



Involving People Living with HIV/AIDS in Research: Guaranteeing the rights of HIV positive study participants

At the 1994 Paris AIDS Summit, 42 national governments committed to "support a Greater Involvement of People Living with HIV/AIDS (GIPA) through an initiative to strengthen the capacity and coordination of networks of people living with HIV/AIDS (PLHA) and community-based organizations". However, little if any systematic research has been undertaken to identify the factors that limit and enhance this involvement in the delivery of community-based HIV/AIDS prevention, care and support services and explore how the involvement of PLHA can have an impact on the quality of these services.

Tata Institute of Social Sciences (TISS) in collaboration with the International HIV/AIDS Alliance and the Horizons Program undertook a study in India to document the models of PLHA involvement and how they affect NGO activities. A similar study has been conducted in three other countries: Burkina Faso, Ecuador and Zambia.

Four NGOs in the State of Maharashtra who represent a cross-section of organizations with different forms and levels of PLHA involvement were identified as study partners. Researchers collected extensive qualitative data (via in-depth interviews, focus group discussions, Participatory Rapid Appraisal (PRA) techniques, and observation) and supporting quantitative data, from 140 respondents who were mainly the service providers and beneficiaries of the participating NGOs, including a large number of PLHA.

A key characteristic of the study was its highly participatory methodology. The principle of involving research subjects in studies is not new. It has been often used for ideological, programmatic and/or methodological purposes. However in research on HIV/AIDS and with PLHA, the practice has often lagged behind the rhetoric. This poster describes how the practical involvement of PLHA in the study was used as a mechanism to protect their rights.

Ethical rationale for the involvement of People Living with HIV/AIDS in the study

Researchers are in general increasingly aware of the rights of study participants, which include:

- Information about the study
- Information about the possible risks and benefits incurred by the participation in the study
- Respect of confidentiality by researchers
- Voluntary participation and right to withdraw from the process at any time

Rights of participants in the Horizons study on the involvement of PLHA were particularly important because many of them were HIV positive or affected people, and any breach in confidentiality by the researchers would have put them at risk in a context where they are stigmatized and discriminated against.

How the involvement of PLHA and other service providers and users guaranteed the respect of their rights: Key Steps and Principles

- **Making the research process accessible and transparent to all participants: Orientation**

At the beginning of the study a participatory orientation workshop was held with representatives from partner NGOs, including PLHA and researchers, in which they discussed the following issues:

- Rationale for the study and objectives
- Stakeholders and their respective interest in the study
- Proposed utilization of the findings
- Proposed methodology
- Rights of participants that should be respected by the researchers and what practical mechanisms could and should be used to ensure the respect of these rights, in particular the use of informed consent forms.



Visibility of PLHA - Drama performed by study participants during a workshop.

- **Adapting the methodology to the needs of the participants: Consultation**

During and after the workshop, members of participating NGOs and researchers reviewed the informed consent forms and adapted them to their needs. The review was carried out with technical support from a Mumbai-based human rights organization, Lawyers Collective.

- **Providing study participants with the skills required for their involvement: Training**

Lawyers Collective also trained researchers and members of the NGOs on how to correctly use the forms.

- **Involving study participants in the informed consent process: Accountability**

In each participating NGO, a small number of service providers were recruited as contact persons who acted as a link between respondents and researchers. They helped mobilizing respondents and, together with the researchers, undertook the informed consent process, making sure that respondents had all the relevant information about the study. Through their involvement in the informed consent process and on-going contact with respondents, contact persons and other NGO members were able to ensure that consent given by respondents to participate in the research was voluntary and based on understanding the reasons, risks and benefits of their participation in the research. They also monitored whether researchers respected confidentiality and the other rights of study participants identified at the beginning of the study.

- **Giving access to the data: Transparency**
- NGO partners were also involved in the analysis and interpretation of the data and the writing of the study reports. Researchers

classified the data and presented preliminary findings in four draft reports. The reports were shared with the representatives from the respective organizations to enable them to validate and analyze the data, as well as identify strategies to enhance involvement of PLHA based on the study findings. They could also ensure that neither the names, surnames or job titles of the respondents were mentioned in the reports when they were quoted.

Outcomes: an empowering experience for study participants

An evaluation of the participatory methodology approach found that:

- There was a high level of satisfaction amongst study participants who felt that their rights were respected: "*PLHA felt for the first time their consent was truly valued*" according to a member of the Maharashtra Network for PLHA-MNP+.
- NGO members, and PLHA in particular, felt that the experience they had gained from their involvement in the research was empowering: Another member of MNP+ noted: "*We now have a technical expertise about what things should be done in research*".
- Because of the emphasis on ethical issues during the research, NGOs also realized that the respect of the rights of PLHA, especially confidentiality, should not be limited to research only but also be central to their work in care and support.



The importance of informed consent - A representative from the Maharashtra Network for Positive People explains how his organization gained informed consent from members and beneficiaries of the network during the study.



Learning to respect confidentiality when taking pictures of PLHA - During a visit to an HIV positive patient, a social worker from one of the participating NGOs sits down in a way that hides the face of the PLHA.

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