



Social Sciences and AIDS vaccine research: The South African experience

South Africa is in the grip of a devastating AIDS epidemic. Although less than 1% of the world's population lives within its borders, the country accounts for some 15% of all HIV infections. Roughly one in six people between the ages of 15 and 49 and more than a quarter of pregnant women in South Africa are thought to be infected with the virus today. But the severity of this epidemic also makes the country an ideal locus for research into HIV prevention and treatment. For one thing, vaccines and other preventive tools need to be assessed in the places where they are likely to be used. For another, South Africa's researchers have accumulated considerable scientific expertise and experience in the field. And, for technical reasons, such studies often proceed far faster and require fewer volunteers when they are done in places with relatively high rates of HIV infection.

Still, AIDS vaccine development is a timeconsuming, complicated and expensive endeavor. It is so because vaccine trials-and all the research that leads up to them-require the participation of thousands of unpaid volunteers who must not only be recruited into the trial in a suitably randomized fashion, but retained in it over the course of three or more years. Given the logistical and social complexities associated with these tasks, a growing number of clinical researchers believe that a firmer grasp of the behavioral and social issues associated with clinical trials will be critical to the sustainability of the global AIDS vaccine effort. "HIV prevention research cannot be done without significant social science support," says Linda-Gail Bekker, a principal investigator with the Desmond Tutu HIV Foundation (DTHF) and a professor at the University of Cape Town.

Without that groundwork, she says, "you risk spending large sums of money without good results to show for it in the end."

The International AIDS Vaccine Initiative (IAVI) considers social science research an integral part of many of its vaccine development partnerships around the world. South Africa is no exception. IAVI has provided technical support, guidance and financing for the social science research conducted by two South African institutions whose parent organizations have long been involved in HIV-related research. One is the HIV vaccine research center run by DTHF in Cape Town, and the other a research facility recently established in Rustenburg by The Aurum Institute. IAVI has also partnered with social scientists associated with the South African AIDS Vaccine Initiative (SAAVI) and Stellenbosch University to arrange two international meetings of researchers to identify gaps in the social science related to HIV prevention research and devise strategies to fill them. Finally, IAVI has actively sought to bring the voices of South Africa's social scientists and clinical researchers involved in such work to the ongoing international discourse on the better integration of the two fields.

In the broadest terms, the social science supported by IAVI at the two research centers explores issues relevant to engaging communities at high risk for HIV infection and recruiting volunteers for AIDS vaccine trials. That includes ensuring that the trials are ethically conducted and retaining participants from start to finish. The research examines everything from the social networks of men who have sex with men (MSM) to prevailing beliefs about HIV and its transmission. It entails

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studies on such things as common attitudes toward voluntary counseling and HIV testing (VCT) and the feasibility of including young people who are at especially high risk for HIV infection—in vaccine-related research.

The DTHF research center is well established in Cape Town, and has long focused its efforts on select communities in the area. Aurum's facility in Rustenburg, on the other hand, was launched only in 2007, and its researchers are still in the process of getting a feel for the variegated communities around the research center.

Social Science in Rustenburg and Cape Town Located in a platinum-rich patch of South Africa's North West Province and host to two major mining operations, Rustenburg is in a state of perpetual demographic flux these days. The new wealth generated by its platinum industry has drawn job hunters, entrepreneurs and fortune seekers from across the country and as far away as Nigeria and Somalia to the city. Yet, despite its lately explosive growth, Rustenburg remains in character more semi-rural than it is metropolitan.

Given its demographic complexity, the first thing Aurum researchers did in Rustenburg was generate a social map of the area—the schools, markets, mining hostels, neighborhoods and, not least, the taverns and other centers of casual and transactional sex. This exercise helped them identify a centrally located site for their facilities. "We were brand new to Rustenburg," says Mary Latka, Program Director for HIV prevention at Aurum, "and the social mapping was a nice way to both introduce ourselves to the community and understand what we were dealing with."

It also uncovered some high-risk populations in the city—for example, a thriving if segregated subculture of men who have sex with men (MSM), and a large number of transgender sex workers. To build on insights provided by the social mapping, Latka and her colleagues then launched qualitative studies assessing the psychological and social barriers to voluntary HIV counseling and testing (VCT), stigma and discrimination related to the infection and common perceptions of sexual risk for HIV in the community. These studies shaped a subsequent "knowledge, attitudes, beliefs and practices"—or KABP—survey of 351 representative Rustenburg households.

This quantitative survey was devised to give researchers a sense of HIV risk behaviors in the community, people's previous experience with VCT, the stigma associated with HIV infection and people's awareness of research on its prevention. Interestingly, confirming insights from the social mapping, nearly 7% of the men who participated in the KABP survey admitted to having had sex with men—a finding that prompted the research center to launch an initiative to explore how best to engage MSM in the area.

DTHF in Cape Town has focused on many of the same issues explored by the Rustenburg researchers, but done so from the perspective of a research center that is well established in its community. For instance, in evaluating prevailing knowledge about HIV, VCT use, risk behaviors and stigma associated with HIV infection in Cape Town communities, it has also been able to measure how these things have changed since 2004, when it last conducted such a survey.

DTHF has also sought to engage communities at especially high risk for HIV infection, including MSM and adolescents. It has conducted one study examining how well adolescents understand HIV risk and vaccine development, the prevalence and quality of risk behaviors in this group and the kinds of social harm youth might incur by participating in HIV-related research. (Mere participation in a study can, for example, be taken by people as confirmation of HIV-positive status, a label that can have concrete social consequences.) Another study examines the feasibility of including people ages 16 to 21 in vaccine trials. It explores their disclosure of sexual activity to parents and their willingness to participate in HIV-related research.

The DTHF team is also studying how best to handle the disclosure of HIV status of adolescent volunteers and help them to cope with the news. Bekker points out that getting this right is of critical importance, recalling that a girl who participated in a DTHF study and tested positive for HIV was thrown out of her house by her parents after her brother told them about her HIV status.

As for MSM studies, DTHF research

" ... social mapping was a nice way to both introduce ourselves to the community and understand what we were dealing with."

—Mary Latka, program director for HIV prevention at the Aurum Institute has explored the social networks of different MSM communities in Cape Town and systematically evaluated various strategies for engaging them in HIV prevention research. It currently has an open protocol that explores in greater detail the relationship between MSM social networks and HIV infection. The study, conducted with MSM volunteers from the Masiphumelele and Nyanga districts, has been wrapped into a surveillance of HIV clades that predominate in the area. It has the potential to illuminate how the distribution of HIV subtypes especially recombinant forms of the virus-relates to sexual behavior. DTHF researchers will, further, examine the degree to which MSM report being discriminated against.

They are also investigating several issues relevant to the ethical conduct of AIDS vaccine trials—asking, among other things, how to meaningfully inform volunteers about the risks of participation and then evaluate their comprehension of trial-related concepts. Another ongoing sociobehavioral study supported by IAVI examines the risk behaviors, frequency of substance abuse and mental health of people who have recently tested positive for HIV, as well as the disclosure of HIV status and the stigma engendered by that choice. Like most others, this study has been integrated into a clinical research protocol—in this case, one that follows volunteers who have recently become HIV positive, tracking the early immune response to HIV and its subsequent evolution as the infection takes hold.

All this work will play a significant role in shaping the clinical research protocols employed by South Africa's AIDS vaccine developers. It will also contribute to an increasingly detailed portrait of the social ethos in which HIV spreads, and the interplay of sexual behavior, culture and biology that perpetuates the country's AIDS epidemic.

Knowing how well a community understands HIV and vaccine research is critical to devising effective recruitment strategies. It is also key to fine-tuning counseling services and the information provided to those who choose to volunteer. The KABP survey completed in Rustenburg prior to the initiation of community outreach and clinical research activities suggests that Aurum researchers have their work cut out for them. It revealed, for instance, that while most people know about condoms and their place in HIV prevention, this knowledge does not translate into safer sexual practice. Further, a quarter of the respondents believed that people with recent infections are less likely than other HIV-positive people to transmit the virus (the opposite is true—people in the acute phase of infection are eight times more likely to infect others).

As for the general understanding of AIDS vaccine research, only a third of the respondents in 351 Rustenburg households understood that the future development of an HIV vaccine held the promise of protecting people from the virus. And just a third of those surveyed believed that it would be safe to participate in an HIV vaccine trial.

Risk and the awareness of risk

These findings will continue to inform Aurum's community education efforts in the area.

"If we don't get recruitment at the best levels, studies take longer and are lot more expensive. If participants aren't retained for the full course of the study, the data may be seriously compromised."

—Daniella Mark, sociobehavioral researcher at the Desmond Tutu HIV Foundation In contrast to the Rustenburg findings, the DTHF study of HIV awareness and practices in Masiphumelele district revealed that VCT usage had climbed significantly and sexually risky behavior declined slightly since 2004. Knowledge about HIV improved only a bit over the period-though, to be fair, it had been relatively high to start with. It is unclear what role, if any, community education programs completed over those four years played in these changes. Indeed, very little is known about just how HIV information disseminated by research centers and other organizations diffuses through the community. "This is a subject that is under-researched throughout the world," says Leslie Swartz, Professor in the Department of Psychology at Stellenbosch University. "There is no empirical basis for measuring the impact of community awareness and education."

Yet everyone agrees that community education is important-misunderstandings and rumors can, after all, derail even the most competently conducted vaccine trial. So is educating volunteers before obtaining their informed consent, which is not just desirable but an ethical requirement. On the basis of previous social science studies, DTHF has trained its counselors to use tools other than checklists to get a better sense of which elements of the instruction they have and have not grasped. That might include, for example, asking questions that require volunteers to explain concepts and recount procedures, rather than give yes and no answers. But determining whether potential volunteers have actually understood what they've been taught still isn't easy. With IAVI's support, the DTHF team is now preparing to conduct a study of the effectiveness and feasibility of using such techniques to verify understanding among volunteers before getting their consent for participation in clinical studies.

A sound understanding of the social context in which counseling and HIV testing services are provided is critically important to HIV-related research. VCT is a key step in many of the processes integral to such research and is a standard source of referral for volunteers. But, as Aurum's Manager for training and psychosocial research Robin Hamilton points out, sociobehavioral research in this area has largely been quantitative in nature. Researchers have rarely delved into the answers people give about their perceptions and usage of VCT, or truly explored the shades of meaning in their responses. "There are some processes we can't access just by adding questions to a survey," notes Anthea Lesch, Lecturer in the Department of Psychology at Stellenbosch University. "We can only really understand them by actually speaking with people."

In line with that thinking, Hamilton devised a study to explore what people in Rustenburg talk about when they talk about VCT. The study solicited opinions from a small but carefully chosen sample of Rustenburg's population, asking them open-ended questions about HIV, the process of testing for it and what it means to be diagnosed as HIV positive. After reviewing the responses, Aurum researchers picked a handful of volunteers with whom to conduct in-depth interviews about some of the issues raised in the initial conversations.

"We discovered some interesting anomalies," says Hamilton. It turns out that people have extensive knowledge of Western, biomedical ideas about HIV—such as the means by which it is transmitted and how it makes people ill. They also know about antiretroviral treatment, that it saves people's lives and that people can live for long periods with HIV if treated. Yet those very people, Hamilton found, also considered an HIV-positive diagnosis to be equivalent to a death sentence, equating it in their responses with "staring death in the face," or with

Perceptions of counseling and testing

having "death walk in the door." The diagnosis itself, it appears, is simply too traumatic. "That," notes Hamilton, "would obviously deter anyone from coming forward to be tested."

A second finding of interest to Hamilton is how a number of people have come to interpret confidentiality. Oddly enough, many believe it to mean that they are not permitted to tell anyone about their HIV status if they test positive for HIV. "So," says Hamilton, "not only do you have to walk around now knowing you're going to die, but you've got to keep it a secret as well because the health-care worker didn't want you to tell anybody." One upshot of these findings, says Hamilton, has been that Aurum's counselors have been urged to explore and address people's fears during the pre-test counseling session.

Interestingly, DTHF researchers have found the opposite to be true in their work with adolescents, who had a decided distaste for extensive discussions of possible outcomes of the HIV testing. "It puts a lot of people off testing," says Daniella Mark, sociobehavioral researcher at DTHF. "They don't want to sit around talking about what-ifs." DTHF has responded by stressing the post-test counseling, in which the discussion is tailored to fit the actual HIV status of the study participant. The difference between the two responses illustrates how important it is to understand the views of different communities in providing services as sensitive as VCT—and the critical role social science can play in achieving that understanding.

This holds true for perceptions of HIV as well. Aside from measuring how many of Rustenburg's residents have used VCT services—more than half the Aurum team has also identified some interesting folk narratives about HIV that have implications for VCT and community education programs. They found that many people who are aware of biomedical explanations for HIV still spoke of the infection being caused by "dirty blood," attributing its spread to the prevalence of abortions or to such things as the neglect by widows of traditional cleansing rituals.

Further, the stigma attached to HIV is so acute in Rustenburg, Aurum's surveys revealed, that even being associated with a clinical trial can provoke stigmatization and social isolation. People in the area are thus understandably concerned about the confidentiality of services provided at centers performing VCT. Many presume that counselors and nurses cannot be trusted to keep their HIV status under wraps. "This has very direct implications for how we've set up our VCT service," says Latka. "We've emphasized to our staff that the issue is not just confidentiality, but the perception of confidentiality." Staff at Aurum have, as a consequence, been asked to refer to people who come to the clinic for VCT not by name but by other identifiers, such as numbers, and to make sure that records of any sort are never left lying around on desks.

Beyond that, the Aurum researchers hope to take special precautionary steps to limit the possibility that participation in the research they conduct will provoke stigmatization. They recommend, among other things, the simultaneous conduct of different protocols, each involving participants of differing HIV status. This, they suggest, might minimize the chance that people in the community will come to associate trial participation in general with any particular HIV status.

The research at DTHF and Aurum also has several implications for the mechanisms by which people are recruited into HIV prevention research. The household survey, for example, helped Latka and her colleagues trace patterns of risk behavior in the Rustenburg area, including the numbers of people reporting multiple partners Recruitment and retention and those reporting symptoms of sexually transmitted diseases. That helped them optimize their strategies and criteria for recruitment: to identify people at relatively high risk for HIV infection but not set the bar so high as to make it impossible to build sufficiently large cohorts.

DTHF researchers have, meanwhile, systematically assessed various strategies for recruitment of volunteers. Both are critical to the success of vaccine trials. "If we don't get recruitment at the best levels," explains Mark, "studies take longer and are lot more expensive. If participants aren't retained for the full course of the study, the data may be seriously compromised. And often those who leave are also those who are at the highest risk for HIV infection."

To optimize their strategies for recruitment, the DTHF team compared several different approaches to the task while building a cohort for an IAVIfunded HIV incidence study. They found that the word-of-mouth approach people drawing friends and relatives into the study—was by far the most effective. This result, says Bekker, has prompted a second round of study to evaluate whether a cohort recruited this way is sufficiently representative of the community at large.

But it is not enough that people be recruited into HIV studies in large numbers. They must also be willing to answer questions about their habits and health history honestly—especially since such answers determine just how high their risk is for HIV infection. High-risk people are not only of particular interest to HIV researchers but also likely to benefit most from preventive behavioral interventions. Soliciting truthful answers from them is thus critical to both effective counseling and the correct implementation of study protocols.

To improve the odds that this happens, DTHF researchers have systematically studied who people are most likely to share information with honestly. They have found that participants are most likely to speak candidly to people with whom they identify on some level. This does not mean, however, that each subgroup of society must be represented in the center's staff. "We've responded," says Bekker, "by doing values orientation for staff and developing guidelines to help them relate better to different kinds of people."

The Aurum team too has learned valuable lessons for volunteer recruitment from its studies. Researchers there have, for example, realized that they need to develop better techniques for engaging and recruiting people from Rustenburg's White community. Door-to-door strategies, they note, are not likely to work very well. They have also learned that selective partnering with government hospitals and clinicsrather than traditional healers and private practitioners-is likely to boost recruitment in general, since their studies reveal that people in Rustenburg tend to get most of their health care at such facilities.

Though men who have sex with men are often marginalized and at considerably higher risk than most for HIV infection, few studies have evaluated the prevalence of HIV in these communities and much remains to be done to educate South Africa's MSM about safe sex practices. Indeed, anecdotal reports from outreach activities in Rustenburg suggest that many of them believe that only heterosexual sex puts people at risk for contracting HIV. There is, therefore, an increasingly urgent need for more information about the HIV epidemic in these particularly vulnerable communities.

So far, according to Hamilton, HIV surveillance of South Africa's MSM population has been limited to a handful of studies that have found

Working with men who have sex with men

"We need to see where the [biomedical and social science research] overlap, and how we can use clinical trials to learn more about the social science, and vice versa."

—Linda-Gail Bekker, a director and principal investigator with the Desmond Tutu HIV Foundation HIV infection rates ranging from 38% to 42% in Cape Town, Pretoria, Johannesburg and Durban. But, as is often the case in work involving marginalized communities, researchers relied on snowball sampling to conduct this surveillance—an approach that may not generate truly representative samples of the population. Another problem, says Hamilton, is that all of the studies were done in urban centers, and about 60% of South Africa's Black people live in rural areas and small towns. Rustenburg, he notes, offers the opportunity to conduct HIV surveillance of MSM in a nonmetropolitan area.

Aurum researchers have already conducted some training of staff to sensitize them to the requirements for working with MSM. They have also systematically evaluated methods for recruiting people into their studies and applied new strategies for doing so successfully. IAVI's support, says Hamilton, has been key to Aurum's outreach, since funding for MSM studies tends to be scarce. New recruitment strategies-which include outreach to educational institutions and tapping peer networks—have significantly boosted MSM recruitment into Aurum's research projects in Rustenburg. Before the initiative, Aurum researchers enrolled 2 out of 289 MSM who were interested in joining studies; after its implementation, they recruited 82 out of 1,699 such people.

But not all MSM can be accessed in the same way. The area's White MSM, who are harder to reach, are likely to respond better to contact via the internet. Rustenburg's Black MSM, as demonstrated by Aurum's initiative, are best approached through their social networks and via events such as discussion groups on MSM issues. "It's interesting," notes Hamilton, "how people in different communities meet in such different ways, and how the means of engaging those people need to be so differentiated." DTHF too has applied its findings to fashion effective recruitment and retention strategies. For example, its researchers found that venue-based recruiting—or going to where the MSM hang out to find volunteersworks better with the White gay community of Cape Town. The more marginalized Black MSM in townships are, meanwhile, better recruited through their social networks and by people who are not overtly gay. Because they do not want to be identified with the gay lifestyle, says Bekker, she has hired two women to recruit MSM in the townships, and the approach appears to be working.

Although social science research has much to offer the field of HIV prevention, its inclusion in biomedical projects remains controversial among HIV researchers. A lot of medical scientists, says Bekker, feel they're overburdened with clinical procedures and the health surveys that already accompany that work. Bekker agrees that vaccine developers need to be more considered about the kinds of social science they add on to their protocols. But they should recognize that ignoring social science entirely risks missing opportunities to improve the efficiency with which they conduct vaccine trials. "We need to see where the [biomedical and social science research] overlap," says Bekker, "and how we can use clinical trials to learn more about the social science, and vice versa."

If biomedical research stands to benefit from social science insight, says Bekker, the reverse is true as well. Analyses of sexual behavior and surveys of how people perceive HIV prevention are, for example, somewhat incomplete if they aren't at some point robustly linked to clinical outcomes, such as rates of HIV infection or pregnancy. Not surprisingly, the psychosocial and behavioral research team has become the fastest growing subgroup of her organization.

Aurum too has been building capacity

Looking ahead

to conduct social science research. Latka and her colleagues have been teaching the staff at Aurum's Rustenburg site about the fundamental principles of research and have started a journal club for staff. More recently, Hamilton has with IAVI's support designed and completed for his staff a pilot course to build skills for social science research. He plans next to invite mid-level members of nongovernmental organizations in Rustenburg to take a similar course. It will cover everything from the development of research proposals to skills for interviewing research subjects and running focus groups. He hopes to ultimately help students formulate and develop social science research projects themselves.

They will have plenty to investigate. Researchers, says Bekker, need to understand better why people agree to join HIV prevention studies and why participants choose to stay in them. They need to improve the criteria used to identify groups at risk for HIV infection, and devise better approaches to getting complete and candid responses from volunteers—much, after all, rides on the truthfulness of their responses. And they need to improve

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risk reduction counseling and figure out how to measure its effects on behavior.

Only a concerted program of social science research conducted in tandem with biomedical studies can even begin to address these and other deficiencies in the field of AIDS vaccine research. In support of that agenda, IAVI co-funded with the US National Institutes of Health a workshop on the integration of behavioral and social science in HIV vaccine research, bringing international researchers to the forum. Bekker, who attended the workshop and acknowledges IAVI's leadership in the arena, has an idea or two about how that effort might be jumpstarted: "I would suggest that whenever a research team is assembled to start devising a protocol, a qualified social scientist be given a seat at the table."

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