chose figure 7. This can be interpreted as a learning experience to dialogue with other sectors and to act with the State: “The big process was to change from a

⁴ The PEM was the result of a multi-sectorial consensus and it was an influence opportunity of PLHA in national policies.

reactive answer to a balanced and constructive work answer, which was not very easy” (Sebastián 15/08/2008).

Learning processes generate capabilities, which are a key element in transformative participation. Figure 6 was chosen by the focus group with Peruanos Positivos – Lima to express the effort and unity of many people to achieve something, like a group of people in an election process, or representing the step in CONAMUSA as a synonym of power. For the representative of Jancha Suyacuy, it reflects the group work that leads to victory. This element is related with the generation of abilities to work in group as a result of their experience participating.

Capabilities for group work are essential for resilience among activists, despite internal conflicts or different interests. Figure 10 was chosen by the Jancha Suyacuy representative as it symbolizes a triumphant group that is linked with the groupwork. For the representative of PROSA, this figure reflected the fact that: “..despite this structure that I criticize, I feel that anyhow, the organizations continue together or continue participating, despite we are in a difficult moment for participation” (Cruz 22/07/2008).

There is a transformation element as the activists’ social network was able to survive and keep the movement alive despite the different problems among the organizations. Something meaningful keeps these groups in the same political environment. It’s not only about sharing the same diagnosis but also sharing activism (and sharing space) in a very adverse context and with particular stigmas.

Different metaphors of space were used here (e.g. expand, grow, small). The emphasize on the country as CONAMUSA’s scenario helps to realize on the insufficient work in the regions so far. But also, it invisibilizes the concentration of resources and activism in Lima. If CONAMUSA has to “grow” in a national level, that not only means to have more budget or infrastructure but also to occupy the space in a different way.

Capabilities have also a space dimension. The capability of working with different groups (one of the most mentioned) implies to be able to interact with others in the same space. Then, it is important to reflect on how this space is managed (shaped) to enable not only competence among organizations but also solidarity and learning. Learn to share the space is crucial to generate more capabilities and transformation.

4.2.- Getting used to multi-sectoriality: Turning advocates into partners

A first tension in participation was identified in the multi-sectorial model of CONAMUSA. This innovative structure brought new challenges and there were few previous references and no opportunities to develop capabilities to face that new challenge.

The novelty was not only participation but multi-sectoriality (Sebastián 15/08/2008). Therefore CONAMUSA implied a double challenge: to gather different State sectors to work on HIV/AIDS and at the same time to gather civil society with these State sectors. There was a lack of multi-sectoriality culture, however, some initial attempts were done. Indeed, different forms of citizen participation had been present in the discourses and policies in public health during the eighties and nineties in Peru, since Alma Ata Declaration (1978)⁵. However, the spaces and levels of that participation were quite different than the model proposed in CONAMUSA. Before CONAMUSA, there was a tendency to go towards multi-sectoriality and civil society consults: “The Health Strategy had to form a committee with the same actors” (Sebastián 15/08/2008). However, there had never been something like CONAMUSA before. Indeed, many other actors referred during the interviews and focus groups, not have had a similar experience before, interacting with different state sectors’ representatives. In the case of HIV/AIDS, the structure was particularly innovative.

However, the model is not new. The civil society-State partnership model is very well known in other contexts. In the case of citizen participation in health in Peru, the closest examples may be the CLAS (Comités Locales de Administración en Salud) in a local level or the Health National Council (Consejo Nacional de Salud) at a national level. But while the latter works mainly as a space of coordination among different State sectors, health professionals or academia, the case of CONAMUSA is different as it has given space not only for NGOs but also to communities of people directly affected by a disease. This element, linked to the presence of the Global Fund cooperation implies also a different distribution of power. Therefore, CONAMUSA’s relevance in national policies is also much different.

According to Cornwall:

“A lot of attention has been placed, in recent years, on creating a new or lending new life to existing institutions that provide opportunities for dialogue and deliberation between different kinds of stakeholders. These differ from the kinds of structures supported by successive waves of local institution-building (see, for example, Esman and Uphoff 1993), in that they are designed as mechanisms for enabling public engagement in governance, rather than simply as instruments for local development and, as such, primarily implementation-focused. These “invited spaces” offer one important vehicle through which development intervention can support more transformative participation.”(2004: 75-76)

Is CONAMUSA an invited space? The Peruvian government had to create a wider participatory space to fulfill the requirements of the GF and

⁵ The Declaration of Alma Ata was the first international declaration underlining the importance of primary health care. The role of community participation is a key element in the document.

receive the fund. CONAMUSA is a particular invited space. In this case the host didn't have any other alternative than extending the invitation: "The possibility to have funds conditioned to the existence of a multi-sectorial space is basically an opportunity to realize what we were demanding for many years" (Cabello 31/07/2008).

This brought change in the political interaction among participant actors and gave the guests a particular power position. However, it was still an invited space with specific regulations to that participation and limitations in the number of representatives.

Within this multi-sectorial space many actors have referred a change in the interaction style, from confrontational to a more dialogical one (Sebastián 15/08/2008, Van Rooijen 11/07/2008). This has required from the activists to develop more skills and abilities for negotiation, consensus and debate in a quite different setting, in which the old styles of claiming rights (through typical advocacy campaigns, marches, sit-ins or media denunciations) don't work as in the past. Now, the activists were in a space in which they shared political responsibilities and in which there were new rules for advocacy and influence. As the representative of PROSA (an organization that belonged in the past to one PLHA platform and is now independent) refers "we propose solutions, not only complaints" (Cruz 22/07/2008).

However, this activists' new role can bring dilemmas: should they be with the State or against the State? (Cruz 22/07/2008). If the activists are now represented in a multi-sectorial space, who will do the old advocacy role? Even more, it is expectable that the challenges in the future will be similar, as there is every time more participation of civil society in the model (Van Rooijen 11/07/2008).

O'Laughlin has raised the concern that these private-public partnership models are part of a "best practice" approach to policies, a new strategy of liberalism to do a self-critique without assuming meaningful changes in its approach to the market or individual property rights, with communities doing what the government cannot manage and rational citizens (clients) strategies. Also, in participatory spaces, the poor are likely to be excluded (O'Laughlin 2006).

However, as Cornwall mentioned, the consequences of invited spaces can be unpredictable. Indeed invited spaces can represent opportunities for transformation if there are certain conditions. One of them is the emergence of sites of radical possibility in which marginalized actors are able to define themselves (learn skills, acquire information, develop alternative narratives) and only then to act (Cornwall 2004). In this sense, the importance of the political viability of the platforms, independent community groups and GAMs is crucial.

Finally, it is interesting to notice that the CCM model reproduces the model of the Global Fund (in terms of participation of PLHA, NGOs, and

governments). As in the Peruvian CCM, the Global Fund had also to deal with initial difficulties of interaction among civil society and governments (Van Rooijen 11/07/2008), learning new ways of advocacy and politics.

4.3.- The effects of funding: the activist-consultant dilemma

When the GF projects began in Peru, they involved many activists working as consultants. They appeared in sub-receptor organizations in different GF projects. On the one hand, those projects needed the experience and social networks of the activists. It represented also recognition of their experience in formal and structured interventions of the GF. On the other hand, this situation caused that the activists had less time for advocacy activities as their jobs implied to be involved in more than one consultancy, trips, etc. To have double “hats” and multiple institutional identities at the same time generates problems (Cruz 22/07/2008). Double identities complicated the monitoring and evaluation roles of CONAMUSA. Of course, there were cases of people that decided not to participate in projects to have time for their activism.

The situation wouldn't be problematic if new activists would have come to take the places that were left. As it was mentioned before, after HAART, less people got involved in activism and GAMs were not the space that used to be. The current duplicity of roles is in part, the consequence of fewer new activists.

Nowadays, the activists integrate or lead consortiums (sub-receptor groups for GF projects). Groups and networks of activists are formed specifically to apply for GF grants: “They are born in the process, when they know about these procedures, otherwise they would have never appeared” (Chujutalli 01/08/2008). Also, there is now more flexibility in the requirements to give those grants, to allow more organizations to apply for sub-receptor positions (Centurión 20/08/2008).

In addition to this, there is a tension between NGOs and communities that complicates the activist-consultant dilemma. There is rivalry among NGOs and communities that has to be understood as part of a wider tension in Peru about NGOs and grassroots groups: “(they say that) you are a NGO, they say it in a contemptuous way like saying that you are not a community answer” (Cruz 22/07/2008). In this particular case, NGOs are perceived as having more presence than communities in CONAMUSA: “they decide to do something and they have more (political) weight... our issues are not that useful” (Stucchi 23/07/2008).

Also, in political terms, the consensus among NGOs is easier than among PLHA communities because they are fewer (Cruz 22/07/2008). Besides this, the fact that NGOs manage funds and have more resources (financial, logistics, experts) has created reactions in the communities which also want to apply for grants (Chujutalli 01/08/2008) and are interested in having more presence in CONAMUSA.

It is important to clarify that some community groups have the juridical form of civil associations (as many big NGOs) and some of them receive small funds. In formal terms many community groups are small NGOs. However, NGO as category was used by the informants to refer to big or middle-size institutions with important resources. Also, many informants from the communities plan to turn their community group into an NGO as this is perceived as an institutional evolution. The activists-consultants are in the middle of these tensions, transiting uneasily among both environments: communities and NGOs (big or middle-size ones).

But let's reflect now with a different frame. If the effect of turning activists into consultants weakens the movement, it's relevant to ask if the negative consequences are a collateral effect of the model *per se*. Regarding development interventions in Lesotho, Ferguson reflects on the negative consequences of development interventions:

“By uncompromisingly reducing poverty to a technical problem, and by promising technical solutions to the sufferings of powerless and oppressed people, the hegemonic problematic of “development” is the principal means through which the question of poverty is de-politicized in the world today.” (1990: 256)

According to Ferguson, the deployment of development can contribute to the de-politicization of a space. He uses the metaphor of an anti-gravity machine to explain how some interventions can suspend politics. But if development can work as an anti-politics machine, it is important to understand its mechanism.

With the model, stigma and individual bio-medical approaches to treatment perform together to disassemble a rising social movement. But to examine its machinery implies to go much further than CONAMUSA and the GF. It also implies to realize that the model may not be an intended purpose of a person or group of people. Good intentions may be deceived by a power architecture that disguises itself, that hides among the numerous details of the model structure.

That is why it's important to realize about these mechanisms. Institutions are not monolithic and there are always different factions and practices, spaces for dissidence and a constant process of negotiation of paradigms. It is important to realize that the agenda has to be re-politicized, as there are pending issues and as it's important to transit from an immediate agenda to a longer-term project that may challenge traditional power structures. In this task, it's important to consider that “sites of radical possibility” play a key role in the dismantling of this anti-politics machinery. They can generate activists that could help to re-politicize this space.

4.4.- GAMs

It has been argued the importance of the sites of radical possibility to deal with the challenges that “invited spaces” bring, such as the advocate-partner issue in a multisectorial model or the activist-consultant dilemma. GAMs may play this role. These spaces are crucial to re-politicize an HIV/AIDS agenda.

A GAM or support group is:

“a space in which a group of people get together to share a common problem. This space is addressed specifically to share our experiences, emotions, joy and other situations related to our condition (...) Then, this space represents the opportunity to share not only what has been mentioned before but also basic knowledge on the problem that brings us here or other activities (fund raising, rides, marches, etc.) that the group may consider necessary to improve our life’s quality” (Prosa 2007: 3).

It’s interesting the reiterative definition of GAM as a “space” in the manuals for GAMs. The first one in Peru was “El Hongo”, that appeared in 1990 (Prosa 2007). Before the treatment, GAMs were originally regarded as spaces to carry a death process with certain peace (Cisneros 21/07/2008).

GAMs were a key space that provided not only emotional support but also information and the opportunity to get together with others to discuss common concerns. In a way, they provided spaces that turned political in a later stage (FG1 18/7/2008).

When PLHA receive their diagnosis, the advisor informs on the possibility to join a GAM. Some problems to join one are the initial denial of the disease (that leads to avoid seeing other people with HIV) and families that want to hide their relatives that live with the virus (FG5 14/08/2008). Therefore, information plays an important role to join a GAM.

GAMs work in different levels. They enable to meet other people that have the same diagnosis and that have faced this situation successfully reducing loneliness feelings (FG4 04/08/2008). They allow also to identify problems (in a group of people with similar concerns) and to use the group dynamics to solve them (FG4 04/08/2008). They can psychologically encourage recovery when comrades also recover and develop their capacities (FG1 18/7/2008). Also, they can enrich self-esteem, and give a moral boost in a loneliness moment (FG5 14/08/2008). They can also help to challenge stigma and prejudices when gives PLHA, the opportunity to meet others that don’t correspond to stereotypes (people that are stable, healthy and that share their experiences) (FG5 14/08/2008).

Nowadays, GAMs have become weak. Groups are smaller and they have different perspectives than at the beginning. Some people have referred that there is not enough new people participating in them and that the original purpose of giving companion to people after his/her diagnosis has changed

(FG4 04/08/2008). The lack of people was attributed in certain focus groups to the post-HAART moment in activism.

This may respond to health policies that privilege biomedical approaches that focus more on individuals than in social determinants (such as social status, gender, education, working conditions, etc.) that affect health.

It is widely acknowledge that socioeconomic forces affect the configuration of HIV/AIDS. According to Farmer, several factors facilitate the emergence of HIV: urbanization, changes in lifestyle, increased intravenous drug abuse, international travel, medical technology; like tuberculosis, HIV is entrenching itself in the ranks of the poor and marginalized (2001).

However the socioeconomic factors are invisibilized by a biomedical approach to HIV/AIDS. According to Robins (2006), this approach in the UK system lies in the liberal notion of responsabilized citizens (knowledgeable and empowered HIV-positive clients) and in the categorization of dissidents as “dysfunctional patients” (who are most exposed to the individualizing and normalizing discourses) that are sent to individual psychological therapy. These processes of “medicalisation” are obstacles to collectivist forms of mobilization, widening the gap between individual-based psychological therapies and the more collectivist, community-based forms of AIDS activism (Robins 2005).

In Peru, GAMs have been an opportunity for challenging an individualistic biomedical discourse. Within them, the doctor-patient power relationship is changed by a dynamic among comrades with egalitarian aspirations. Also, citizens learn about the disease in an empowering process. That way, the once alienating medical jargon is faced, conquered, tamed. Dysfunctionalities are addressed with peer support and problems shared. There is a chance to talk about problems that are not commonly discussed with doctors (unemployment, discrimination, etc.) that are related to HIV/AIDS but not in a biomedical way.

But GAMs are not enough. They are an opportunity to re-politicize HIV/AIDS but there is a point in which GAMs’ participants may be looking for a different level of participation, in which they could be involved in a wider political level, to face structural problems (abuse in hospitals, lack of medicines, etc). When the activist wants to do more, “the activist feels that her world in a GAM is limited, that she needs to go out and fly” (FG5 14/08/2008). Then, there is a need to go to other spaces to participate in public arenas. This transition is described like a “stair”, a spatial metaphor that suggests the idea of levels in participatory spaces, levels (spaces) with hierarchy and graduality: “If you cannot go with me I can go, and up there I will find other, and this other will take me to other, it is like a ladder” (FG5 14/08/2008).

Chapter 5

Conclusions: Challenging Theories

The found evidence has raised new questions and has posed challenges to current participation theories in different levels. In the following lines, some problematic knots and topics that may contribute to the participation debates are grouped around two issues:

5.1.- Necessity Participation

An important element found during this research was the motivation and circumstances behind PLHA participation. It was clear that the decision to become an activist was really not only hard but costly for the ones who wanted to participate. If every participation experience represents a cost, in the case of HIV/AIDS this cost was very high. To become an activist implies to turn discrimination into stigma. Participation in this case implies a public sign that marks and distinguishes (separates) the activists and makes them more vulnerable to discrimination in private and public spaces. Stigmas were used to mark traitors in the ancient Greece. Nowadays, social norms manufacture new “traitors”, those who don’t follow the norms of the polis, or at least look like that due to their diagnosis (a dimension of the stigma is the fact that people imagine and assume behaviors and lifestyles in the activists, whether they are real or not).

Stigma is the price that they had to pay for their participation. Activists had to assume this high cost to live, as their life was already in danger. Participation was a necessity to get the medicines and survive. Their participation was not only hard, but it would have been unwanted under different conditions. That is why necessity participation implies an enormous amount of courage and generosity. As one activist said, “when you are a child you don’t dream to become an activist living with HIV”⁶.

But what is necessity participation? We have to start acknowledging that there is certain amount of necessity behind every form of participation. Beyond the idealistic models of platonic citizens that fulfill their human activity through political action, many people participate for necessities. However necessity participation is a specific form of participation that appears when the life of the people involved is in risk unless participation is done.

Under this context, participants are able to accept unpleasant situations and high costs for their participation. It is not the promise of participation theories about human fulfillment through citizenship awareness. It is neither the Freirean promise of liberation in community. At least, this was not

⁶ Personal conversation with one PLHA activist. July 18th 2008.

expected at the beginning. However, it is fair to say, that within this kind of participation, capabilities can also be created, turning an originally adverse situation into new opportunities (unexpected consequences of their participation were clear elements in the rivers' drawings).

Another characteristic of this participation is that, as in few opportunities, the level of involvement among the activists is deeper than in other civil society cases of participation in which life is not at risk. The fact that the activists share the same diagnosis gives a different feature to the political interaction. Of course, there are leadership problems, lack of representativeness, and power conflicts as in any other social group. However, it is notorious that something more meaningful keeps them together. The groups have a difficult coexistence (specially after the presence of the GF projects which makes them to compete for funds) but they are always sharing the same space. They have to.

In this point, it's interesting to go back to the metaphor already mentioned by an activist to refer to the HAART (the element that reduced the necessity level): it was like Jesus Christ (See section 3.4). It was like redemption of the need to participate. It gave the activists freedom to choose about their political action. Free individuals don't have to participate if they don't want. Despite that, many chose to continue participating. In necessity participation, there are people that will continue participating once the necessity has gone, as they have discovered that their participation can have an effect in their lives beyond the necessity.

Participation and Time

Participation is time. Time is not only a cost in participation, but also its essence. Empowerment, social transformation and all the other positive consequences that are attributed to participation require time.

Different perceptions of time affect participation. Necessity participation is characterized by a particular framing of time (scarcity, urgency). This frame has many consequences in participation and in the construction of political identities (urgency identities). It is important to notice that this framing of time is not only shared by PLHA as this elaboration is shared and reproduced by donors, NGOs or governments. All share the perception that something has to be done quickly.

The negative consequences of HAART in the HIV/AIDS social movement is in part a consequence of politics-without-time. Emergency politics without time to generate long-term political agendas may bring benefits in the short-term but also negative consequences.

Necessity Identities

Necessity participation can encourage the emergence of necessity identities and a necessity citizenship with similar characteristics to this case.

These identities can be a strategy to avoid negative categorizations such as “risk groups”. Assuming an HIV/AIDS activist identity may be costly but at the end, it gives opportunities to survive and certain level of personal development. These identities can provide alternative narratives and possibilities for personal development. In certain cases, even unthinkable opportunities if this person wouldn’t be living with HIV/AIDS (Cáceres 16/07/2008), like trips, courses or training. In a context of general depoliticization these identities were an opportunity to start a political activity.

Necessity identities can be fluid as they may disappear when necessity is overcome as in the post-HAART period in Peru (this may be different in other contexts when there are other factors intervening in the continuation of activism). In the UK, the coverage of the health system is related with a weaker HIV activist’s identity, while in South Africa, people that can afford private health care are reluctant to take part in HIV/AIDS activism (Robins 2006).

These identities are guided by urgency. This reality challenges the Habermasian ideals of rational dialogue in deliberative spaces. Urgency demands reactions with not enough space (time) for reflection, with consequences in the generation of capacities and a long-term agenda. To overcome this, it is crucial to understand this citizenship, its urgency and its non-rational components.

On the Tanaka’s model

Initially, I took the Tanaka’s model as part of the theoretical framework considering that the levels of complexity may have a role in the different forms of participation. After all, HIV/AIDS appears epidemiologically related to cities with high levels of commerce, high amount of population, complex social interactions, etc. Therefore, it was expectable that the forms of participation in HIV/AIDS issues would correspond to high complexity levels in the Tanaka’s model.

It was not the case. What I found in the stories of PLHA activism was necessity participation in high complex communities (big cities in which the epidemic was more concentrated). As has been seen, these complex communities developed many characteristics of the low complexity ones described by Tanaka. Therefore, something different, something not considered in the Tanaka’s model happened in this case: necessity participation.

It is not the complexity of communities, but the levels of necessity which determines the forms of participation. In certain contexts, necessities can appear in low complexity communities (e.g. water access in a poor village) but in other cases, it can appear in high complexity communities (it is the case of HIV/AIDS activism).

Challenging Necessity Participation

Having said this, it is important to acknowledge some challenges for the notion of necessity participation. First, religious frames enabled the continuation of activism in post-HAART South Africa (see section 3.4). What are the costs of this? Does necessity participation mean to appeal to religious frames to maintain the levels of participation once necessity has gone? Are there other possible paths to face the post-HAART lack of participation? It is possible to have alternative elaborations of time with non-religious frames. For instance, part of a political awareness process may mean to realize that our life time is always limited in every human experience and the consciousness of this temporal limitation may encourage participation and political action.

Second, is the necessities frame a good approach for the participation experience of PLHA? Discussing the findings of this document with people working in HIV/AIDS issues, I discovered that many of them have thought in this particular type of participation. Some of them called it “survival” participation. However, I considered that the “necessity” frame provides a flexible term that makes possible to talk about levels in this necessity and to think in a continuum instead of a binary (yes or no) concept (like the “survival” frame may suggest). However, it’s fair to say that it is not just about necessities but about how these necessities are framed, as these frames are crucial for people to understand (give sense to) their own activism. I am aware that the word “necessity” brings a heavy luggage of meanings in development debates. Nevertheless, I think this is exactly why this term may be more interesting as it can enrich the debate.

Relevance for development organizations

A first issue is the importance of time in participation. In the case of CONAMUSA, time is visibly related to two problematic knots: the activist-consultant dilemma (no time to involve new activists) and the post-HAART political decline (no time to generate a long-term agenda). The amount of money that Peru received from the Global Fund for HIV and TB related projects is up to now \$69,088,979 (The Global Fund). There have been many mentions to how the GF affected the different groups and activism in general, changing power relationships, dynamics and practices in civil society. It is important to reflect on this impact, the ways to reinforce its positive effects and to avoid the negative ones. The GF financial aid has had an evident impact in the political environment, developing competence for funds and encouraging part of the activist-consultant dilemma. An alternative to reduce negative impacts may be to implement the funding by sequences (Cáceres 16/07/2008), giving time for adaptation and new ways of organization.

A second element is the importance of the approach. HIV/AIDS is not only a biomedical issue. Narratives and frames around development interventions can make a difference. The examples provided on the ARV introduction in different countries illustrate this. Frames are related with the post-HAART political crisis and the movement’s de-politicization.

A third issue is the power inequality. Necessity participation is a concept that reminds the limitations of participatory spaces in which participants under necessity don't have the same power (nor time) than other actors. Rational approaches to dialogue and deliberation can be limiting.

How to turn necessity participation in a transformative process that could go beyond immediate agendas? Once the urgent agenda is covered, it's important that those who have decided to continue their political action (in a new context with more options), could lead this transition. To go beyond the immediate interests requires the capacity to reflect on an agenda that not necessarily will affect them directly but that will have a deeper social transformation. For that it is important to develop capacities in those who have chosen to stay, to have a level of reflection deep enough to postpone immediate agendas in order to dedicate efforts to build a deeper transformation (prevention, sexual diversity or to change the construction of AIDS as a stigmatizing disease).

This reflection on necessity participation in HIV/AIDS can also be used for the analysis of other cases of necessity and social action, not only regarding other diseases, but also in issues like water, food or housing.

5.2.- The importance of micro-participation

Levels of participation

One activist talked about her experience in GAMs and other activism spaces as a ladder (see section 4.4). This suggested the idea of different levels of participation.

This research on CONAMUSA led to reflect on the GAMs. The relationship was clear. It was not possible understand one process without the other. Activism in the inter-institutional level is related with what happens in a micro level⁷. Therefore, it is plausible to think in a system of different levels of participation with different possibilities and limitations: GAMs, independent activist's groups, platforms, COREMUSAS and CONAMUSA. They all influence each other.

In this research it is clear that if the micro-participation level (GAMs) doesn't work, it affects participation in a national level. The lack of new activists in the GAMs' level generated problems in the CONAMUSA's level (through roles' duplicity and left places by activists that went back to their regular works or got involved in new activities as consultants of the GF projects).

GAMs as sites of radical possibility

⁷ I took the idea of participation levels from Alex Shankland. Conversation on 3rd november 2004.

GAMs may be the sites of radical possibility that Cornwall refers. It is important that citizens have spaces for interaction with others, especially those who are more excluded and disempowered. GAMs play this role with PLHA. But how many spaces have the other citizens to interact with others, to talk about personal problems, get support from peers, and then maybe move to a process of political awareness and action? Modern societies are oriented to alienate individuals, produce and focus on “urgent matters” (again an element of time). It was in the atypical case of HIV/AIDS that citizens got together in a new way of interaction that, under normal circumstances, would not have happened. GAMs also defy the typical biomedical approach based in a doctor-patient relationship with clear power inequality and a de-politicizing medical discourse that can alienate, isolate, separate. On the contrary, being in a group is an opportunity to become a political being through dialogue. For some, dialogue is a mutual process that can even lead to liberation of human beings (Freire 1996).

GAMs were an opportunity to gather a group of people that otherwise would have been isolated from each other and with few opportunities for collective action. GAMs brought the opportunity to work with individuals departing from a personal level of awareness: physical (to accept their own diagnosis) and psychological (to face the anger, depression, denial and mourning stages). Some participants and groups (not all of them) moved then to a macro-political level of awareness to work on the urgent matters that affected their own health. Therefore, GAMs were a space in which people with an HIV diagnosis could get together to move to activism.

The personal is political (and the therapeutic too)

The reasons why GAMs can be the foundation of other levels of activism rely in the personal dimensions of politics. It was Carol Hanisch the one who coined the phrase in a paper on 1969, in the middle of a debate in the feminist movement on if the consciousness-raising groups were just “personal therapy” on personal problems and “not political” (Hanisch 2006). The paper is a fierce defense of, coincidentally, therapy groups as political therapy:

“I went, and I continue to go to these meetings because I have gotten a political understanding which all my reading, all my “political discussions”, all my “political action”, all my four-odd years in the movement never gave me”(Hanisch 1969: 2).

A close interpretation is done by Pateman who affirms that the major impact of this idea has been to unmask the ideological character of liberal claims about the private and public (Pateman 1989). Both dimensions are mutually related: “These feminists critiques of the dichotomy between private and public stress that the categories refer to two interrelated dimensions of the structure of liberal-patriarchalism” (Pateman 1989: 133).

If the therapeutic is political, then GAMs, a space originally considered as “just therapeutic” can be an opportunity for awareness and action.

GAM'S experience could be transferred to other arenas (like education, literacy, employment, etc.). For this, it's crucial to depart from personal experiences and support to move then to other levels of organization. To achieve this, it's important to have active spaces in the different possible levels of participation.

Challenging micro-participation

It is important to consider that GAMs can be subject of the following critics:

First, GAMs are not spaces exempt from power. There are undeniable power relationship within them. Even more, GAMs may reproduce inequalities of society (after all, its members belong to a wider system of beliefs and practices). For this reason, it is important that they could be democratic spaces, having clear rules and dialogue to enable their political sustainability.

Second, GAMS can be turned into part of a confessional culture, softening up citizens and enabling social control of the participants' discontent. A culture of conflict avoidance can conduce to hide discomfort and anger. That is why it is important to rotate and distribute leaderships in the group. Also, the existence of other spaces and the interaction among GAMs is crucial.

The levels of participation and GIPA

The UNAIDS Policy Brief on the GIPA Principle mentions different levels of participation's benefits that can be related with the levels proposed here: self-esteem in an individual level, change of perceptions at an organizations' level and facing prejudice at the community and social level (Unaid 2007). However, it is not clear about the mechanisms that can enable the mobility from one level to other. Also, the importance of GAMs as an opportunity for political awareness and participation should be recognized by GIPA.

Another element that is absent in this document and that needs to be considered is the importance of democratic practices in participatory spaces for their institutional sustainability in the different levels. Only with this frame, the power relationships among the actors (in the different modalities of participation that the document mentions) can be managed.

In addition to this, the UNAIDS document proposes modalities of involvement of PLHA (Unaid 2007) that have to be understood as goals in the different levels of participation. It is difficult (and not recommendable) that only one level could accomplish with all the modalities⁸. It is important to have diversity of spaces and to maintain the independence of the sites of radical possibility. Therefore, for a full involvement of PLHA, it is important to have

⁸The modalities are: policy-making process; programme development and implementation; leadership and support, group networking and sharing; advocacy; campaigns and public speaking; personal; and treatment roll-out and preparedness.

participatory spaces in the different levels. Even more, GIPA's modalities of involvement cannot be realized without the GAMs.

Relevance for development organizations and for CONAMUSA

The levels of participation and the importance of GAMs bring different implications. First, it is important to reinforce the GAM system to have new activists in CONAMUSA. With that, it is possible to have political sustainability in the model, face the activist-consultant dilemma and create alternative ways of organizations when the funds are affecting the political environment.

Second, it is crucial to have democratic frameworks in the different levels. It's essential to have a strong democratic system to make the PLHA representation in CONAMUSA, sustainable in political terms. Only in that way, PLHA can effectively influence on policies and gain legitimacy with other actors. For that purpose, it's important to have clear election rules not only in the CCM, but also encourage clear rules in its constituents. In the case of the representation of PLHA, the system has been largely discussed. A problematic point is who can vote (if individuals, groups or platforms) and under what conditions (if there are any requirements to entitle a person, group or platform to vote). The debates around this issue have generated problems in the past, weakening the PLHA movement.

Stronger democratic frameworks also mean the renovation of the CONAMUSA Presidency among different State sectors (not only Health) and civil society actors (Cruz 22/07/2008). Additionally, this representation has to be less generic, giving space for more diversity as the case of gays, transgenders or sex workers are different (Centurión 20/08/2008).

A better system of inclusion may represent more influence for the independent groups (Chujutalli 01/08/2008) and for the regions' groups (where the agenda problems are now based). A possibility is to encourage a system that includes the COREMUSAS in CONAMUSA (FG1 18/7/2008). That would give more legitimacy, a wider constituency and more influence power and sustainability.

Third, different levels of participation imply a focus on capabilities to enable the mobility among the levels. A constant element in the interviews and focus groups is the importance of capabilities in the PLHA movement regarding technical, organizational and political issues. Many informants have complained about the lack of training opportunities for activists. This problem has many aspects. One of them is the surprisingly lack of contact among activists from the north and the south working on HIV AIDS issues. It seems like not even UNGASS could develop strong networks among communities (it is true that there were some post-UNGASS NGOs networks but not communities' networks). It is important to realize about the possibilities of this kind of exchanges as a source of capabilities and opportunities for political awareness and social action.

A different aspect of this problem is the lack of awareness in the national level. It is important to develop a human resources policy as a country, investing in PLHA education (Sebastián 15/08/2008). A policy to strengthen the role of GAMS can also help to create capabilities.

Only this way, the PLHA movement can propose solutions and influence policies. Indeed, it's more possible to do advocacy if the activists manage the language of public policy, public health, epidemiology, human rights and legal frameworks. And there is even more possibilities to influence if an activist not only denounces but also proposes solutions. For certain informants, that would also bring together communities and NGOs.

As necessity participation favors the development of certain type of capabilities (social, relational) it is important to offer also spaces and time for the development of other capabilities that are more related with the skills for deliberation, tolerance, dialogue, etc.

This issue goes beyond the Peruvian case. It's important to develop capabilities for a successful CCM, in the model itself (Van Rooijen 11/07/2008).

5.3.- A final word

GAMS, time, activists, metaphors, ARV, participation. These words have shaped this research giving sense to voices, memories and hopes. These words have also been promises of citizenship. But participation can be an elusive promise. In the case of HIV/AIDS it can represent the difference among life and death. Citizenship built in this particular scenario can not only bring change but also can raise questions and defy paradigms. With this research I hope that some clues have been found to make this promise real.

HIV/AIDS is plenty of metaphors and meanings. One of the most terrible and dehumanizing ones is the categorization of PLHA as "others". This research is an effort to recognize and emphasize dignity in this group (the same dignity that deserves any other human group), understanding the stories of PLHA as possibilities of the human experience. What does it mean to be human under the conditions of HIV/AIDS? Only understanding the research in this way, links can be the developed with other groups of civil society. Only this way, dignity can be a common ground (and not just a mere euphemism for pity).

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ANNEX A

Using Participatory Techniques

The use of participatory techniques reinforced the advantages of using focus groups in this particular research. The chosen techniques were intended to explore the use of metaphors by the participants. The following techniques were used:

a) The River of my Participation

Participants were given A3 sheets of paper with colors and pencils. They were asked to draw the river of their lives and tell through this drawing, the story of their participation. With this technique, it was possible to discuss later commonalities, differences, decisive moments and the role of CONAMUSA in their rivers. Thus, the participants could discuss their personal stories of activism related with their diagnosis and their political action. A sample of these drawings can be found in Annex B.

b) Choosing Images

Eleven different images were placed in the floor, corresponding to different possible forms of participation. Participants were asked to choose a combination of images that could depict their experience participating in CONAMUSA. One of the images was a question mark that could be used by participants if they had a better image. Thus, it was possible to rank the images and discuss about their feelings when participating, the reasons why certain images were chosen and certain forms of participation referred. The full list of images can be found in Annex C; they were inspired in different forms of participation described by Sarah White. Some pictures of the chosen images can be found in Annex D.

The rivers and the images contributed to deal with differences in power relations. They helped to work with people with different levels of literacy, encouraging confidence to express their opinions and thoughts. Working in the floor enabled to set up an egalitarian atmosphere in a ludic way, contributing to the sense of ownership during the process.

The work with focus groups was complemented by individual semi-structured interviews, when the particular characteristics of the informants entailed difficulties in the former (e.g. people who decided not to participate in CONAMUSA and for whom a focus group may create difficulties to speak freely on sensitive issues). Interviews were also useful to triangulate the information. Triangulation was used not only to find repetitions, but also to discover differences.

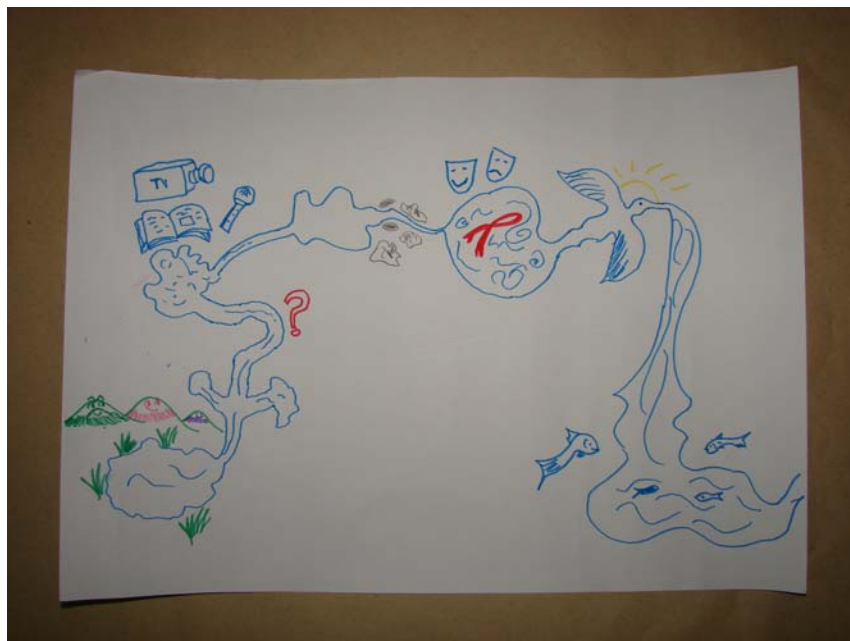
ANNEX B

RIVERS OF PARTICIPATION (SAMPLE)

1. Peruanos positivos regions



2. Peruanos Positivos Lima



3.- Alianza en Acción +



4.- Plataforma Callao



5.- Red Peruana de Mujeres



ANNEX C
LIST OF IMAGES
(Choosing Images Technique)



Figure No. 1



Figure No. 2

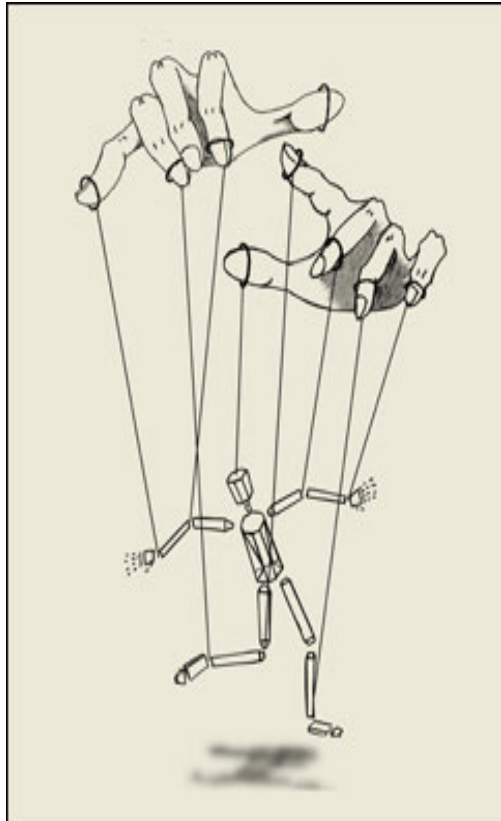


Figure No. 3



Figure No. 4



Figure No. 5



Figure No. 6



Figure No. 7



Figure No.8



Figure No. 9

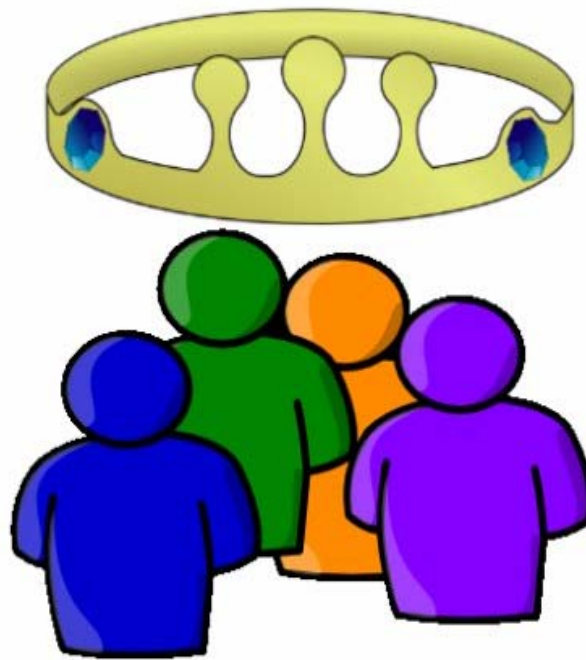


Figure No. 10



Figure No. 11

ANNEX D
Choosing Images



ANNEX E

Results Table of Images

Who	Chosen Images (in order of importance)	Meanings (chosen images)
Focus Group 1 (Focus Group Peruanos Positivos Regions)	Centre: 6 - 9 Periphery: 7-8-5-10-4-2	<p>6: You can hear our voices. It's a working group building something, the country answer.</p> <p>9: they are our representatives (a man and a woman), they don't know which path take, they don't know the voices of all of us due to few communication to know the necessities in different places of the country. This is linked to the participation of all of us, to give them feedback and ideas so they can take them to CONAMUSA.</p> <p>8: it appeared as an idea's seed, now it's growing as a plant</p> <p>5 and 7: Is the work of all of us.</p> <p>10: I saw it as a round working table, a multi-sector table, where everyone has the same voice and vote, an articulated circle.</p> <p>4: The affected communities that CONAMUSA represents and the people that support us</p> <p>2: so small in comparison to the load of things to do</p>
Focus Group 2 (Focus Group Peruanos Positivos Lima)	2-6- 9-7-5 3-4-10-11-8	<p>6: the effort union of many people to achieve something. A group of people in an election process. It can mean that step in CONAMUSA as a power synonym. If you don't know how to manage it, it can have the contrary effect to your election purpose. The fist gives you certain representativeness. If you don't understand that representativeness you can go to the extreme to use that power for different</p>

		<p>circumstances.</p> <p>9: two people with two roads and they don't know where to go. The representatives don't have guides to proceed. They have done a good role, but we need to improve communication canals with the grassroots to improve the management level.</p> <p>2: It's an enormous weight for the PLHA representation. It is too much effort and debilitation.</p> <p>3: Is the ignorance that could lead to manipulation inside (Care's puppet).</p> <p>5: Team work. It is important the transference of information, and avoid gaps.</p> <p>4: PLHA get stronger with the information provided, altogether we can be strong.</p> <p>10: The colors represent the different sectors and CONAMUSA is conformed by different sectors. The crown can represent power and what they need.</p> <p>8: The group is growing like a seed, getting stronger. You have to take care of it, there is a voice from all the community.</p>
<p>Focus Group 3 (Focus Group Alianza en Acción +)</p>	<p>10-3-1-2-9-4</p> <p>In the periphery: 11</p>	<p>10:our objective is that Alianza has an space as representative in CONAMUSA. I am very proud that a PLHA is the Executive Secretary of CONAMUSA (this didn't happen before).</p> <p>11 (depicting benefitted NGOs): only these NGOs have benefits, PLHA only have HAART.</p> <p>3: Is how our representatives are. Is linked with</p> <p>1: Alianza doesn't have voice nor vote. We don't have anything, in the past they called us for meetings, but not now. We don't have a vote that influences in decisions and solutions but we are in a process of fight. If you are not a representative you cannot raise your voice. The ideal goal is to have representatives from different platforms.</p> <p>2: our representatives are saturated (you have other work otherwise, you don't</p>

		<p>eat, as the CONAMUSA role is <i>ad honorem</i>).</p> <p>9: When PLHA started they didn't have a north, an agenda, they had no orientation.</p> <p>4: let's leave the two representatives to form the CCM. They have more relevance.</p>
<p>Focus Group 4 (Focus Group Plataforma Callao)</p>	<p>1-6-10-3-9-2 11-5-7</p>	<p>10: it's the institutions that want to govern, lead (State, civil society, NGOs)</p> <p>2: NGOs want to own CONAMUSA and are taking away resources.</p> <p>1: Our voice is weak, we are silent, overwhelmed, they hear us but they don't take us into account.</p> <p>3: we are manipulated</p> <p>9: if we don't speak, we are without guide, we don't know which path to follow</p> <p>6: The NGO, they have unity and power to manipulate</p> <p>11: They are like ants that are creating paths</p> <p>5-7: reflects the community work of PLHA</p> <p>8: it's the hope that we have, our commitment</p>
<p>Focus Group 5 (Focus Group Red Peruana de Mujeres)</p>	<p>11-3-9 1-5-6</p>	<p>9: every person goes to his or her side (interests)</p> <p>3: there is manipulation for trips, etc.</p> <p>1: many are not organized, they don't know about this topic</p> <p>5: We are building on a solid base. We are few, but working.</p> <p>11: a balance, that tries to balance this situation (e.g. the Executive Secretary in CONAMUSA is a PLHA and he tries to do so)</p> <p>6: There is a strong pressure from all the community</p>
<p>Interviewee 1 (Global Fund)</p>	<p>6 8</p>	<p>6: the delegation of PLHA is seen as the voice of the people with the disease, and perceived as a force. They are also hidden.</p> <p>8: We are still young, vulnerable and we need to grow (communities and civil society).</p>
<p>Interviewee</p>	<p>8-7-6-9-11</p>	<p>8: We are sowing something new.</p>

2 (Health Ministry)		<p>7: There has been a group work. 6: Their energy (of PLHA) that has helped us to advance. 9: We have had to take decisions about with paths to take, and there were very reflexive moments about this. 11: movilization of PLHA (not in all the community, only in theirs).</p>
Interviewee 3 (Key informant)		<p>11: a little dog that barks only when he is interested in that (is a comfortable role, in a quiet position, and with distance to problems).</p>
Interviewee 4 (NGO Care)	10-2-6-7-8-9-3-5-4	<p>10: Is an association with an interlocutor (the Global Fund) 2: It's so difficult to be in CONAMUSA with the four rounds that it's a heavy load. The human resource is like the bike, small compared to the load. 6: Is the base, CONAMUSA is constituted by the impulse of activisms from NGOs, platforms, networks. 7: There is a public-private association 8: That public-private association is a promise 9: Is a space where alternatives are observed (from technical-financial alternatives to problems) 3: There are manipulation processes in CONAMUSA because there are many interests on the table. 5: The Executive Secretary are the people who work (but let's omit the "security" elements – in the photo) 4: The assembly is a heterogeneous group without much information.</p>
Interviewee 5 (NGO Vía Libre)	8-6-2-5	<p>8: The plant, something is blooming, and it will be a tree later. The multi-sectorial process is still incipient. The big tree is the sustainability of this process. 6: The quest for synergies, a common work, joining efforts, from different</p>

		<p>sectors. Be together doesn't mean to have the same thoughts. Sometimes we have very different ideas. The fist (force) could be the PEM (Multi-sectorial National Strategic Plan).</p> <p>5: We need work, we need workers, the majority of actors spend their time implementing projects, and there is not enough time to work on public policy.</p> <p>2: Somebody (CONAMUSA) is moving something really heavy</p> <p>7: There are many hands to work</p> <p>9: Are roads that can be proposed (PEM).</p>
Interviewee 6 (community INPACVIH)	1-6-8 3-5	<p>1: If I go, I prefer to be silent. If you express an opinion, you are not taken into account.</p> <p>6: We have lost this. As civil society in a moment our fight was like that, all the groups were close, in the times of Colectivo por la Vida. With the GF the organizations start to work in consortiums and the rivalry starts.</p> <p>8: based in our work, we have been trying to articulate with other independent organizations to apply to the Global Fund rounds. We all have to have the opportunity to participate in the Global Found rounds. We participated in a round and we started an empowering process with other organizations that were not supported by these initiatives.</p> <p>3: There is many people that are still manipulated, and that continue in these spaces</p> <p>5: We have to see the depth of all this for a new building, in the HIV/AIDS social movement and in the PLHA movement.</p>
Interviewee 7 (community PROSA)	9-10-3	<p>9: They don't know where they go regarding CONAMUSA. CONAMUSA is an initial process and its structure has to be reconsidered. I don't know where I go as CONAMUSA.</p> <p>10: Despite the structure (of CONAMUSA), the organizations continue together despite that we are in a difficult moment of participation.</p>

		<p>3: It reflects the manipulation as a consequence of CONAMUSA's structure. It's not an immediate manipulation but it's the consequence of an unclear structure.</p> <p>11: Green color, hope. This structure as every initial process is going to change.</p>
<p>Interviewee 8 (Luz de Esperanza - Janca Suyacuy)</p>	<p>6-10-11</p>	<p>6: It reflects groupwork to win. We all together can win.</p> <p>10: the triumphant group. It's linked with No. 6</p> <p>11: Is the image of all our not accomplished wishes. The work with the community for no discrimination.</p>

ANNEX F
FOCUS GROUPS PROGRAMME

Time	Activity	Description	Responsible	Materials	Suggested questions for discussion
0.0 – 0.10	Opening (presentations)	<p>The facilitator will thank the participants for their assistance, and will explain the purposes of the research. He will explain the confidentiality rules and will ask permission to use a recorder during the session.</p> <p>The facilitator will ask for participants' names, organizations and a hobbies.</p>	Facilitator /observer		Assistance List
0.10- 0.20	Introduction: The river of my participation	The facilitator will ask the participants to draw the story of their participation, since they were children until now through a river depicting good and bad moments.	Facilitator /observer	A3 paper (thick, as poster board), colour pencils, sharpers.	

		A model will be provided. After the exercise (5 minutes), the facilitator will ask to share thoughts with a partner			
0.20-0.40	Discussion on the rivers of my participation	After sharing the drawings, participants will compare them, making emphasis in the questions, developing a debate.	Facilitator /observer		<p>What are the common elements among the rivers?</p> <p>What are the different elements among them?</p> <p>What was a decisive moment in the river?</p> <p>Where is CONAMUSA in the river?</p> <p>In which sense being positive is related to the participation in the river?</p> <p>What happens to other positive people that you know that don't participate in CONAMUSA?</p>

0.40 – 1.20	Choosing Images	Place the 11 images in the floor, explaining that the question mark is a “joker”. Participants have to choose the images that depict their feelings participating in CONAMUSA	Facilitator /observer	11 images Photo camera	How do I feel my participation in CONAMUSA? Which images depict this participation? Choose more than one. Order the images. Why did you chose these images? Why didn't you chose others?
1.20 – 2.00	Venn Diagrams	First, the facilitator will ask a brainstorm of main actors in CONAMUSA, and specially organizations of people living with HIV AIDS. Then, in the floor, the group will do a Venn Diagram reflecting the influence of these actors. After this, an analysis will be done on the relationships among these	Facilitator /observer	Flipcharts Markers Circles (poster board paper) Fine markers	a) Brainstorm: actors in CONAMUSA and actors in organizations of people living with HIV/AIDS b) From all these organizations, which are the most influential in policy elaboration in CONAMUSA?

		organizations (expressed through proximity and distance).			c) How do these organizations relate each other?
2.00 – 2.10	Ending	The facilitator will post a final question to summarize the session and have feedback.	Facilitator /observer		How could CONAMUSA may influence in policies in a more effective way? How could people living with HIV/AIDS may influence in policies in a more effective way?

ANNEX G
INTERVIEW GUIDE

Interviewee code :

Date :

Time :

Introduction, presentation, authorization to take part in the interview and to record.

1.- Do you participate in Conamusa? Why to participate in Conamusa?

2.- How far do you participate and how it has changed over time? Why?

If the interviewee participates: 3a, 4a

3a.- Which of the following pictures depicts your experience participating in CONAMUSA? You can choose more than one. Why? (*Show the List of Images*)

4a.- Do you think your participation in CONAMUSA has had impact in HIV/AIDS national policies? Can you give some examples of that?

If the interviewee doesn't participate: 3b, 4b

3b.- Which of these pictures depict good participation in your organization? You can choose more than one (*Show the List of Images*).

Now, which of these pictures depict your view of participation of people living with HIV/AIDS in CONAMUSA? You can choose more than one (*Show the List of Images*). How different are the first group of images and the second one? Why?

4b.- Who influences policies in HIV/AIDS? Can you give some examples of that?

5.- How could CONAMUSA may influence policies more effectively?

ANNEX H

LIST OF FOCUS GROUPS AND INTERVIEWS

1.- Focus Groups:

5 focus groups were organized with 4 networks of groups of PLHA that participate in CONAMUSA's related fora. The networks are called "Platforms" as they gather not only individuals but organizations. There were two focus groups with Peruanos Positivos as it is the oldest group with the largest constituency, and with a stronger presence in different regions in Peru. Coincidentally, a national conference in Lima with the regional representatives of Peruanos Positivos was held during the same days of the fieldwork. This was the opportunity to have one focus group with these representatives.

FOCUS GROUPS

Name	Number	Code for quotation	Number of Participants	Date
Peruanos Positivos Regions	Focus Group 1	FG1	9	18.7.2008
Peruanos Positivos Lima	Focus Group 2	FG2	6	22.7.2008
Alianza en Acción +	Focus Group 3	FG3	6	25.7.2008
Plataforma Callao	Focus Group 4	FG4	8	4.8.2008
Red Peruana de Mujeres viviendo con VIH y SIDA	Focus Group 5	FG5	9	14.8.2008

2.- Interviews:

A snowball sampling technique was used to identify interviewees:

INTERVIEWEES

Sector	Name	Post	Institution	Date
1 Representative of the Health Ministry that participates in CONAMUSA	Jose Luis Sebastián	Director of the National Health Strategy of Prevention and Control of STI and HIV/AIDS	Health Ministry	15.8.2008
1 Representative of CONAMUSA (technical adviser)	Fernando Cisneros	Executive Secretary	CONAMUSA	21.7.2008
2 representatives of civil society organizations that participate in CONAMUSA: NGOs	Robinson Cabello	Executive Director	Vía Libre	31.7.2008
	Carlos Centurión y Agüero	Responsible for the Programmes' Area in the Unit of Programmes' Management of the Global Fund.	CARE-Peru	20.8.2008
3 PLHA that are part of organizations	Miriam Stucchi	Representative	Jancha Suyacuy	23.7.2008

that consider themselves as “Independants” from the “Platforms” and fora in which PLHA participate in CONAMUSA	Julio Cesar Cruz	Representative	PROSA	22.7.2008
	Fernando Chujutalli	Representative	INPACVIH	1.8.2008
1 former representative of the Global Fund	Peter Van Rooijen	Former member of the Board of the Global Fund as the Board member for the Developed Country NGOs -currently involved in the Delegation Executive Director of ICSS.	Global Fund International Civil Society Support – ICSS.	11.7.2008
1 key informant (independent researcher not participating in CONAMUSA)	Carlos Cáceres	HIV/AIDS researcher	Universidad Peruana Cayetano Heredia – UPCH.	16.7.2008