In your opinion, does HIV prevention work or not? Figures show that the epidemic will become even worse than the current annual pace of 5 million people contracting HIV and other 3 million dying due to AIDS (UNAIDS, 2003). Given the fact that redressing the social determinants of HIV/AIDS has been showing critical deficiencies to halt this epidemic, a highly effective and affordable HIV vaccine is the biggest hope we have to stop the spread of HIV. Based on this rationale, the question is: what can communicators do to accelerate the development of this vaccine?

This article focuses on developing a communications framework for HIV vaccine trials. Based on the experience of the biggest international network in the HIV vaccine trials arena –the HIV Vaccine Trials Network (HVTN)– responses to a web-based survey of 95 people from 17 cities and 21 research sites across the globe pointed out: 1. Critical socio-cultural differences regarding HIV vaccine trials across 4 regions (Africa and Asia, the Caribbean, South America and USA) that are not addressed by the HVTN; 2. The critical need of promoting stronger debate about HIV vaccines in order to secure political support and participation of volunteers; 3. The need to strengthen the voice of community representatives to fuel community ownership and collective action.

BACKGROUND

HIV Vaccines

Modern world is not just a communications “global village”, but also a global village exchanging viruses. For 25 years now, HIV/AIDS has never stopped affecting the life of millions of peoples and dozens of countries and at present more than 40 millions live with HIV around the world).

So far, prevention efforts (on mother-to-child transmission; treating
other Sexually Transmitted Infections; educating for behaviour change; treating abuse of illicit drugs; testing blood; promoting condoms and syringe exchange—ranging from massive communication campaigns to face-to-face counselling—have contributed to slow but not to stop the spread of HIV. For the worse, fewer than one in five people at risk worldwide have access to prevention interventions (Bill and Melinda Gates Foundation, 2003). On the other hand, current antiretroviral therapies cannot cure HIV/AIDS; require a close follow-up; cause unpleasant adverse effects; and are unaffordable for the majority of people and countries living with HIV/AIDS. Moreover, the developed world is getting used to AIDS. For all these reasons, I do agree with Dr. Hu’s statement: “a safe, effective, and affordable vaccine remains to be the best long-term hope” (Hu, 2003) to stop HIV dissemination.

Explained in simple terms, a preventive HIV vaccine will teach the immune system to recognize and protect the body against HIV/AIDS. Its search started in 1983 when the etiological agent of AIDS was discovered, and four years later, the very first research project involving humans in order to test a candidate HIV Vaccine was started (Wakefield, 2001).

In order to test HIV vaccines, thousands of participants of all races, genders and socioeconomic backgrounds are needed to determine if the candidate HIV vaccine is safe and efficacious. This issue is of great importance, particularly in the developing world. Firstly, because most infections occur in that part of the world. Secondly, because in order to produce valid and timely results, efficacy trials need to be conducted in populations with high incidences of HIV infections. Finally, because the genetic variability of HIV may necessitate testing candidate vaccines in different areas in the world. However, recruiting participants to test candidate HIV vaccines is a challenging task. Because AIDS is fatal, it would not be ethical to use live, dead or attenuated components of HIV on the candidate vaccine. Therefore, the only way to develop candidate vaccines is through copying a section of the virus. While doing so, some HIV vaccines could provoke “false-HIV results” on people who received them, which in turn fuels the stigma and discrimination related to AIDS and clinical trials projects.

At present, many local research organizations—from now I will refer to them in this article as sites—, international networks and governments are trying to find an HIV vaccine. According to the International AIDS Vaccine Initiative (IAVI, 2004), only in 2003 19 new vaccine trials were started in 13 countries, involving 17,737 volunteers and 21 candidate HIV vaccines. Among all those participants, the biggest international network is the HIV Vaccine Trials Network (www.HVTN.org), funded by the U.S. government.
From a communication for development perspective, the most appropriate paradigm to revise this project is multiplicity, based on the principle that each society must define development for itself to find its own strategy (Servaes, 1999). This way, people find more lasting solutions than when they are not involved in such problem solving (Lindsey, 2001). Accordingly, community education on HIV vaccines is linked to Freire's idea of empowerment through education, where people are responsible of their own learning process and not merely empty recipients filled out by the knowledge of experts who are alien to their communities (Freire, 1970). Key to this approach is the recognition that individual and interpersonal experiences interact with the social, economic, and political context in which people live.

HIV/AIDS communication is supported by three main approaches: Behaviour Change Communication (BCC), Communication for Social Change (CSC), and Advocacy Communication (AC). According to HealthComms [1], BCC is a result and project oriented approach, which encourages people to make informed choices. CSC emphasises community empowerment, is process oriented, promotes debate rather than focusing on products and messages, and is based on a belief that behaviour change is dependent on social change. Finally, AC is an organised attempt to influence the political climate, policy and programme decisions, public perceptions of social norms, funding decisions and community support. Among the three of them, BCC has been the dominant paradigm, but it has also been severely criticized as ethnocentric, shaped by top-down views of development, and designed and executed by foreign specialists. For the worse, BCC excludes political and socio-economic variables influencing HIV transmission.

The project I discuss in this article chose the CSC approach, summarised by the Rockefeller Foundation (Panos Institute, 2003) as follows:

- Communities should be the agents of their own change.
- Social change is more likely to be sustainable if the most affected individuals and communities own the process and content of communication.
- It must encourage debate and negotiation rather than the transmission of information.
- Emphasis on outcomes should go beyond individual behaviour to social
Towards a communication framework for HIV vaccine trials

Aiming to provide a consistent rationale for community education and communication programmes on the HIV vaccines arena, I find that the best model for this arena would be the result of adapting the framework developed by UNAIDS/PennState University (1999) to meet the particular needs of HIV vaccine trials. This framework was developed through an active exchange process led by researchers and practitioners from the communications field from Africa, Asia, Latin America and the Caribbean. Later on, the development of this framework included the experience from first world settings. Main findings from this process were the following five contextual domains:

1. **Government** actions can either promote or hinder efforts to reach the goals of AIDS communications. In national efforts to prevent HIV—such as permitting or not an HIV vaccine trial to take place in the country—political will is critical.

2. Lower **socio-economic status** increases the vulnerability to many diseases and infections, including HIV/AIDS. In fact, poor people are more likely to develop AIDS sooner than those of a higher socio-economic status.

3. **Culture** is defined by UNAIDS as the collective consciousness of a community. It is shaped by a sense of shared history, language, and psychology.

4. **Gender** is defined as the opportunities, roles, responsibilities, relationships and personal identities that a group considers adequate for women and men. While sex is biologically determined, gender is socially defined.

5. **Spirituality** is a much broader and more inclusive concept than religion. It encompasses hope, faith, self-transcendence, the recognition of mortality, and the maintenance of interpersonal and intra-personal relationships.

According to Panos/UNFPA (2001) and Servaes (1999), this framework calls for moving away from individual-level theories and models of preventive health behaviours (health belief models, theory of reasoned action, stages of change, hierarchy of effects model, social cognitive theory, diffusion of innovations, and others) to more multilevel, cultural, and contextual explanations and interventions. However, to accomplish not only effective communication environments but also active participation on HIV vaccine trials it is required to engage and involve
critical civil society. This demands the capacity to deal with the fear of being treated as guinea pigs; the fear of testing “false-positive” for many years; the stigma and discrimination derived from being associated with AIDS; and in some parts of the world, since HVTN is funded by the U.S. government, an anti-American feeling. Given these particularities, theoretically speaking, the model was missing other two crucial areas for this field: advocacy, and the particularities of HIV vaccine trials. This resulted on promoting a new theoretical seven-area model that was tested through statistical analysis. The analysis provided information leading to adopt only six of these areas as statistically significant to be included in the communications framework for HIV vaccine trials.

**METHODOLOGY**

**Problem formulation**

In 26 cities around the world, HVTN multidisciplinary research teams test candidate HIV vaccines in their fellow community members. Involving lay people in this kind of projects demands a structural approach to meet a number of needs, ranging from the permission of local governments to conduct these trials, to the delivery of messages that make potential participants feel confident in receiving these substances. Accordingly, there is the need to develop a communications framework to provide logic and sequence to involve communities into HIV vaccines initiatives and to ramp up enrolment of participants into their research projects.

**Research question**

How appropriate is the UNAIDS/PennState University communications framework (1999) for the HIV vaccine trials needs?

**Objectives**

1. To identify main similarities and differences on HIV vaccine educational programmes taking place in the U.S and in the developing world in order to support their communication programmes.

2. To assess the communications performance and identify particular needs of different sites to improve HVTN’s performance.

3. To develop a communications framework to improve upcoming
educational and recruitment programmes in the HIV vaccines’ field.

Methods

This multi-site project took place from October 2003 to May 2004. Based on the feedback of colleagues from both fields, communication for development and community education on HIV vaccines, a final version for a web-based survey was ready to use among Community Educators and Recruiters (CER) and Community Advisory Board (CAB) members. The survey was divided into the following areas:

1. In your city, where respondents recorded their reaction to how AIDS is affecting their society and how local people are fighting against this epidemic;

2. CAB, where participants responded according to their perception about the involvement of CAB members on HIV vaccine trials;

3. Educating communities on HIV vaccine trials, about the main barriers and facilitators when educating communities about this research projects;

4. Communication skills, a rapid assessment on the communications unit for each site;

5. Training interests, a space to identify what are the most important areas to train personnel supporting/working on this arena;

6. Control data, a section to identify the diversity of people working on community education in this field.

Because of geographical distances, potential costs in telephone calls, and especially time, the plan envisioned surveying participants for this project through a web-based survey. Secondly, to avoid potential language barriers, the project provided three language versions for this survey: English, Portuguese and Spanish. Finally, to improve the response rate, personal e-mails were sent to each potential participant to invite them to spread the word about this project and to fill out the survey. The survey was connected to an original MS Access database designed to capture the data provided by respondents. The collected data were then exported to SPSS version 11.5, where the statistical analyses were conducted. Those analyses were as follows: frequencies; mean; standard error of the mean; crosstabs; correlations; alpha of Cronbach; T-student; linear regressions and factorial analysis.

Limitations
I must acknowledge that even if the web-based survey was presented in three languages and despite the fact that it was properly tested prior to launching, the digital divide between U.S. sites and those located in the developing world could interfere in the access of people to filling it out. Furthermore, since people who responded to the survey were in-depth related to the HVTN, results may not be entirely representative for the whole communities to which they belong.

**RESULTS**

**Participants’ profile**

Ninety-five people across the HVTN responded to the web-based survey. 28 of them chose the Spanish version, 58 the English version, and nine responded in Portuguese. Sites in the U.S and in the developing world were 48% and 52% respectively. Six out of 10 respondents were women, and 1 out of 4 was homosexual or bisexual. Almost 7 out of 10 of them were Catholics or Christians and 15% reported themselves as Atheists. Only three participants reported themselves as poor and other four as wealthy. Finally, 3 out of 4 CAB representatives had more than 2 years providing feedback to their own sites to improve social impact.

**Differences on how local communities fight against AIDS**

Among 21 variables for this area, the item “AIDS represents a socio-economic emergency in your city” achieved the biggest score while “Lay people know about HIV vaccine trials” got the lowest score. Furthermore, the item “Civil society tends to be active when fighting against AIDS” showed the biggest difference between both developed and developing worlds. A reasonable explanation for this finding is how community based organizations and non-governmental organizations in the developing world are still highly motivated in securing solutions to tackle HIV/AIDS because of the high incidence and prevalence of this epidemic among their populations.

Another variable reporting critical differences between US and non-US sites was that “Church groups contribute to stopping the spread of AIDS”. Respondents from Chiang Mai, Gaborone and Soweto agreed on how important the role of their local religious groups is when providing support for People Living with HIV/AIDS (PLWA).
The role of the Community Advisory Boards in this search

The Community Advisory Board (CAB) bridges the interests of both researchers and the community, in order to achieve the best possible social impact. Results from this area showed the critical necessity of CAB members to improve their current skills in order to involve their own communities on this search. Based on the finding of Morin (Morin et al., 2003) that having a mission statement is associated with better attendance and a more active participation, it has been interesting to find that the majority of CABs has a mission statement, which was linked to the item “There is a high-commitment among CAB members”. The last item achieved one of the biggest scores for this area.

Analysis of this area permitted to identify two important insights: The need to keep clarifying the limits between the CAB and the Ethics committee and the low international participation of CAB members is the result of language barriers. The latter item achieved a highly significant p-value of 0.00 and a mean of 4.66 (in a 1-6 scale where six meant “Strongly agree”). This highlights the necessity of addressing language difficulties to promote involvement of those who cannot speak English.

Barriers and facilitators when educating communities on HIV vaccines trials

The survey found the following as the most important obstacles to the promotion of HIV vaccines: AIDS stigma; the time that it will take to develop an effective and affordable vaccine; and the “false-positive” results that a volunteer can experience after receiving a vaccine. As the most important facilitators, respondents identified the quality of the clinic services; the personal interest in belonging to the “discovery” of a vaccine; and the collaborations with other local institutions.

Among the three most important differences between US and non-US sites, one was the item ‘community mobilization’. Since people in the U.S. do not die anymore because of AIDS, community mobilization has become harder to reach than in the past. On the other hand, people outside the U.S. worry about this epidemic that keeps growing every day. Another interesting issue for this area in the survey was related to the level of expectations about HIV vaccines. Since clinical trials have been taking place in the U.S. for many years now, expectations about this vaccine are becoming a barrier, because this is a “marathon” while many people thought to be a “short run process”. On the other hand, people from non-U.S. sites are still conducting their first HIV vaccine trials and their communication strategies are based on the high potential of these research projects to stop the spread of HIV.
At the regional level, there are some aspects to highlight. The first one is the differences on how the Caribbean sites have been involving other local institutions, and how HIV/AIDS affecting now larger number of heterosexuals facilitates the recruitment of participants. Similar situation appear connected to the sense of loss of a close friend/relative, which achieved high scores no matter where. Another important issue arising from this area was to identify how important is the interest in belonging to the discovery of a vaccine. All these insights must be considered when designing communication campaigns.

Training needs and communication capacities in HVTN sites

Based on the work/support to their local sites and using a scale from 1 to 6, where 1 meant “Novice” and 6 meant “Expert”, respondents recorded their reactions to different items used to describe the level of communication expertise they find in their site. On average, participants perceived their sites as strong as regards producing messages that humanize people living with HIV/AIDS; respecting gender-oriented principles; and producing printed materials. On the other hand, the main perceived weaknesses were connected to disseminating messages through digital media; promoting close relationship with local government; promoting close bonds with media representatives; and managing media crises.

A regional analysis pointed out that African, Asian and Caribbean sites enjoy a closer relationship with the government than those located in South America and the U.S. Based on the results, it could be interesting to learn from the Caribbean sites when promoting consensus with other local organizations, and from sites in South America when raising awareness and recruiting participants through traditional and new mass media.

DISCUSSION

Based on results introduced above, and explained in more detail in my Master thesis, the following discussion is presented according to the areas that found not only theoretical but also statistical support. Finally, I will present a communications framework for HIV vaccine trials.

Government policy

Political will to tackle HIV/AIDS was the result of media advocacy
initiatives. Lessons from the early stage of the AIDS epidemic shall be considered now in the search of an HIV vaccine. Based on the results of this project, I noted that just a few sites enjoy strong connections with their own governments and, especially in the developing world, this could turn into a main problem because of political instability; the permission of local governments to run HIV vaccine trials can be affected.

Strong commitment from governmental bodies and grassroots organizations is mandatory to secure sustainability in the search of HIV vaccines at a glocal level. Operationalizing a communications framework for HIV vaccine trials shall consider promoting legislations, like tax reduction for companies involved in this search; the allocation of funding for promoting HIV vaccine trials through the health sector; and once the vaccine is ready to delivery, the allocation of funds for promoting and accelerating the vaccination process.

**Socio-economic strata (SES)**

Many HIV viruses and AIDS epidemics are disseminated across the globe, not only because many sub-types of HIV and many driving factors co-exist, but also because HIV/AIDS is socially constructed. According to this rationale and the findings of this research, the AIDS epidemic represents a chicken-and-egg dilemma for the developing world. This epidemic is fuelled by low education, SES inequalities, unemployment, malnutrition, lack of infrastructure in health care systems among other factors, but at the same time, the impact of this epidemic in the economy of these countries is much bigger than in the developed world.

To operationalise the communications framework for HIV vaccine trials on issues related to SES, a variety of issues ranging from what mechanisms may ethically stimulate the participation of low-income-volunteers to the level of exposure to HIV false-positive results among participants with poverty malnutrition must be considered.

**Culture**

Sites can and must learn from one another, but should always be aware of cultural differences. Experience in this respect warns against sharing communication materials developed in different regions, no matter if their targets use the same language. For example, in Botswana, gayness could be seen not only as disrespectful but also as against the law, and therefore communication pieces from other sites could be seen as encouraging homosexuality. On the other hand, sharing lessons learnt can improve outcomes and save money.
Gender relations

Given the fact that the economic dependence on men and the acceptance of male promiscuity increase the vulnerability of women to the AIDS epidemic in many societies across the globe, it will be worth to find out the roles, opportunities and expectations of both men and women on the search for an HIV vaccine. Accordingly, communication solutions should be designed to contribute to eliminate negative stereotypes of women that may influence HIV dissemination.

Spirituality

Even when the majority of participants “believe” in one way or in another, their scores showed that their religious groups do not meet AIDS needs. However, those groups provide critical support for PLWA. For our field of interest, this area can provide an organised approach for gaining support from relatives and close friends of PLWA to encourage them to support the fight against AIDS through participating in HIV vaccine trials. Therefore, it would be interesting to start building bridges with spiritual institutions to appeal to their altruistic members. Doing so, communicators at each site must consider the level of influence of spiritual leaders –including traditional healers, voodoo priests, and others– in their community and which mechanisms spiritual organisations use to engage with governmental, private and civil society bodies.

HIV vaccine trials management

HIV vaccine trials cannot take place without volunteers. On the one hand, recruiting participants in time and on the other hand, promoting informed debates about the risks and benefits of becoming a volunteer are both crucial aspects to be considered in this area. Given the high risk of jeopardizing the trust of communities on HIV vaccine trials, the safety of participants and the delivery of accurate information about the progress of this search must be prioritized.

Communications framework for HIV vaccine trials

So far, different aspects based on the results for the survey I refer to and the communications framework developed by UNAIDS/Penn State University (1999) have been revised but adapted to the HIV vaccines
In order to provide a logic sequence that prepares the communities at large to become more involved into the HIV vaccines initiative and to ramp up enrolment of participants into their research projects, some critical aspects from the Integrated Model of Communication for Social Change (IMCFSC) will be incorporated (Figueroa et al., 2002). By doing so, this Communications framework for HIV vaccine trials will be the result of both sources: the rationale behind the UNAIDS/Penn State University (1999) framework and the fine sequence provided by the IMCFSC model.

The IMCFSC describes an iterative process where catalysts, community dialogue and collective action work consequentially to provoke constructive social change. Even when IMCFSC identifies six potential catalysts, our communications framework for HIV vaccine trials has its own six catalysts, already described in the previous section: government policy; socio-economic strata; culture; gender; spirituality and HIV vaccine trials management. Evaluation on how to enhance the relationship with government representatives, contribute to alleviate poverty, promote the sense of trust toward HIV vaccine trials, reduce negative stereotypes of men and women participants, and identify and respect spiritual beliefs, must be shaped by a clear vision of HIV vaccine trials management to act as catalysts for the framework presented below.

According to this framework, community dialogue and collective action provide a continuum process towards promoting more community involvement in HIV vaccine trials across the globe. Community dialogue comprises the following eight steps:
1. Recognition of a problem –as result of a catalyst, someone in the community becomes aware of the existence of a problem.

2. Identification and Involvement of Leaders and Stakeholders –eventually, someone exercises leadership and takes responsibility to label and try to solve the problem.

3. Clarification of Perceptions –unless a consensus can be reached regarding the nature of the problem and its causes, it will be difficult to find an adequate course of action.

4. Vision of the future –it is important that this vision involves the voice of community stakeholders.

5. Setting objectives –achievable goal setting creates high level of group motivation.

6. Options for action –must be aimed to the identification of resources to undertake those actions.

7. Consensus on Action –once a detailed plan is at hand, it must gain agreement among stakeholders. In fact, the more a community is “involved and committed”, the higher the empowerment and sense of collective self-efficacy.


According to Figueroa et al. (2002), the collective action level describes the process of executing the action plan and the evaluation of its outcomes. The model identifies the following key action steps:

1. Assignment of responsibilities –taking the plan into action through specific task forces according to deadlines;

2. Mobilization of organizations –its goal is to lobby other institutions to achieve their support in this mutual and beneficial relationship;

3. Implementation –this step refers to the actual execution of the action plan and its monitoring;

4. Participatory evaluation –the comparison of the outcomes to the shared vision and original objectives is an important self-evaluation process. For purposes of group motivation and reward, it is important that most of the community participate in the evaluation process. This way, the lessons learnt about what worked, and why, can be shared throughout the community. By the end of this process, it is expected that both individual
and social change take place through measurable indicators such as enrolment rate and media coverage of stories related to HIV vaccine trials.

**RECOMMENDATIONS**

The following views are my own, and do not represent those of any site or network mentioned in this article.

**Communications at the network level**

To improve international participation and involvement, HVTN should take into account to use of the following five languages for all the materials produced by their communications unit, ranging from the website and graphic profiles to good practices guidelines: English, French, Portuguese, Spanish and Thai.

Among training interests, it is highly important to note that communication methods and tools was the top priority, representing almost three more times the voice of those interested in improving their knowledge on HIV vaccines. This should be addressed as soon as possible. A cost-effective alternative to meet training needs of both educators and CAB members is to design, test and initiate on-line training.

It is also important to design and maintain a database in order to improve the exchange of resources and the quality of social impact measurement.

Strategies that promote local community ownership should be encouraged and awarded. An annual award should be created to reinforce a comprehensive initiative on how to involve communities through communications and education.

**Communications at the sites level**

This project was based on the rationale that for ensuring sustainability and best results, communities should own HIV vaccine trials. To do so, sites have to think on the needs of journalist and their audiences; be on alert for original stories among their volunteers; and never do anything that would compromise their credibility. For those sites that have been involved in this search for many years now, in order to re-launch the interest of media in HIV vaccine research the use of humour to deflect opposition and apathy must be considered, as well as the incorporation of new media into
their educational programs.

To involve potential participants in this search key messages that appeal to the sense of belonging to the discovery of a vaccine and empathy for the loss of a close friend/relative must be developed and tested.

The communications framework for HIV vaccine trials

To develop indicators to evaluate social change, in-depth evaluations of messages, attitudes and behaviours within communities are necessary. To do so, the voice of Community Educators and Recruiters; Community Advisory Board members; and HIV vaccine volunteers must be heard. It is imperative to take into account alternatives to establish long-term relationships with governmental representatives. For this issue, it is necessary to find out what are the key lessons of the sites located in the Caribbean, which proved to be the more successful region on this issue.

MA, MSc. Research Associate at the Social Sciences Research Unit, Institute of Education, University of London. His research interests include social inequalities and HIV/AIDS. This article is based on his Master thesis of the same title (May 2004) promotinghealth@gmail.com
