

# Community involvement in HIV Brazil: a case study

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taked from a Jorge Beloqui´s presentation

# Background

- Since October 1991 the Brazilian AIDS/NGOs began to follow up the national and global HIV vaccine strategies.
- From the first moment vaccine were perceived as an important public health issues in AIDS.
- Many NGOs were interested.

# Background

- Brazilians community members thought that **them were able** to supervise the vaccine trials sponsored from abroad in order that they were conducted in an ethical way and with future access
- Thus the lemma was “ scientific and ethical excellency”, to overcome suspicions. This approach led AIDS/NGOs to a familiarity with **ethics** and **access** issues.

# AIDS/NGOs representatives

- A National Committee on HIV vaccines was created in 1992. At the request of the National AIDS Program, a 5 AIDS/NGO representations was created at the National HIV Vaccine Committee, elected every 2 years at the National AIDS/NGO Meeting.
- This was the first elected national representation of Brazilian AIDS/NGOs (1992)

# Activities

- 7 national meetings were organised (1994, 1996, 1998, 2003, 2005, 2007, 2009) together with the National Meeting of People Affected by HIV/AIDS, or with the National AIDS/NGOs Meetings, thus **integrating** vaccine activities within general AIDS activities
- 22 issues of a Bulletin were published, CD ROM
- currently two CABs (Rio de Janeiro 1999 and São Paulo 2001) are formed, based on AIDS/NGOs
- Vax publications (since 2004)

# Activities

- Example of collaboration: the first Term of Informed Consent was discussed by 120 persons from AIDS/NGOs in 1994
- Example of collaboration: the representatives took an active involvement in the production of the three National HIV Vaccine Plans
- Experience about ethics discussion was useful for questioning of Merck Trial 028 for indinavir in 1996

# Activities

- First Latinamerican Meeting on HIV Vaccines for the community (São Paulo, October 2001) (3 and a half days, 90 participants from Brazil and 10 from other Latinamerican countries and Europe (MH, IAVI, Unaids)
- Inclusion in the Minimum AIDS Program of the State of São Paulo AIDS/NGOs Forum of an item regarding Vaccines research and technology transfer

# Important Features

- Most Vaccine Committee representatives have been PWHIV/AIDS since the beginning
- A trial on therapeutic vaccines (Phase I) has been developed in Recife (published in Nature, 2004) and 3 more are oncoming

# Community role (I)

- Ensure adequate ethical and scientific standards. Treatment, information andcounseling for volunteers
- Sensitivity on discrimination on volunteers or vulnerable populations participating in the research

## Community role (II)

- Access to the products in the research.  
How? Relevant and accessible Products for the country and the community. Local production, intellectual property?
- To give our opinion from our community perspective
- To ask things that are not asked between researchers

# Community role (III)

- Do not be afraid of not having scientific knowledge. We don´t participate because we are scientists, but because we are community representatives. Scientists know nothing in general about communities. Interdisciplinarity.
- Publicize informations relevant for our communities
- Do not be afraid of not knowing English
- But study and deepen knowledge on issues important for our community
- We think that the Committee is not a place to BEGIN to learn but rather to participate in it we should have a previous basis on the subject

# Obstacles for access

- Intellectual Property Monopolies
- Lack of Technology Transfer
- Lack of tiered prices

# The challenges of ethics and access remain 18 years after

- Because any type of clinical trial is performed in developing countries and the pressure to reduce the international ethical standards. Since 1998, and with the HIV vaccine trials.
- Because of the worse conditions for local production of drugs and vaccines in developing countries due to TRIPS agreement and others, and the pressure of developed country against generic production

# Conclusions (I)

- Since the very beginning the vaccine activities were inserted in the national meetings (AIDS/NGOs National Meetings for election of representatives, and Meeting of People Affected by HIV/AIDS )
- The NGOs involved in these activities also develop many other AIDS related activities

# Conclusions (II)

- Most NGOs participate in the election of the representatives in the National Committee, thus establishing a link and responsibility
- Prevention and assistance are perceived as a Public Health Policy continuum and in the case of AIDS, it is closely linked to rights and human rights

# Thank You!