Do you share a syringe and needle with others?
No, I don't share it with anybody.

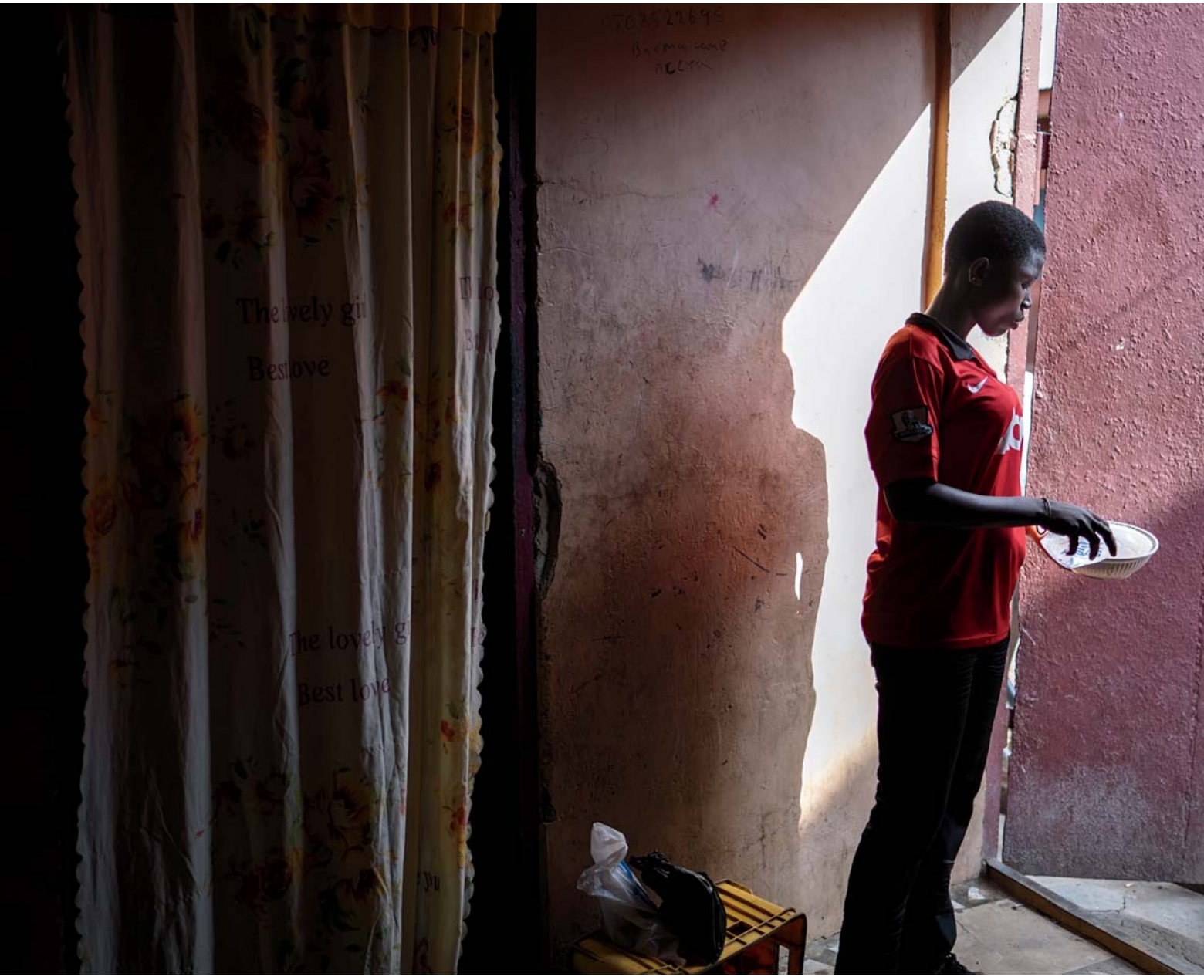
But do you share it with your boyfriend?
Yes…I can share it with him.

Why?
Because I trust him.

—*AN IV DRUG USER IN KUMASI, GHANA*

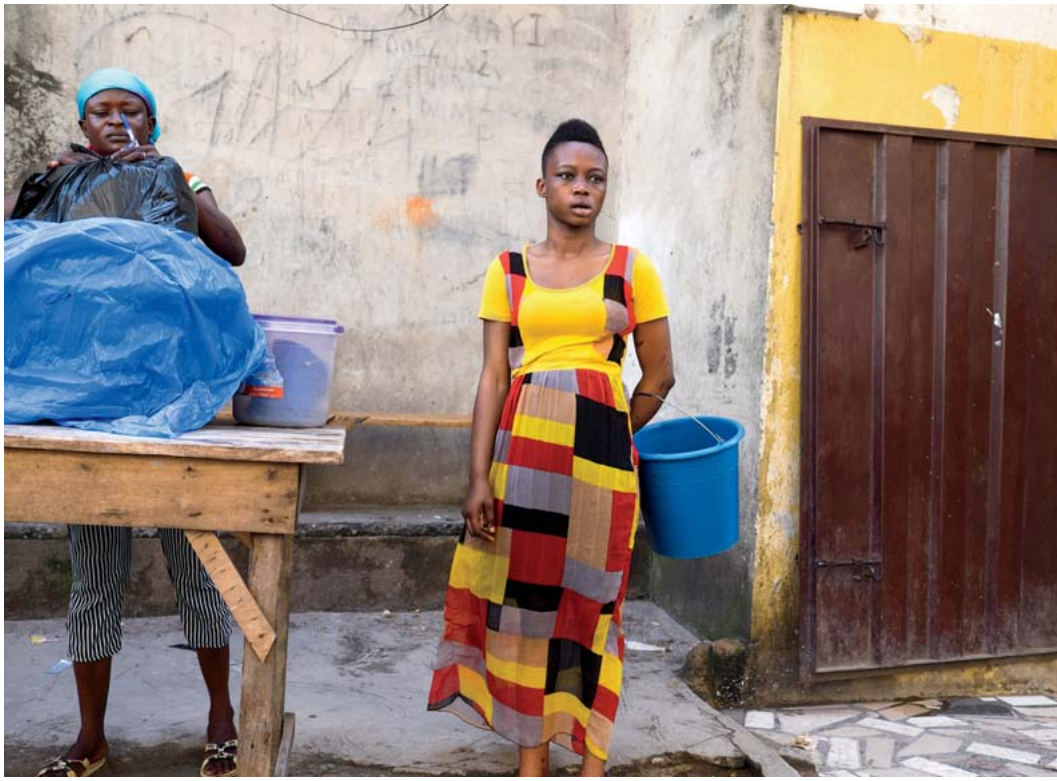
What Big Data Won't Tell You

A SERIES OF SMALL STUDIES IN GHANA MAY SPARK BIG CHANGES IN THAT COUNTRY'S RESPONSE TO HIV / BY SUSAN SELIGSON



Among a wider population of Kumasi's young women, the researchers learned, sex is currency, if not a livelihood. It is not considered prostitution for young women, bar workers, or university students to trade sex for money or favors.

PHOTOGRAPH BY NANA KOFI ACQUAH



The Asafo ghetto is a few yards and a world apart from the boulevards lined with appliance and furniture shops. Here, a pulsating world unfolds among tumbledown hovels, and much of what's for sale isn't legal.

THE SCIENCE OF GLOBAL health is propelled by statistics. The larger a research study's sample size, the more accurately researchers can map trends in health issues from infant mortality to the spread of HIV. But it's not always about the numbers. That's what Jennifer Beard, a School of Public Health assistant professor of global health and a principal investigator in the BU Center for Global Health & Development (CGHD), found when she and several University colleagues teamed with leading HIV scientists from Ghana's Kwame Nkrumah University of Science and Technology (KNUST) to conduct a series of small-scale qualitative studies of high-risk populations in the city of Kumasi. Boston University global health researchers, internationally respected for their HIV assessments in Kenya, South Africa, and Vietnam, are now helping Ghana point its HIV treatment and prevention in new directions.

On a torpid June afternoon, KNUST field coordinator Rose Adjei, researcher Francis Gaisie-Essuman, and Beard (SPH'06) pile into Adjei's SUV and head to Kumasi's main taxi stand to collect two community insiders, who have offered to guide them into the Asafo ghetto for an up-close look at the difficult daily living conditions there. A warren of fetid alleyways, the ghetto is a few yards and a world apart from the nearby boulevards, with their appliance, furniture, and fabric shops and the sprawl of what is reputed to be the largest open-air market in West Africa. Here, a pulsating world unfolds among the tumbledown hovels, and much of what's for sale isn't legal. Girls in their teens laze despondently at the doors of nondescript brothels, waiting to lead customers to mattresses in bare, gloomy chambers separated by bedsheets emblazoned with kittens and hearts. Outside, drug users lie splayed over benches as toddlers dart about, their mothers dredging laundry or pounding *fufu*, the Ghanaian cassava staple, babies at their breasts.

IF YOU TAKE THE DRUG, it doesn't even come to your mind to use condoms.—FEMALE INJECTION DRUG USER

Recruited through a chain of acquaintances of acquaintances, the study participants agreed to meet interviewers outside the ghetto in locations considered safe, where one interviewer poses questions and the second takes meticulous notes. "It was all about building trust," says KNUST coinvestigator Thomas Agyarko-Poku. "We had to ask open-ended questions, we had to probe. We had to ask the interviewees, what do you mean?"

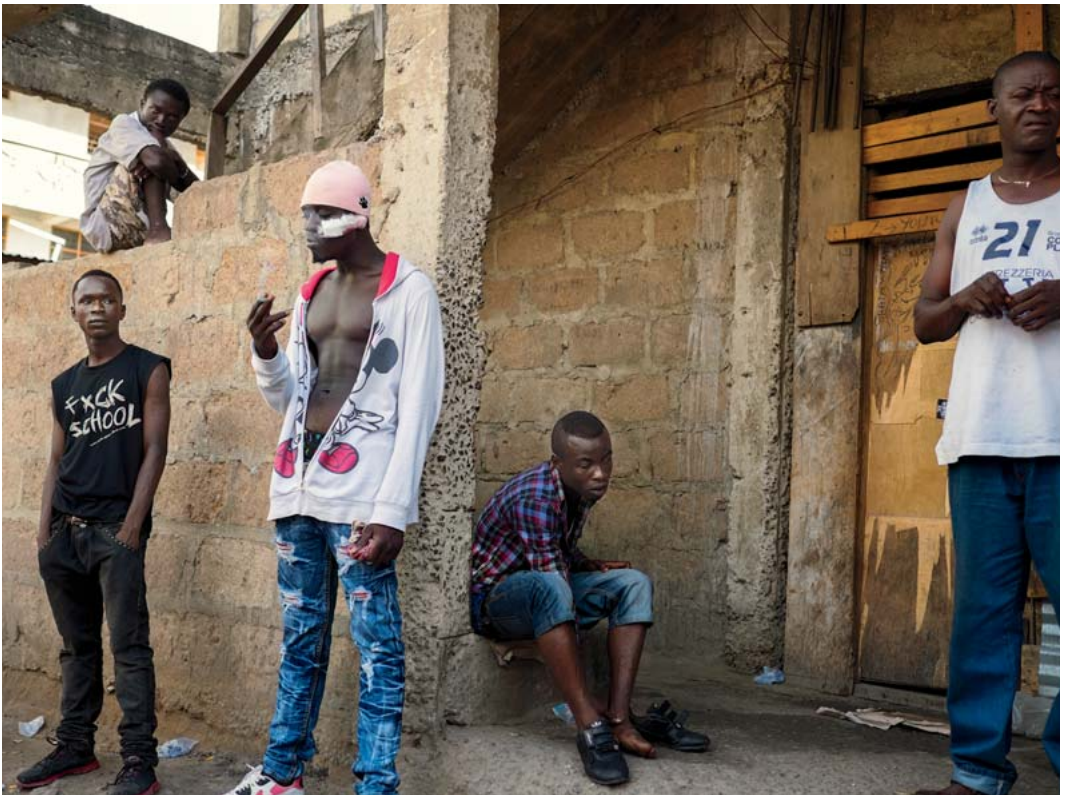
Each interview was conducted by two trained interviewers fluent in both English and Twi, the dominant language of the Ashanti, who make up much of Ghana's population. After the interviews and field notes were transcribed from Twi, which is not a commonly written language, to English, the researchers checked them word by word for accuracy and completeness, then proceeded to painstakingly code and analyze the results, which included information from HIV status and birthplace to lifestyle and health care access.

THE GOAL: AN HIV RATE OF ZERO NEW INFECTIONS

While Swaziland, Namibia, and South Africa are plagued by a prevalence of HIV infection among adults of 26.5 percent, 13.3 percent, and 17.9 percent, respectively, in Ghana the prevalence of HIV overall is 1.4 percent, according to the World Health Organization. After a slow start, Ghana has made great strides in the last decade in combating the spread of HIV, says Beard, who co-led the studies, conducted jointly by the team of Ghanaian researchers and a repertory of SPH faculty and graduates, including Lisa Messersmith, an associate professor of global health; Lora Sabin, who was the technical lead researcher on three of the studies; Monica Onyango (SPH'99), who worked with Beard on several studies; and Monita Baba Djara (SPH'13), an SPH instructor based at Management Sciences for Health, a global nonprofit organization.

Ghana has rapidly scaled up antiretroviral therapy (ART), a cocktail of drugs that controls the spread of the virus and protects the immune system, since 2005. By 2011, 150 health

IN 2013 there were nearly 225,000 people living with HIV in Ghana and about 10,000 AIDS-related deaths.



facilities were providing ART to more than 60,000 people, an increase from fewer than 5,000 just six years earlier, with 70 to 80 percent still in treatment after one year. Still, the most recent data, for 2013, show there were nearly 225,000 people living with HIV in Ghana, about 8,000 reported new infections, and about 10,000 AIDS-related deaths, down from 12,000 the previous year, according to the Ghana AIDS Commission. The commission reports a higher-than-average prevalence in Kumasi and southern Ashanti region, the focus of Beard's research.

The Ghana AIDS Commission has set a lofty goal of getting the HIV rate down to zero new infections by 2015, and it hopes to address the needs of high-risk groups through prevention, testing, and treatment. But as of mid-2014, while prevention and counseling services to sex workers and men who have sex with men (MSM) were on the rise—a result of programs funded by the United States Agency for International Development (USAID)—their infection rate continued to climb. And IV drug users, at very high risk, were getting no services at all. HIV prevalence among female sex workers is 11 percent nationwide and 13 percent in Kumasi. Prevalence among MSM is 18 percent in Ghana, 14 percent in Kumasi, and 33 percent in greater Accra, Ghana's capital.

"Africa has been like an ostrich," says co–principal investigator Yaw "Sax" Adu-Sarkodie, a professor of clinical microbiology and dean of KNUST School of Medical Sciences. "The bottom line," says Agyarko-Poku, HIV coordinator for the Ashanti region and executive director of the Ashanti king's charitable foundation, "is the Ghana Health Service—the largest provider in Ghana—isn't providing for these people."

THE SEARCH FOR MEANING, NOT MAGNITUDE

In 2010, the Ghana AIDS Commission agreed that further study was necessary to understand the behaviors and needs of the uncounted, and often uncountable, at-risk groups that dwell at society's margins: sex workers, bar girls, drug injectors (referred to as an "invisible population") and their partners, and destitute migrants belonging to these categories who are unable to buy into Ghana's national health system and end up having to pay as they go.

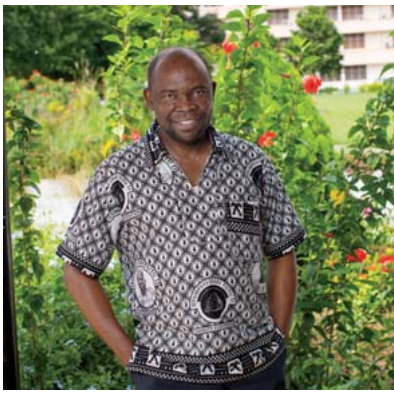
Four years ago, the BU/KNUST team received an $800,000 grant from USAID to conduct nine qualitative studies of key at-risk populations—a mandate to record the "real-life experiences" of these people, says Messersmith. For each study, done in collaboration with USAID and the Ghana AIDS Commission, the researchers sat down with individuals or small groups, 100 or fewer subjects in all, to learn about their behaviors, social and economic status, urgent needs, and challenges.

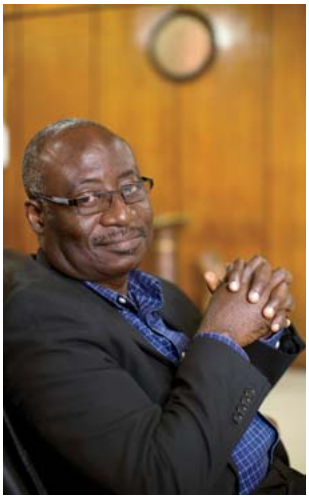
The studies looked separately at female sex workers who are "seaters"—older women with roofs over their heads and established clienteles—and the much younger "roamers." (The seaters have higher HIV infection rates, which could be due to more years of high-risk behavior.) They also looked at IV drug injectors who sleep on the streets and pay for heroin or cocaine with money earned wrangling lorry passengers at the bus depot, selling what's left of their belongings, begging, conning, filching, or resorting to armed robbery.

The researchers learned some surprising things. They found that drug injectors do not consider using the same needles as their intimate partners to be "sharing." Nor did they consider it to be needle sharing or reusing when they rummaged for used needles in the dumpsters behind hospitals. They also learned that some female sex workers were buying and selling attractive boys as their protectors, a counterintuitive turn on the notion

WE USE CONDOMS with our clients so there is no way we can use condoms with our intimate partners too. We have unprotected sex with them.
—FEMALE SEX WORKER

PHOTOGRAPHS BY NANA KOFI ACQUAH





The School of Public Health team (top left, clockwise from left): Jennifer Beard (SPH'06), program manager Ariel Falconer (SPH'15), Lisa Messersmith, coinvestigator Lora Sabin, and research fellow Paul Ashigbie (SPH'17); KNUST coinvestigator Thomas Agyarko-Poku (top right); and co–principal investigator Yaw "Sax" Adu-Sarkodie (right).

of pimps, and that while female sex workers were frequently subjected to male violence, they were sometimes physically abusive as well.

Among a wider population of Kumasi's young women, the researchers learned, sex is currency, if not a livelihood. It is not considered prostitution for young women, bar workers, or university students to trade sex for money or favors. And these women, the researchers say, are particularly vulnerable, accounting for 64 percent of new infections among those age 15 to 24.

In the BU/KNUST team's study of female bar workers, 12 of 24 male patrons reported engaging in "transactional" sex with the bar workers, who earn 100 cedis (US $27) or less a month. But the bar workers considered the sex they have with customers different from the sex offered by the roamers who visit the bars to pick up clients. And while a majority of the bar girls were aware that having transactional sex makes them vulnerable to HIV, some believed they were at no more risk than other young women and that they would not become infected if their partners were faithful to them.

The team also studied the prevention needs of female university students between the ages of 20 and 29 who trade sex, usually with financially stable older men, for material goods. Sex in exchange for gifts, phones, clothing, shoes, housing, school fees and uniforms, even food, was perceived to be common and considered a social norm.

I INJECTED THE DRUGS because my boyfriend taught me because he injects it. We used the same needle because he used it first and after he gave it to me. I got interested because he does it always and any time he injects the drugs he usually felt sleepy, so one day I told him I wanted to try it and since then I have not stopped injecting drugs.—INJECTION DRUG USER

"The study participants reported feeling pressured to keep up their physical appearance and became involved in transactional sex to improve their social status," wrote the researchers. In terms of HIV vulnerability, the findings were concerning. "Female students often forego using condoms when seeking something material in return for sex," according to the researchers, and, like actual sex workers, "some said that higher monetary value is placed on unprotected sex as compared to sex with a condom."

One of the virtues of the qualitative study model is that it can be done in a timely way. When the interviewers learned that many female sex workers had boyfriends they considered to be their protectors and intimate life partners, they were able to locate and question these men. Though condom use in the group has been studied before, the BU/KNUST study was different "because it set out to really understand more clearly who these men are and what these relationships are like," says Beard. "We were motivated to understand HIV vulnerability, but we also wanted to know about things like shared support, violence, and power dynamics."

In interviews and focus groups of 24 so-called intimate partners of female sex workers, some of roamers, some of seaters, the researchers learned the men fell into distinct categories: area boys—around and providing assistance but not sexually involved; or fresh or steady boys—in sexual relationships with female sex workers. "My partner only operates in the evening; therefore during the day we make time to be with each other," one subject said. Of the sex workers with boyfriends, slightly more than half said they never used condoms with their nonpaying partners.

Of the nine studies conducted, the IV drug injector study proved most surprising. It involved in-depth interviews with 20 men and 10 women, and focus groups of 16 people whose average duration of drug use was more than 10 years. Except for one woman who had a home, the subjects told the researchers they slept outside in the ghetto, in front of kiosks or shops, and spent all of their earnings on cocaine and heroin. And though new needles are available cheaply at pharmacies,

MANY DRUG injectors pleaded with the researchers to get them help quitting their habits.

most feared the scrutiny they faced there and reported they foraged for needles and syringes in hospital refuse and reused those needles. In addition, many of the drug injectors pleaded with the researchers to get them help quitting their habits; rehabilitation services in Kumasi are mostly faith-based, aimed at rescuing wayward souls.

RESPONSES REVEAL NUANCES

The results of the research, headed by the BU team, the Ghanaian researchers, and a large Ghanaian field team, under the umbrella "Operations Research among Key Populations in Kumasi," are aimed at helping the Ghana AIDS Commission and affiliated nongovernmental organizations (NGOs), such as Strengthening HIV/AIDS Response Partnership with Evidenced-Based Results (SHARPER), better serve the nine key groups studied.

The data were presented, starting last May, to the Ghana AIDS Commission and the representatives of the US Centers for Disease Control and Prevention, along with police, narcotics control agencies, the Ghana Health Service, and others.

"We're trying to spread the word about the drug injector study" in hopes that Ghana will consider needle exchange and methadone programs, which don't exist now, says Beard, who joined the team in a presentation at the third National HIV/AIDS Research Conference sponsored by the Ghana AIDS Commission in September 2013.

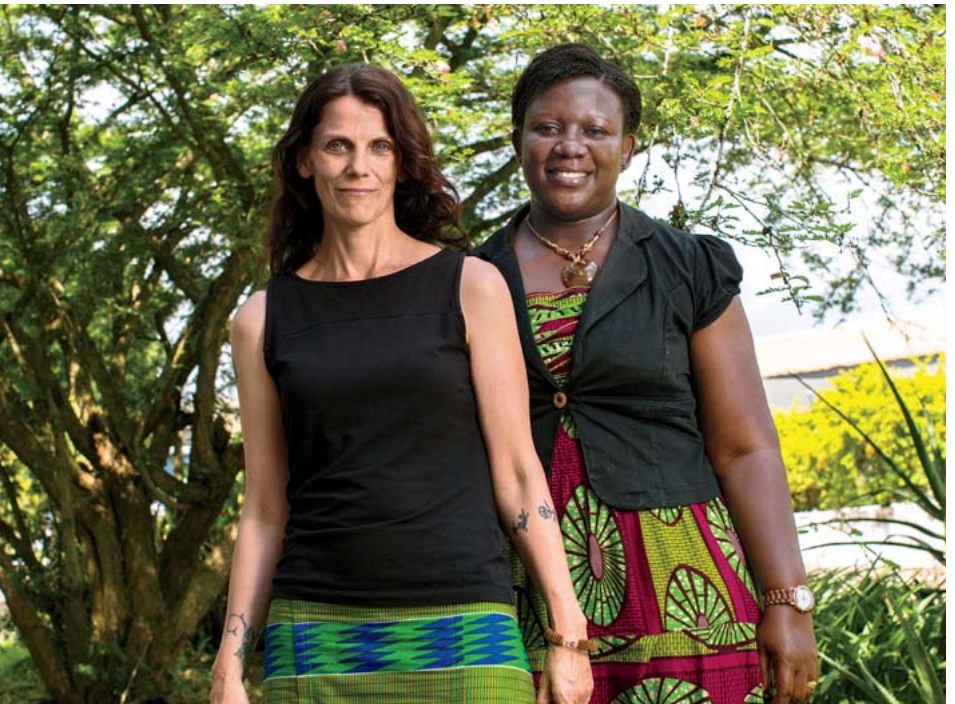
In many ways, the team's findings are already making a difference, says Kimberly Green, Ghana country director and chief of party of the SHARPER project. For one thing, the BU/KNUST study of young female sex workers "helped us to develop an intervention specifically for this population, including peer education" focused on improving knowledge of HIV prevention and sexual and reproductive health, says Green. While her NGO had focused mostly on HIV prevention among young MSM, the key populations study of older MSM inspired SHARPER to use social media to reach these men as well. And the BU/KNUST team's small study of younger MSM raised "issues we were not addressing in our prevention program—issues like self-esteem, mental health, and drug and alcohol abuse," Green says. "We developed specific peer education training on these issues, which were very well received among young men who have sex with men." She adds that one of the participants said, "For the first time, I learned that I could feel good about myself and that I could be respected."

I MET MY FRESH BOY in a nightclub. He looked handsome, so I liked him. I inquired about him from a friend who told me he had a girlfriend who was also a sex worker. We met with the girlfriend to negotiate with her to allow me to have him as my boyfriend. She agreed and I had to pay her 3,500 Ghanaian cedis (US $943) on the backdrop that she has spent a lot on my fresh boy.—FEMALE SEX WORKER

Revealing as they can be, qualitative studies have notable drawbacks. "We have this really good data, with a lot of people paying attention to it," says Beard. "But we don't have magnitude." In their presentation to the Ghana AIDS Commission, the researchers describe "tension between doing studies that are short and sharp and the desire to talk to more people and ask more questions." And as with anthropological research, the data are not generalizable; they are "specific only to that population at that time," says Beard. But, she adds, "we can use qualitative data to hypothesize that our findings are also applicable in Accra or Cape Coast," another Ghanaian city. The key here, she says, "is that qualitative research helps us to understand better what questions to ask and how to word them when doing quantitative research, and it also helps us to understand the nuances underlying the numbers."

The study results will trigger new thinking among Ghanaian clinicians and researchers. For example, the term "sharing needles" is used globally in public health surveys, but subjects can interpret it in different ways, the researchers found. "The language around public health is our own language, which ends up going into these large surveys: Have you ever shared needles?" Larger studies couldn't do "the sort of probing that was our whole purpose," says Beard. In fact, the BU/KNUST study, by virtue of its intimacy, provided information big data could not.

"What's great about these studies is that they not only inform program and policy issues but the development of questionnaires that are valid," says Messersmith. "So surveys that actually get at what you are trying to measure get it right. Among drug injectors, for example, an HIV epidemic can go from zero to 75 percent in a couple of years, so if you don't get to it soon, then it can be devastating. We can't wait. It's not ethical to wait." ■



"We're trying to spread the word about the drug injector study," says Beard (left), with KNUST field coordinator Rose Adjei.

NANA KOFI ACQUAH (BELOW AND FACING PAGE, TOP RIGHT AND BOTTOM); CYDNEY SCOTT (FACING PAGE, TOP LEFT)