iavi SPOTlights

BUILDING STRONGER BRIDGES

Bolstering the effectiveness of community advisory boards in Southern Africa

Conceived in the US more than two decades ago, the community advisory board, or CAB, has long been the favored mechanism for engaging communities in the HIV research conducted in their midst. These boards are typically assembled by research centers and filled with representatives who support the general objectives of the work done there. But they are expected to function as independent entities, charged with ensuring that the research center works ethically with the volunteers it recruits for its clinical studies. They are also expected to advise scientists on their study protocols, explain the research to the surrounding community and relay people's concerns and questions about the studies to the research center.

Convening a board capable of taking on such a broad range of responsibilities—and doing it all without pay—has never been easy. But as a growing roster of HIV research projects has shifted from industrialized countries to less technologically and economically advanced ones, the task has become exceptionally complex. "We get representatives from the community, fair and fine," says Samukeliso Dube, African Program Leader for the Global Campaign for Microbicides (GCM). "But what is their role? The concept is that they should be educated enough about research to go out and disseminate information in the community. But is that happening? Are they really the ears of the researchers and the eyes of the community? Or are they just rubber stamps for clinical trials?"

To ensure that they are considerably more than rubber stamps, the International AIDS Vaccine Initiative (IAVI) has developed a comprehensive program to help collaborating research centers assemble CABs appropriately and train their members. With financial support from the European Union, IAVI's Southern Africa Regional Office helps research center staff select CAB members and cultivate their communication and community engagement skills. It also provides the materials and expertise for their instruction on the scientific basis, processes and ethics of AIDS vaccine research. Since 2006, IAVI has conducted 15 capacity building sessions of this sort with 13 adult and adolescent CABs, reaching more than 300 CAB members from South Africa and Zambia. But it does not work in a vacuum. Its training sessions are done in collaboration with research center staff—who are, in IAVI's view, primarily responsible for training advisors—and build upon similar instruction provided by other organizations such as the South African AIDS Vaccine Initiative (SAAVI) and the HIV Vaccine Trials Network (HVTN).

The second arm of IAVI's program seeks to build CAB capacity by enabling networking and exchange between CABs across the region—a hallmark of IAVI's approach. Such exchanges help reduce the isolation in which CAB members work, build consensus about locally relevant mechanisms of community engagement and promote the sharing of best practices for such efforts. IAVI has since 2007 organized three such meetings. The first revolved around the roles and responsibilities of CAB members and strategies for community engagement. The

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—Patricia Southwood, Communications Manager at the South African AIDS Vaccine Initiative

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second emphasized the science of AIDS vaccine research and understanding research protocols and Good Clinical Practice (GCP). The last, held in the winter of 2009 in South Africa, included an update on AIDS vaccine and microbicide research and several participatory exercises devised to help CABs better represent their communities.

This report describes IAVI's program to build CAB capacity in South Africa and Zambia, and examines how its work has supported the community engagement efforts of research centers in the region.

Picking the right people: Balancing representation and capability

Over the course of the last decade, CABs have become indispensable to the conduct of HIV prevention research. A trial conducted without one would be viewed with suspicion by a variety of outside observers, including funders and, not least, the community. But assembling a CAB that functions optimally isn't easy. What, for example, is a sufficiently representative CAB? How do you best educate CAB members who may have little or no background in science on the concepts of immunology, ethics and clinical product development that are relevant to their duties? Or, even more fundamentally, how do you best train them to inform the community and relay its concerns to the research center?

Of course, neither IAVI nor any of the organizations with which it collaborates have a pat formula for accomplishing all of this. But given its uniquely global experience in community engagement, IAVI has identified some features that appear to be common to most effective CABs. It has tapped this experience to compile a CAB Toolkit that offers concrete guidelines on the selection and training of community advisors, and shared it with partners in Zambia and South Africa.

IAVI has also identified some salient features of effective CABs. Above all, they enjoy the active support of principle investigators (PIs) at the research centers with which they work. They are, further, guided by skilled community liaison officers (CLOs), who continually monitor the strengths and address the weaknesses of the board as a whole and each of its members. Finally, to the extent possible, they reflect the diversity of the communities they represent. CAB members might be political leaders, priests or representatives of communities most likely to be involved in large-scale HIV vaccine trials. Or they might work in fields that bring them into close contact with people at high risk for exposure to HIV. That includes traditional healers—who are visited by about 80% of South Africans—and community or corporate health workers.

The advantage of recruiting such people into CABs is that they often have ample opportunity to share information about vaccine trials with the community at large. Take Phistos Molaole, the Deputy Secretary of a CAB that IAVI has helped to train at the Aurum Institute for Health Research center in Rustenburg. A peer educator at Impala Platinum, Molaole has a job that gives him frequent access to mine workers. These are primarily young men, many of whom have only recently migrated to the booming city from rural areas and may well prove to be prime candidates for future recruitment into HIV prevention studies. Required to give weekly talks on HIV and its prevention to workers who return from home leave, Molaole routinely weaves information he has picked up from his training as a CAB member into these educational sessions.

Many of the people appointed to CABs in South Africa also work for prominent nongovernmental, faith-based or community service organizations. Such advisors are likely to be trusted sources of HIV-related information for people in their communities. And they are passionate about their work. Nombeko Mpongo, a veteran advisor on one of the CABs convened by the Desmond Tutu HIV Foundation (DTHF) in Cape Town, is a case in point. In addition to the work she does for the municipality employee wellness program, Mpongo is active in several church programs that serve HIV-positive people and is often tapped by people in her community to explain HIV related news, such as clinical trial results. "Prevention is very important to us," she says, "but the biggest reason I have for joining this CAB is to make sure that the community is involved in AIDS vaccines before they are even available. When antiretroviral drugs were introduced here, the communities were not involved in the process, and that caused a lot of chaos. We had to fight and do *toyi-toyi* [a

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dance associated with protest] for access to the medicines."

But picking the right people for any CAB can be a tricky business. Consider the case of the CAB convened in 2004 by the Zambia-Emory HIV Research Project (ZEHRP) in Lusaka, which works closely with IAVI on several research projects. A team dedicated to community engagement had sought to build a reasonably representative CAB, but done so solely on the basis of the appointees' stature in their communities. That proved to be a problem. Despite repeated attempts to engage and train them, some of the advisors were not turning up to CAB meetings. Others seemed confused by the information they were expected to learn, or so reticent that they contributed little to the discussions. "We realized," says William Kilembe, ZEHRP Lusaka Medical Director, "that many of them would not be able to represent the research very well when difficult questions came up in community meetings."

The Lusaka community engagement officers found the help they needed at a global CAB exchange meeting organized by IAVI in Nairobi in 2007. This meeting brought together CLOs from all of IAVI's collaborating research centers in India and Africa and was followed by an exchange workshop among CAB members from East and Southern Africa. There, the Zambian team learned how their counterparts at other research centers had addressed the same issue: ensuring that CABs are not only adequately representative but also capable of carrying out the duties of board members. They then returned to Lusaka and devised an assessment tool to figure out which members of the board needed to be replaced, based in part on their literacy, command of English—the lingua franca of scientific research—and ability to grasp critical research concepts, as well as their interest in continued participation.

Following the assessments, the research center asked half the CAB to step down. "It was a mutual decision," says Kilembe. "They were saying, 'I have actually found this a challenge,' and 'I don't think I can manage this.'" The Lusaka team subsequently asked its CLO to identify potential CAB members, keeping the lessons learned at the exchange meeting in mind. ZEHRP ultimately added nine new people to the board—including pastors, teachers, a nurse and HIV activists—all of whom were required to submit CVs. The community engagement workers describe the current board as being "eager and committed" to the work at hand. "We have involved them very well this year in the research center's activities," says Kilembe.

Adolescent CAB members discuss their capacity-building needs during the adolescent community advisory board camp organized by the Desmond Tutu HIV Foundation and sponsored by IAVI in July 2007.

CLOs aren't the only people asked to think carefully about representation. CAB members too are trained by IAVI to identify obstacles to their ability to represent their communities. The second Southern African CAB exchange meeting, for example, included exercises in values clarification, in which CAB members were asked to examine their prejudices about various subgroups of society. IAVI did not expect that the exercise would alter their closely held beliefs. But it did intend to remind them that those views often have to be set aside in the service of CAB duties. This is important, says Tsietsi Mokhele, the IAVI Regional Program Officer in Southern Africa, who oversees CAB capacity building efforts. As candidate vaccines are tested in progressively larger populations, he notes, they are increasingly likely to involve people who are often stigmatized—such as sex workers and men who have sex with men. CAB members must reassess their biases in order to represent their communities effectively, and be able to work with those who have different perspectives or lifestyles.

A CAB that is both capable and truly representative of its community can be an invaluable asset in times of crisis. When the STEP/Phambili trials were abruptly suspended

Community advisors hold a group discussion during the IAVI global CAB meeting held in Nairobi in June 2006.

in 2007, the fallout was widely expected to be terrible. It was a Phase II-B trial of a candidate AIDS vaccine for which there were high expectations, not least in Soweto, where one of the Phambili trial sites was located. To complicate matters, information from the STEP trial suggested that some people who had received the candidate vaccine might be at higher risk for HIV infection.

With support from HVTN—which sponsored the trial—the CAB convened by the Perinatal HIV Research Unit (PHRU) handled the crisis dexterously. Its members first called an emergency meeting with the PI and sketched out a sequence of steps by which trial participants and the community at large would be informed of the news. "We could not allow outsiders to come into our community and give this news first," one CAB member explains. If they had permitted that, he says, "the trust between us and the community, which took so long to build, would certainly be destroyed."

Following the meeting, the CAB, working with trial staff, sent out SMS messages calling all participants to the research center. Some cell phone numbers had changed, but because the CAB had kept meticulous notes on participants, they managed to reach those people as well, in some cases leaving detailed letters at the homes of those who were unavailable. Sinazo Pato, the PHRU CLO, says that the research center was very concerned about how the CAB members were going to take the news. But they took it surprisingly well, something she attributes to their understanding of how biomedical research works.

Building capacity

Much effort goes into cultivating that understanding. IAVI shares with CLOs a number of educational materials—including a collection of documents known as the VaxLit Toolkit—that it has developed on the science, processes and critical concepts associated with ethical AIDS vaccine development. IAVI also stresses instruction on GCP guidelines, since a grasp of its requirements is critical to a CAB's ability to follow closely the work going on at the research center. Although SAAVI and the research centers themselves offer similar training to CAB members, reiteration of the scientific concepts through multiple training sessions can only help.

There are many reasons for this. For one thing, says Acting Director of SAAVI, Elise Levendal, some CABs in South Africa have had to deal with a high turnover rate. Trained advisors sometimes relocate, stop participating for work-related reasons, or simply burn out, taking with them a good deal of institutional memory and ability. The advisors are also frequently given mixed messages about their roles, says Levendal, leaving them uncertain about whether they're independent advisors to researchers (the right answer) or recruiters for vaccine trials (the wrong one). Beyond that, given the fast pace at which HIV research is advancing, CAB members need to have their training routinely refreshed. "Building CAB capacity is an ongoing program," says Mokhele. "It takes time to get fully-fledged, confident, independent CAB members who understand their roles and responsibilities and can raise issues with researchers. They must be trained to meaningfully review research protocols—particularly the informed consent documents—and must understand issues around the rights of the participants."

CABs in the region remain a long way from being able to do that without assistance, according to PIs and community engagement staff. Many CAB members themselves believe it shows. "Issues relevant to communities are not always adequately addressed," says David Galetta, a pastor and CAB member with DTHF who also sits on the University of Cape Town's Research Ethics Committee. "This is a challenge that we as CABs are facing—to raise our capacity level [in ethics and science] to the point where we become competent to fully review study protocols."

Demystifying vaccine science

To help build that capacity, IAVI works closely with PIs and other research center staff to elucidate complex issues and technical material for CAB members. Whenever he can, Mokhele also invites experienced former CAB members to help instruct attendees. "They have the ability to demystify research," he explains. "They can break scientific concepts down into language that can be understood by the average CAB member." IAVI also invites other organizations to assist in the technical training. GCM has, for example, participated in CAB exchanges and training sessions, and has worked with IAVI to bring in people from other advocacy organizations—such as the Treatment Action Campaign, which focuses on human rights issues associated with the AIDS pandemic—to share information on their areas of expertise.

This has several advantages. It emphasizes the importance of a comprehensive response to the AIDS pandemic: one involving not just vaccine development, but other modes of prevention, as well as programs for the care of those already living with HIV. It also encourages a cross-fertilization of ideas between people who work in HIV-related areas but whose paths rarely cross. Finally, it helps ensure that community workers not ordinarily involved in AIDS vaccine trials are aware of the legitimacy of the vaccine development going on in the region. This provides a measure of insurance against misunderstandings that might easily disrupt the conduct of vaccine trials.

Because it is well contextualized, the breadth of information provided by IAVI and its partner organizations establishes firm foundations upon which to build CAB capacity. The vaccine science is explained not only in the context of HIV prevention and AIDS, but human rights and research ethics as well. Overwhelming though it may seem, this approach has valuable long-term benefits. "You want to build in people the capacity to look critically at what's going on in their community," says Patricia Southwood, Communications Manager at SAAVI. "These are issues that apply not only to AIDS vaccines but to any other research as well."

Still, the science remains a bit of a slog for most CAB members. The difficulty of the subject matter, says Linda-Gail Bekker, a Director and PI with DTHF and a professor at the University of Cape Town who has worked closely with IAVI on a variety of clinical and social science research projects, is only compounded by the proliferation of preventive tools under investigation. But if difficult to master, it is also widely appreciated. "What drives CAB members to stay on board," says Bekker, "is that they have a tremendous hunger for knowledge. Imparting that knowledge is what nurtures our relationship. It is, in a way, my currency for keeping them involved."

Yet even a CAB challenged by the scientific material can provide valuable advice if it has a firm finger on the pulse of the community. For example, the adolescent CAB at DTHF made very useful comments on the material the research center produced to recruit adolescents for a study. Bekker says the materials were sent back to her with sharp instructions to remove the cartoons and pictures that had been inserted to illustrate various messages. The adolescent advisors pointed out that they were far too patronizing. Similarly, aware that potential volunteers may not understand that their blood would be stored in a laboratory indefinitely, CAB members working with PHRU insisted that this fact be spelled out unambiguously in the informed consent materials. Not everyone, they noted, would be comfortable with the idea.

CABs can also serve as valuable monitors of the standards maintained by research centers. Matilda Mogale, the former PHRU CLO, recalls that advisors would make random, unannounced visits to the site when a clinical study was underway. They would circulate among the volunteers, asking them how they felt they were being treated by the research center. When Mogale tried to join them, she was shooed away by CAB members, who feared her presence would compromise the independence of their inquiry.

Refining community engagement skills

A CAB can only be that sure of itself if its members enjoy the support of the PI, believe in their role and are adequately equipped to perform their duties. "Capacity does not just mean understanding the science behind the

"It takes time to get fully- fledged confident, independent CAB members who understand their roles and responsibilities and can raise issues with researchers."

—Tsietsi Mokhele, IAVI Regional Program Officer in Southern Africa

research," says Dube. "It is also about being able to articulate community issues to researchers and vice versa. IAVI has gone beyond training people on technical issues, such as vaccine science. It has stressed training in soft skills that are essential to the functioning of a CAB as well."

For one thing, the program has sought to help CABs develop skills to effectively collect feedback from public meetings. "CABs," says Mokhele, "should be able to tell researchers about people's concerns and fears, and the common myths and misconceptions about the research that are circulating in the community." Training to that end covers such things as public presentation, the documentation of disagreements and the identification of key issues at community meetings. In the last CAB exchange, for instance, attendees were instructed on the use of matrices to analyze and prioritize the concerns voiced by people at community meetings. A participatory exercise, meanwhile, helped them build mapping and critical analysis skills.

In that exercise, CAB members from Lusaka constructed a sort of demographic map of the area around their research center. With the assistance of other attendees, they then figured out the deficiencies in their representation of the community. As they went through this exercise, the non-CAB participants—mainly CLOs and community advocates—observed the process in several groups of two to three, tracking such things as levels of participation, the main comments and questions that were raised and the points on which everyone seemed to agree. In the end, each subgroup presented a critique and analysis of the process and its conclusions, and the presentations were, in turn, critiqued by the other participants. Thus, while the Lusaka CAB came out of the experience with practical pointers about how better to represent its community, the other attendees received hands-on training in communication skills and methods for the efficient tracking and analysis of large meetings.

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—Samukeliso Dube, African Program Leader for the Global Campaign for Microbicides

Empowering the advisors

In addition to such training, IAVI also stresses familiarity with the Good Participatory Practice in Biomedical Research (GPP) guidelines developed by UNAIDS and the AIDS Vaccine Advocacy Coalition—material that is often spottily covered in the education of CABs in the region. (Mokhele says that when he asked a group of 28 CAB members at a forum if any of them had received training in GPP, only four said they had.) Exposure to the guidelines can be empowering: it gives CAB members standards against which to evaluate the community engagement efforts of the research center with which they work. Members of one relatively inexperienced CAB, for example, say they drew heavily on IAVI's GPP training in deciding to confront a PI about the inadequate time and support they have been given to review protocols—and what they consider the PI's general inaccessibility.

Not all CABs are alike, however, so IAVI tailors its training in non-scientific, "soft" skills to the needs of each of the groups it works with, and does an assessment each year to figure out what those needs are. Mokhele has arranged sessions on adolescent sexual health for one adolescent CAB at DTHF and another, newer one, at PHRU, and stressed their training on leadership and decision-making skills. One adolescent CAB member at PHRU points out that though it took more than an hour for many of them to grasp what leadership meant in the context of their work in the CAB, they now have a new appreciation of their responsibility to their community.

IAVI's training has, further, helped them develop skills and a systematic plan for advocacy in Soweto, including an implementation strategy that involves targeting distinct niches in their community. Some plan, for example, to conduct AIDS vaccine advocacy through the church groups in which they are active. Others have focused on schools. One CAB member says that the information she has shared with students on HIV and AIDS vaccine research has captured the interest of Soweto school teachers and principals. Many, she says, have said they would like to incorporate the material into school curricula.

It is not just CAB members who benefit from IAVI's training and exchange meetings. "I often find I get really important feedback from CAB workshops," says Bekker. "We can fine tune our own strategies based on what they learn." Ditto for CLOs. "It's been encouraging meeting

members from other CABs," says Sinazo Pato, the CLO for PHRU's prevention CAB. "You work on your own, and sometimes you wonder, 'am I doing things right?'"

A work in progress

CLO's aren't the only people wondering about that. Indeed, despite their critical importance to AIDS vaccine research, it remains unclear how faithfully the membership of a CAB should reflect its community. Further, there remains considerable disagreement about what faithful representation precisely means. There are, for example, only 23 people in the Aurum CAB in Rustenburg, a city of more than 45 distinct communities that is said to be one of the fastest growing in Africa. As the CLO Ben Makhoana points out, the CAB—selected primarily from the ranks of local nongovernmental and service organizations—remains far from achieving adequate representation. Its impact, he guesses, has probably been somewhat limited by this fact.

The same can be said for the DTHF CAB in Cape Town. "It's a problem we're facing," says Galetta. "We are only 22, and the community is 300,000 people. We need a militaristic sort of plan in which each segment of the community is systematically represented." The idea is commendable, but is such absolute representation feasible? In a perfect world, perhaps. Yet as the experience in Lusaka amply demonstrates, not all people best able to represent a community will be educationally equipped, or even willing, to participate in a CAB. What is probably most important in constituting a CAB is ensuring that its members bring perspectives on the research process that are sufficiently diverse and distinct from those of researchers. Ultimately a CAB should reflect the knowledge and needs of those that will be affected by research, and open channels of communication with the outside world. It is, however, unrealistic to expect any CAB to represent every district or subgroup in a given community.

Further, CABs must be convened in a manner appropriate to their local context, and adapt their work and objectives to the realities of the communities and the populations engaged by a research center. An urban CAB devised

Nora Moufe leads an energizer during the IAVI regional community advisory board workshop held in Johannesburg in June 2009. She is a member of the Medical University of South Africa CAB.

to cover an entire city, for instance, would be very different from a CAB from a small rural community. Likewise, a CAB working with a research center that engages all types of populations in multiple protocols should reflect that diversity. But if the work focuses on, say, men who have sex with men, addressing the need for adequate representation may mean something entirely different. There are, in other words, a set of principles that orient CABs, but how we define appropriate representation and community engagement can vary significantly—and for valid reasons.

And once the CAB is assembled, questions remain about how best to help its members educate the community. After all, if abilities and literacy levels vary drastically in CABs, they do so even more within communities. Pato recalls, for instance, that a pretest IAVI gave to community members attending an AIDS vaccine informational event—used to gauge how effective the session had been—was about twice as long as needed. The test might have worked for other audiences, she says, but the people in Soweto who attended the meeting found its length and difficulty somewhat discouraging. Can strategies and materials for community outreach be designed to address such variability?

It is, further, very difficult to determine just how efficiently CABs transfer their knowledge to the community at large, no matter what methods might have been used to accomplish the feat. "The tools for evaluating our community engagement are poor at best," says Bekker. "We are well intentioned, but we have not done the studies needed to truly understand this area." (IAVI's support for social science research on community engagement in Southern Africa is the

focus of a companion report.) But, as Bekker is quick to point out, this does not mean that the capacity building efforts of IAVI and its sister organizations in South Africa have been in vain. The things CAB members must have a working knowledge of—GCP, the protection of volunteer rights and the ethical conduct of studies—are broadly applicable to clinical research. "This kind of capacity is transferable," says Bekker. "This is not just about the research sites. By doing this we enrich communities as well."

Community engagement in research is itself a fast evolving field. At its best, a CAB represents a new and dynamic mechanism for communities to influence how clinical research is conducted. The experiences of CABs working with IAVI in Southern Africa demonstrate that successful community engagement to that end is not only possible but of benefit to both society and the AIDS vaccine field. Their successes also represent a significant victory for the field: just a few years ago it was generally believed that neither effective community engagement nor ethical AIDS vaccine trials were possible in most developing countries. We hope that the practices and lessons described in this document will help other HIV research organizations deal with their own community engagement challenges—and ultimately empower communities in developing countries to become active participants in the global effort to put an end to the AIDS pandemic.

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—Linda-Gail Bekker, a Director and Principal Investigator with the Desmond Tutu HIV Foundation

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