

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, Unaid))
- 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 and counseling 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!