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## Scrambling for Africa

Johanna Tayloe Crane

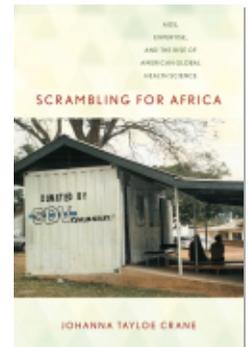
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## Chapter 4

# RESEARCH AND DEVELOPMENT

The years between 2005 and 2009 were marked by massive changes at the Immune Wellness Clinic in Mbarara, wrought by the simultaneous scaling-up of free HIV treatment programs and the rapid growth of an international research presence. Patient enrollment at the clinic nearly doubled following the arrival of free antiretrovirals via PEPFAR and the Global Fund, and by 2009 there were over 7,000 patients receiving regular care, over 5,000 of whom were on ARVs. In addition, the clinic's staff—not only doctors, but nurses, counselors, and laboratory workers—also grew, as did the space occupied by the clinic. This expansion was funded almost entirely by PEPFAR, the larger and wealthier of the two aid programs. In addition to providing free antiretrovirals for nearly 4,000 patients, PEPFAR money also paid for CD4 and viral load testing, drugs for opportunistic infections, salaries for most of the new clinic staff, computers for record keeping and data collection, and a large two-story building, opened in 2006, that became the clinic's new home.

Beale's research presence in Mbarara expanded in tandem with the clinic, outgrowing its original quarters in the renovated shipping container to occupy several spaces around the medical campus, including a small, three-room office building that the research project built for itself. By 2009, in addition to the flagship HIV treatment study, there were nine smaller studies in Mbarara being overseen by Beale or his colleagues. All told, these internationally-funded studies employed nearly seventy people and enrolled over 500 patients. In the small building housing Eve Ozobia's office, a former conference room had been converted to office space shared by three full-time data staff and one soft-spoken college student, who had been hired part-time to run the study's completed surveys through a data scanner, transmitting the information back to the United States. Beale's project had also taken over another larger office building just up the road. Formerly occupied by the local chapter of The AIDS Support Organization (TASO, which had moved to a new building), it now housed several project administrators, a laboratory coordinator, and a host of research assistants. In addition, Beale's grants had paid for the expansion of a building adjacent to the clinic, where his and other studies shared a collection of small rooms that were used for both blood collection and interviewing. A short distance from the clinic and university campus, the global health program at Beale's university was renting and refurbishing a guest house where its faculty, graduate students, and program donors could stay when visiting the Mbarara research site.

Thus, the simultaneous scaling-up of both PEPFAR and Beale's research endeavors significantly impacted not just patient care but also physical and technological infrastructure, employment opportunities, administration, laboratory procedures, and record keeping at the Wellness Clinic. The treatment programs were humanitarian in nature, in that they provided medical assistance aimed at saving lives in an epidemic that was seen as having reached emergency proportions in Africa. Beale's research program was scientific in intent. But the simultaneity of their growth and the fact that they were both characterized by a large influx of American dollars sometimes made them difficult to distinguish from one another on the ground, blurring perceptions of what constituted scientific versus humanitarian activity. The distinction between aid and science was further confused by the fact that PEPFAR required a significant amount of clinical data collection

(for accountability purposes) and that both Beale and some of his Ugandan collaborators envisioned his research projects as helping the clinic by both enhancing patient care and building local infrastructure.

In this chapter, I chronicle the transformation of the Immune Wellness Clinic into a site of global HIV research, paying particular attention to the entanglement of scientific activities with medical humanitarianism and economic development. The awkward relationship between science, aid, and development is, I argue, a defining characteristic of global health research. It is also what makes global health an inherently postcolonial endeavor. Since the waning of the colonial era in the second half of the twentieth century, relations between African nations and “the West” have been increasingly defined by the politics of aid and development, in which North American and European countries serve as “donors” to impoverished, formerly colonized “client” nations (Ferguson 1994).<sup>1</sup> For example, in Uganda, nearly half of the national budget is funded by foreign aid (Mwenda 2005). Currently, Ugandans receive biomedical care through a patchwork of government services, private providers (including pharmacists and injectionists), and local and international nongovernmental organizations and charities (Whyte 1991, 1992; Birungi 1998; Mogensen 2005). The HIV epidemic emerged in the context of this patchwork, giving rise not only to an unprecedented, disease-specific international aid response, but also to transnational scientific inquiry previously unmatched in scope and scale. This was academic science, aimed at producing not only useful interventions to fight the epidemic but also conference presentations, journal publications, and grant renewals from bodies like the National Institutes of Health. But as anthropologists and others have described, the value of transnational medical research in Africa often lies as much in its social benefits as in its scientific findings (Kelly and Geissler 2011; Whyte 2011; Kelly 2011; Lairumbi et al. 2012). In Uganda, this foreign-funded research often provided a level of care unavailable from the public health sector—including some

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1. “Like ‘civilization’ in the nineteenth century, ‘development’ is the name not only for a value, but also for a dominant problematic or interpretive grid through which the impoverished regions of the world are known to us” (Ferguson 1994, xiii). It is worth noting that in recent years China has also emerged as a powerful donor in Africa, to the consternation of U.S. and U.K. authorities (McGreal 2007).

of the earliest access to free antiretroviral drugs on the continent (Whyte et al. 2004). Thus, it is perhaps not surprising that these scientific endeavors would be imagined both as a form of medical humanitarianism and, with the funding of new research and health care institutions, a form of economic development.

Existing anthropological work on postcolonial science highlights how the relationships of exchange that characterize any scientific endeavor—exchange of tissue or botanical samples, of blood, of data, of technology and results—are inevitably shaped by the inequalities of the present as well as “haunted” by those of the colonial past (Lowe 2006, 42). In other words, in a postcolonial context, the power dynamics and hierarchies of “normal science” take on additional meaning and complexity, since they are inevitably infused with the politics of national autonomy, “Western” political and economic hegemony, and (often) race. This chapter builds on this work with the aim of understanding how the rise of global health science—and particularly the U.S. AIDS research community’s “turn toward Africa”—is impacting doctors and researchers in Uganda, a country in which AIDS has wrought both intense suffering and an unprecedented rush of international resources and economic opportunities.

In Mbarara, the Ugandan doctors and research staff I encountered were ambivalent about the transformation of their semirural HIV clinic into a site of global health science, and they alternately described international money as “opening Uganda’s doors” and “killing our health system.” Though contradictory, both are fair assessments of the positive and negative impact of the recent influx of (mostly) American dollars into the Ugandan health care sector. In the first part of this chapter, I describe Dr. Beale’s creation and “donation” of an electronic patient database to the clinic, and explore how the overlap of scientific and charitable intentions fed into disagreements over ownership of the database and whose interests it served. In the second part of the chapter, I focus on the perspectives of Mbarara clinicians and aspiring researchers, who alternately expressed both gratitude and resentment over the presence of international science—including my own ethnographic research—and aid. Overall, I argue that the entanglement of research with development makes it especially difficult for U.S. and Ugandan physicians and researchers to forge the kind of equitable scientific collaborations to which they all aspire.

## **Dr. Atuhaire's Register**

Dr. John Atuhaire became interested in medicine at a young age. While in secondary school, he so excelled in biology that his father jokingly began addressing him as “doctor.” Later, he would serve as a student health prefect at his boarding school, dispensing medications and transporting students to the hospital during the evenings and weekends when the school nurse was not in. During his last years of high school, Dr. Atuhaire lost his father to AIDS. Nonetheless, his father’s nickname for him proved prescient, and upon graduating Atuhaire would win a government scholarship to study medicine at MUST.<sup>2</sup> By this time, his mother was also suffering from the disease. It was the late 1990s, and the discovery of effective antiretroviral therapy had already begun to transform the life expectancies of AIDS patients in wealthy countries. Atuhaire knew this, and despite the astronomical cost of the medications, he hoped that by becoming a doctor he might be able to help his mother. “I had a big desire that I would become a doctor, make some money, and be able to start treating her myself. Be able to buy her antiretroviral drugs and be able to give her the medical assistance that she would have loved to find,” he told me in 2004. Tragically, she died just three years after his father’s passing, and two years before he finished medical school. “She died before I finished, before I became a doctor,” he told me. “So I couldn’t do much.” Even if Atuhaire had been able to complete his training before his mother died, it is unlikely that he would have been able to afford to buy her antiretroviral medications on the low pay public sector doctors in Uganda earn. Atuhaire was well aware of this, but he still wanted to try.<sup>3</sup>

The loss of both his parents to AIDS further fueled Atuhaire’s affinity for medicine, and drew him toward work caring for other patients with AIDS. During his one-year clinical internship Atuhaire began rotating through the Immune Wellness Clinic, which Dr. Salter had founded only a couple of years earlier, where he began treating HIV patients. He got along well with

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2. In Uganda medicine is offered as an undergraduate degree, similarly to the British system.

3. Atuhaire told me that in 1998 a month’s worth of antiretroviral medications cost 500,000 Ugandan shillings, or the equivalent of roughly US\$250. This was equal to a full month’s salary for a medical officer working in the public sector (Matsiko and Kiwanuka 2003).

Salter, and found he excelled at the work. He found that the loss of his parents made him particularly well suited to being an HIV doctor:

So I basically I know what an HIV patient goes through. Because I have seen my parents go through it. And I think what I should have done for my parents, I should be able now to give it to others who deserve it. That's one of the things that makes me feel comfortable and like the job which I am doing. Because I don't have my parents now, but I'm doing what I should have done today to other people who are having this same problem.

Upon completing his internship, Dr. Salter encouraged him to come and work at the clinic. Although there was no salaried job available at the time of Atuhaire's graduation, there was word that a position would likely be posted soon, so he agreed to work on a volunteer basis until a paid position opened up. At that time, the clinic operated only on Wednesdays and Fridays. Atuhaire made ends meet by working for pay in private clinics during evenings and on days when he was not volunteering. After three months as a volunteer, he applied and was hired to work in the clinic full time. Simultaneously, the clinic expanded its hours to stay open five days a week.

By this time, it was early 2003, and although free antiretrovirals had not arrived yet, generic HIV drugs from India were increasingly available in Uganda. Those whose families could afford the pills began buying them, and the number of Atuhaire's patients on ARVs steadily increased. In addition, the clinic's overall patient load grew rapidly as the possibility of treatment and the expanded clinic hours drew more people to seek care. As the clinic's first full-time employee, Atuhaire identified the need for a systematic way to keep track of the growing number of patients on antiretrovirals. "When I came to the clinic, there was nobody who was officially assigned to take care of the clinic," he told me. "So there was nobody who was like organizing the clinic data. People would just come in and see patients and write in the file and throw the file somewhere. And that was all."

When the Ministry of Health questioned him about the number of patients receiving antiretroviral therapy at the Wellness Clinic, Atuhaire was frustrated with his inability to answer precisely:

For instance, somebody would come and say, "How many patients did you have on antiretroviral drugs?" And none of us would answer! Someone would

say, “maybe like a hundred?” I would say, “maybe like fifty?” We had patients on ARVs but nobody would go through the files to dig out the information, store it somewhere, ready it for analysis so that you can easily answer certain questions of what services we are providing, whom we are providing care for. . . . I said, how can we be providing care to a cohort of patients which is increasing every day but we have no information that we can analyze?

As a result, Dr. Atuhaire took it upon himself to start a “small register”—essentially a handwritten ledger book—in which he recorded basic information about all the clinic’s patients on antiretroviral therapy. In his entries he included a patient’s name, medical record number, address, sex, medications, and the date he or she started antiretrovirals. Using the register as a reference, he could now respond accurately to questions about the clinic’s services. He recounted to me:

So if somebody would come to me and say, “What drugs are you offering?” then I would quickly go to that register and look through and say, “We have so many, maybe twenty patients, on Triomune; we have ten patients on [the antiretroviral] efavirenz; we have a group of maybe twenty patients who started ARVs two years ago.” . . . We were able to know how many patients we have, know what kind of medications that they’re taking, know how many females, know how many males.

A few months after Dr. Atuhaire began keeping the register, he attended an HIV-medicine training program at the IDI in Kampala, where he made Dr. Beale’s acquaintance. By this time, Beale was searching for a less urban location where he could relocate his Kampala-based study of ARV treatment and drug resistance. He began asking questions about patients on antiretroviral treatment at the Wellness Clinic, and Dr. Atuhaire brought out his register to show him the numbers. Beale was impressed, and immediately recognized the research value of the information. He also saw how the burden of record keeping could easily get out of hand for Atuhaire as the clinic’s enrollment continued to grow. After making a trip to Mbarara to visit the clinic and meet Dr. Salter and the other medical faculty, Beale proposed a research collaboration. He would relocate his study to Mbarara, using patients at the Immune Wellness Clinic as his study subjects. As a part of the proposal, he offered to create a computerized patient database and donate

it to the clinic with the intention of simultaneously improving patient care and collecting valuable research data.

## Donation

Through Atuhaire and Beale's efforts, the clinic's medical records underwent a transformation from clinical files into scientific data. Through this process, the clinic itself was remade into a site of global health research. For Atuhaire, who, unlike Beale, was a full-time practicing clinician with no previous background in research,<sup>4</sup> this transformation seemed to reframe his reflections on the original clinic register he had created. For example, when we spoke in 2004, after the computerized database was initiated, he described his efforts not in terms of a "register" but as "an automated system of saving the data" using a handwritten "spreadsheet" that he described by referencing the Excel software used for the computerized database:

I came to the clinic, and I took it upon myself that we should now have an automated system of saving the data. We did not have an electronic database, but I designed kind of like, um, an Excel spreadsheet. And then made photocopies of that Excel spreadsheet. And I started recording all the data that patients had in their files.

This shift from medical records to clinic data was not the only transformation wrought by the introduction of the electronic database. In addition, the database worked to reconfigure the ownership of the information collected within it by making Beale's American research team, as the database's creators, claimants to the clinic's records.

As the database grew, its value as a research tool became increasingly obvious to both the Americans and the Ugandan physician-researchers and university administrators at Mbarara medical school. Not only was the database critical to securing scientific grants to support Beale's ongoing research, but it also served to attract new international research projects to the Wellness Clinic. These projects were highly valued by both the clinic and

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4. Beale was also a clinician, but by this time his clinical practice was very small, and he spent the majority of his time working on research projects.

the university administration because of the resources they brought. These resources included both clinically useful technological infrastructure like machines to measure CD4 counts and viral loads, as well as other benefits such as new well-paid jobs, scientific opportunities for local researchers, prestigious affiliation with well-known foreign research universities, and eventually new clinic buildings and facilities.

Given the benefits and material resources that the U.S.-funded research project brought to the cash-strapped clinic, it is not surprising that Beale's group envisioned their research in both scientific *and* charitable terms. In the words of Eve Ozobia, "We had a research agenda and we had a philanthropic agenda." The electronic database was born out of the research agenda; it was crucial to making the Wellness Clinic a feasible American research site that could both garner grant support from funding organizations like the NIH and produce data suited for publication in top scholarly journals. But the group also had a genuine desire to help the clinic, and they met this philanthropic agenda by giving the database to the clinic as a "donation," one that they perceived would benefit patient care.

When we discussed the database in retrospect in 2009, Ozobia described its early development as "very informal." It was initially drafted by one of Beale's American medical students and developed on a shoestring budget because at the time Beale did not yet have funding to support the project. The student traveled to Mbarara for three weeks and created a simple patient database on his personal laptop, which he then donated (laptop included) to the Wellness Clinic. As Ozobia described it to me, "It was a very casual conversation. 'Oh,' you know, 'we can do this.' 'By the way, we can leave our laptop.' 'By the way, we have a medical student who can do this for three weeks.' 'By the way, we have data management support that can come and help.'"<sup>5</sup> Over time, clinic enrollment grew, and the database became increasingly formalized and detailed. Data management staff from Beale's team in San Francisco traveled back and forth between California and Uganda, working closely with Andrew Byaruhanga, Beale's data manager in Mbarara, to upgrade the system. The arrival of free antiretrovirals in late 2004 caused the number of patients enrolled at the clinic to skyrocket. In

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5. Marissa Mika (2009) describes a similar informality in her analysis of collaborations between American researchers and the Uganda Cancer Institute in the early 1970s.

Ozobia's words, "Once PEPFAR funds became available and treatment became available, the clinic went from being a 1,000-person clinic to several thousand, overnight." This growth in numbers increased the research value of both the clinic and its database, and Dr. Beale's success began to pique the interest of other international researchers interested in working in Mbarara. The database became an indispensable research tool and the key-stone of several successful grant applications.

As Beale's research project director, Ozobia occupied a unique position. She lived in Mbarara and served as the principal interlocutor between Beale and his Ugandan collaborators at the clinic and university. Her personal and family roots in both the United States and Africa proved to be an asset in this role as liaison. But she told me that her identity as both "African" and "American" was also stressful at times when tensions arose between the Americans and Ugandans, as they eventually did over the clinic database. Trouble began to brew in 2005 when two teams of foreign researchers, one American and one Swiss, approached the Immune Wellness Clinic about collaborating. By this time, the clinic and the Department of Internal Medicine were headed by a young Ugandan physician named Iris Akiki. Beale became concerned when the outside researchers approached Akiki but not himself about use of the clinic data. Given that the cost of the database and its upkeep (which had grown considerably with the size of the clinic) were largely paid for by Beale's grant money, his feelings of ownership were not unreasonable. In fact, they were completely normal—even expected—within the parameters of U.S. science, where it is taken for granted that research funding and data ownership go together. However, as Ozobia would remind him, the database had been initiated as a "donation" to the clinic, and, as such, the clinic owned it.

Yet, because of the informal nature in which the database had been initiated, there was no official paperwork documenting its ownership status. In addition, it seems likely that Beale and Akiki had become entangled in the social and affective expectations of reciprocity that often come with gifts, even those framed as development projects or humanitarian donations (Hodžić 2006; Bornstein 2010). In other words, Beale may have unconsciously expected that Akiki would reciprocate his gift of the database by gifting him control over its data in return. Akiki, for her part, had already given Beale something in granting him research access to the clinic's valuable patient cohort, and likely resented his moves to assert scientific ownership

over a clinic she directed—especially since she, too, had research aspirations of her own.

In Ozobia's view, the informal way in which the database was first proposed and developed reflected the unequal nature of the partnership between Beale and his Mbarara colleagues. Despite his good intentions, she argued, Beale's desire to "donate" to the Wellness Clinic was problematic in that it positioned his Ugandan collaborators as recipients of charity. Reflecting on the conflict to me, she asserted in what she called her "African voice:" "If you're giving me a handout, you don't see me as an equal." (Or perhaps, I thought, as a fellow scientist.) Had the collaboration been between Beale and an American colleague, she felt that rights to the database would have been explicitly negotiated from the start—something she did not hesitate to say to Beale directly. As a result, the parties involved had to retroactively work out a data-sharing agreement that would both respect the Ugandan clinic's ownership of its patient information and Beale's considerable financial and scientific investment in it. This agreement was eventually achieved, but the conflict engendered lingering feelings of wariness among the collaborators.

## **Compensation**

The conflict over the database was not limited to questions of ownership. In creating the database, the American researchers fundamentally changed the way that clinicians in the HIV clinic recorded patient visits. This was not simply a one-time change, but one that took several iterations as the database structure was refined and its software was updated. For Beale's team—including Andrew Byaruhanga, who as data manager oversaw the process on a daily basis—the transformation from what they perceived as haphazard handwritten clinical notes to orderly, standardized data collection was a source of pride. They developed a visually striking PowerPoint presentation detailing the shift from records written freehand on unlined paper to a computer-generated, research-quality "clinical encounter form," and this became an integral part of professional presentations given by Beale, Byaruhanga, and other colleagues about their work in Mbarara. In the presentation, images of patient medical records taken between 2005 (figure 4) and 2008 (figure 5) provided visual evidence for the transformation of clinical notes into research-quality data.

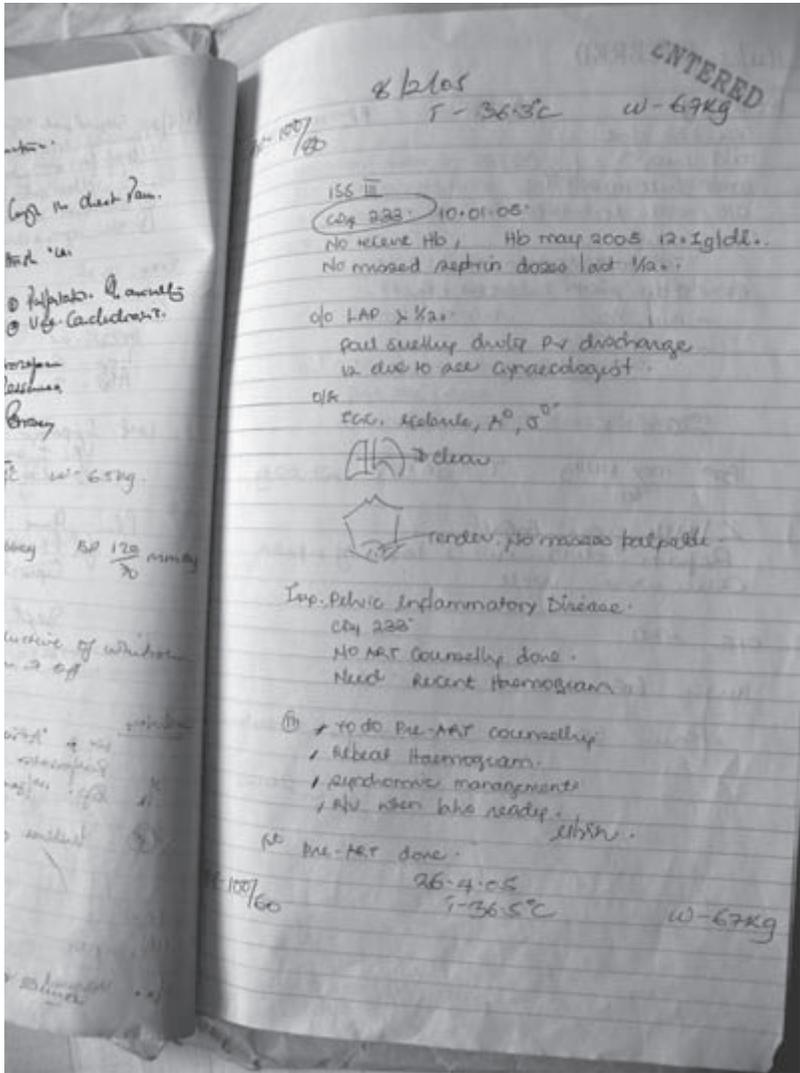


Figure 4: A page from the clinic's 2005 register. (Photo by Michael Kanyesigye.)

In the minds of the researchers, the standardization of medical record keeping necessitated by the database had obvious clinical benefits as well, providing clinicians with an organized, reliable, and current source of information on the patients under their care. This was, after all, why Dr. Atuhaire had begun keeping a register to begin with. In addition, it was through this framing of the database that researchers were able to see their work not only as science, but as a philanthropic venture that aided patient care in an under-resourced setting.

The views of many of the clinicians working within the Wellness Clinic were quite different. Their perspectives speak both to concerns about what turning patients into “data points” does to the work of caregiving (Adams 2010b), and to the social relations of postcolonial scientific collaboration. Although Atuhaire was the clinic’s only full-time clinician when the database project began in 2003, a few years later this was no longer the case. The explosion of clinic enrollment due to the arrival of free treatment programs had necessitated the hiring of several other full-time medical officers. In addition, medical faculty at the university rotated through the clinic on a monthly basis. Accustomed to simply recording their visit notes on a blank sheet of paper, some doctors found the increasingly detailed “encounter forms” designed by Beale’s data team a time-consuming annoyance.<sup>6</sup> By requiring them to complete highly structured standardized forms rather than write descriptive clinical notes, some doctors in Mbarara felt that the research project was asking them to do research work without compensating them for it. The explanation offered by the American researchers—that the project was in fact “helping them” provide care—did not sit well. Despite the researchers’ insistence on the clinical utility of the database, this was not how many of the clinicians initially viewed or experienced the project, which had been implemented with little input from them.

The main exception to this, of course, was Dr. Atuhaire, who served as the American researchers’ clinical consultant from the beginning and was also Beale’s local applicant to MUST’s Institutional Review Board—a

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6. Susan Reynolds Whyte argues that paper is an important mediator of relationships in Ugandan health care settings, and its use and exchange often enact relations of power (2011). Whyte focuses on the power distinction between care providers (“those who write”) and care recipients (“those who are written”), but her observation might also apply here to the relationship between “those who write” (clinicians) and those who “code” (researchers).

version May 08, 2008		ADULT RETURN VISIT FORM		Date of visit: / /	
Patient ID:		ART Number:			
Surname:		Other names:			
Treat category	<input type="checkbox"/> N/A <input type="checkbox"/> Widow	<input type="checkbox"/> Orphan Care taker <input type="checkbox"/> Spouse of poor woman	<input type="checkbox"/> Health worker <input type="checkbox"/> JCRC transfer	<input type="checkbox"/> Poor woman <input type="checkbox"/> Other	<input type="checkbox"/> Pregnant
Address/Phone Change? <input type="checkbox"/> No <input type="checkbox"/> Yes <i>If yes specify new address below</i>					
District:		Sub County/Division:		Parish/Ward:	
Village/LC1:		Phone number:		Landlord Name:	
Family planning (mark all that apply)	<input type="checkbox"/> N/A (not sexually active) <input type="checkbox"/> sterilization/hysterectomy <input type="checkbox"/> other:	<input type="checkbox"/> none <input type="checkbox"/> diaphragm/cervical cap	<input type="checkbox"/> condoms <input type="checkbox"/> IUD	<input type="checkbox"/> oral contraceptive pill <input type="checkbox"/> natural family / rhythm	<input type="checkbox"/> injectible hormones (Depo-provera, etc.)
Discordance Any sexual partners in the last 4 weeks known to be HIV-negative? <input type="checkbox"/> no <input type="checkbox"/> yes					
Health education today? (mark all that apply)	<input type="checkbox"/> none <input type="checkbox"/> ABC	<input type="checkbox"/> Prevention <input type="checkbox"/> Positive living	<input type="checkbox"/> Family planning <input type="checkbox"/> Disclosure	<input type="checkbox"/> pMTCT <input type="checkbox"/> VCT	<input type="checkbox"/> Discordance <input type="checkbox"/> Other
Women only:	Pregnant now? <input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> unknown	If yes: <b>No months:</b> _____			
	Are you in PMTCT? <input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> unknown	If yes: <b>Which ARVs?</b> <input type="checkbox"/> AZT <input type="checkbox"/> NVP <input type="checkbox"/> full therapy <input type="checkbox"/> unknown			
	Delivered since last visit? <input type="checkbox"/> no <input type="checkbox"/> yes → Date: / /	Feeding method: <input type="checkbox"/> breast <input type="checkbox"/> formula <input type="checkbox"/> both			
Has your Infant received NVP or AZT? <input type="checkbox"/> yes <input type="checkbox"/> no					
Vital signs:	weight[kg]:	BP: /	temp[°C]:	pulse:	resp rate:
Nurse's name :		Signature:			
CURRENT MEDICATIONS (defined as taken during last 7 days)					
ARV	<input type="checkbox"/> Not on ARV's				
<i>If patient was on ARV's since last visit but stopped, why?</i>					
Failure: <input type="checkbox"/> clinical failure <input type="checkbox"/> immunologic failure <input type="checkbox"/> virologic failure					
Toxicity: <input type="checkbox"/> anemia/neutropenia <input type="checkbox"/> nausea/vomiting <input type="checkbox"/> peripheral neuropathy <input type="checkbox"/> dizziness <input type="checkbox"/> sleep disturbance <input type="checkbox"/> lipodystrophy <input type="checkbox"/> diarrhoea <input type="checkbox"/> rash <input type="checkbox"/> liver tox					
Misc: <input type="checkbox"/> gave away meds <input type="checkbox"/> no money <input type="checkbox"/> no transport <input type="checkbox"/> felt meds no help <input type="checkbox"/> felt well enough to stop <input type="checkbox"/> poor adherence <input type="checkbox"/> pregnancy <input type="checkbox"/> stockout <input type="checkbox"/> new TB tx <input type="checkbox"/> finished pMTCT <input type="checkbox"/> Other, specify:					
<input type="checkbox"/> On ARV's (specify):					
<input type="checkbox"/> AZT (zidovudine)		<input type="checkbox"/> CBV (AZT/3TC)	<input type="checkbox"/> NVP (nevirapine)	<input type="checkbox"/> Atripla (DFI/FTC/EFV)	
<input type="checkbox"/> 3TC (lamivudine)		<input type="checkbox"/> ABC (abacavir)	<input type="checkbox"/> EFV (efavirenz)	<input type="checkbox"/> Other:	
<input type="checkbox"/> D4T 30 (stavudine)		<input type="checkbox"/> TDF (tenofovir)	<input type="checkbox"/> Kaletra (lopinavir or Atova)		
<input type="checkbox"/> DDI (didanosine)		<input type="checkbox"/> Truvada (TDF/FTC)	<input type="checkbox"/> Triomune 30 (NVP/D4T/3TC)		
ARV adherence (last month): <input type="checkbox"/> Good (>95%) <input type="checkbox"/> Fair (85-94%) <input type="checkbox"/> Poor (<85%)			Doses missed: Reason:		
OI Medications					
PCP	<input type="checkbox"/> none <input type="checkbox"/> septrin proph <input type="checkbox"/> dapsone proph <input type="checkbox"/> septrin tx	Adherence (non-adherent defined as missed > 5 days in previous 30) <input type="checkbox"/> adherent <input type="checkbox"/> non-adherent Reason:			
TB	<input type="checkbox"/> none <input type="checkbox"/> SRHZE <input type="checkbox"/> RHZE <input type="checkbox"/> EH <input type="checkbox"/> RHE <input type="checkbox"/> R H <input type="checkbox"/> INH	<input type="checkbox"/> adherent <input type="checkbox"/> non-adherent Reason:			
CCM	<input type="checkbox"/> none <input type="checkbox"/> diflucan proph <input type="checkbox"/> diflucan tx	<input type="checkbox"/> adherent <input type="checkbox"/> non-adherent Reason:			
CURRENT SYMPTOMS					
Clinical presentation: <input type="checkbox"/> no complaints <input type="checkbox"/> complaints					
Presenting complaints: (circle chief complaint, tick other symptoms)					
General	<input type="checkbox"/> fever <input type="checkbox"/> weight loss <input type="checkbox"/> chills/rigors <input type="checkbox"/> fatigue <input type="checkbox"/> night sweats	<input type="checkbox"/> red eyes <input type="checkbox"/> eye itching <input type="checkbox"/> visual difficulties <input type="checkbox"/> nasal congestion <input type="checkbox"/> running nose <input type="checkbox"/> nose bleeding	<input type="checkbox"/> vomiting <input type="checkbox"/> abdominal pain <input type="checkbox"/> diarrhea <input type="checkbox"/> constipation <input type="checkbox"/> yellow eyes <input type="checkbox"/> poor appetite	LNMP: / /	<input type="checkbox"/> confusion <input type="checkbox"/> forgetfulness
HEENT	<input type="checkbox"/> dysphagia <input type="checkbox"/> odynophagia <input type="checkbox"/> oral sores <input type="checkbox"/> sore throat <input type="checkbox"/> hearing prob <input type="checkbox"/> earache	<input type="checkbox"/> cough-dry <input type="checkbox"/> cough-productive <input type="checkbox"/> haemoptysis <input type="checkbox"/> chest pain <input type="checkbox"/> SOB	<input type="checkbox"/> vaginal discharge <input type="checkbox"/> urethral discharge <input type="checkbox"/> genital itching <input type="checkbox"/> dysuria <input type="checkbox"/> hematuria	<input type="checkbox"/> muscle pain <input type="checkbox"/> focal weakness <input type="checkbox"/> seizures <input type="checkbox"/> neck stiffness <input type="checkbox"/> numbness <input type="checkbox"/> hand/feet pains	<input type="checkbox"/> psychiatric <input type="checkbox"/> depression <input type="checkbox"/> anxiety <input type="checkbox"/> mania <input type="checkbox"/> hearing voices <input type="checkbox"/> other hallucinations
Other symptoms:	<input type="checkbox"/> Gastrointestinal <input type="checkbox"/> nausea	<input type="checkbox"/> genital warts <input type="checkbox"/> genital ulcer(s)		<input type="checkbox"/> Dermatologic <input type="checkbox"/> Skin Lesion / Rash	Distribution <input type="checkbox"/> localized <input type="checkbox"/> general <input type="checkbox"/> itchy <input type="checkbox"/> Symptoms <input type="checkbox"/> painful
ARV side effects:	<input type="checkbox"/> N/A (not on ARV's) <input type="checkbox"/> none <input type="checkbox"/> nightmares <input type="checkbox"/> lipodystrophy <input type="checkbox"/> peripheral neuropathy <input type="checkbox"/> rash <input type="checkbox"/> fatigue <input type="checkbox"/> nausea <input type="checkbox"/> vomiting <input type="checkbox"/> diarrhea <input type="checkbox"/> jaundice <input type="checkbox"/> dizziness <input type="checkbox"/> depression <input type="checkbox"/> abdominal pain <input type="checkbox"/> Other:				
PHYSICAL EXAMINATION					
Functional status:	<input type="checkbox"/> working <input type="checkbox"/> ambulatory <input type="checkbox"/> bed ridden	Karnofsky: %			
General exam:	<input type="checkbox"/> well <input type="checkbox"/> chronically sick appearing <input type="checkbox"/> acutely sick appearing				
Oropharynx:	<input type="checkbox"/> normal <input type="checkbox"/> abnormal	Chest:	<input type="checkbox"/> normal <input type="checkbox"/> abnormal		
Eyes:	<input type="checkbox"/> normal <input type="checkbox"/> abnormal	Heart:	<input type="checkbox"/> normal <input type="checkbox"/> abnormal		
Lymph nodes:	<input type="checkbox"/> normal <input type="checkbox"/> abnormal	Abdomen:	<input type="checkbox"/> normal <input type="checkbox"/> abnormal		
Ears:	<input type="checkbox"/> normal <input type="checkbox"/> abnormal	Urogenital/pevic:	<input type="checkbox"/> normal <input type="checkbox"/> abnormal		
Neck:	<input type="checkbox"/> normal <input type="checkbox"/> abnormal	Extremities:	<input type="checkbox"/> normal <input type="checkbox"/> abnormal		
Skin:	<input type="checkbox"/> normal <input type="checkbox"/> abnormal	Psychiatric:	<input type="checkbox"/> normal <input type="checkbox"/> abnormal		
Comments on abnormalities:					

Figure 5: The 2008 patient “encounter form.”

## ASSESSMENT

Active HIV related diagnoses: (tick all current conditions and highest current stage)

<input type="checkbox"/> WHO STAGE 1	<input type="checkbox"/> WHO STAGE 4
<input type="checkbox"/> Asymptomatic	<input type="checkbox"/> HIV wasting Syndrome
<input type="checkbox"/> Generalized lymphadenopathy	<input type="checkbox"/> Extrapulmonary TB (includes treatment phase)
<input type="checkbox"/> WHO STAGE 2	<input type="checkbox"/> Oral or genital ulcers (HSV) > 1 month duration
<input type="checkbox"/> Unexplained weight loss of < 10%	<input type="checkbox"/> CMV retinitis or CMV in other organ system
<input type="checkbox"/> Recurrent URI (sinusitis, otitis, pharyngitis, etc)	<input type="checkbox"/> PCP pneumonia
<input type="checkbox"/> Herpes zoster	<input type="checkbox"/> Esophageal candidiasis
<input type="checkbox"/> Angular chelitis	<input type="checkbox"/> Kaposi's sarcoma (includes treatment phase)
<input type="checkbox"/> Recurrent oral ulceration	<input type="checkbox"/> CNS toxoplasmosis
<input type="checkbox"/> Papular pruritic eruptions	<input type="checkbox"/> Cryptococcal meningitis/disseminated (inc treatment)
<input type="checkbox"/> Seborrheic dermatitis	<input type="checkbox"/> Invasive cervical cancer
<input type="checkbox"/> Fungal nail infection	<input type="checkbox"/> Atypical leishmaniasis
<input type="checkbox"/> WHO STAGE 3	<input type="checkbox"/> Lymphoma (includes treatment phase)
<input type="checkbox"/> Unexplained weight loss of > 10%	<input type="checkbox"/> Recent septicemia
<input type="checkbox"/> Unexplained chronic diarrhea > 1 month	<input type="checkbox"/> Recurrent bacterial pneumonia
<input type="checkbox"/> Unexplained chronic fever > 1 month	<input type="checkbox"/> HIV encephalopathy
<input type="checkbox"/> Pulmonary tuberculosis (includes treatment phase)	<input type="checkbox"/> Progressive multifocal leukoencephalopathy
<input type="checkbox"/> Persistent oral candidiasis	<input type="checkbox"/> Disseminated non-tuberculous mycobacteria
<input type="checkbox"/> Necrotizing stomatitis or gingivitis	<input type="checkbox"/> Cryptosporidiosis or isosporiasis
<input type="checkbox"/> Hb < 8 g/dl, or ANC < 500 or platelets < 50	<input type="checkbox"/> Disseminated mycosis
<input type="checkbox"/> Oral hairy leukoplakia	<input type="checkbox"/> Symptomatic HIV-nephropathy
<input type="checkbox"/> Severe bacterial infection (pneumonia, etc)	<input type="checkbox"/> Symptomatic HIV-associated cardiomyopathy

Other Active Diagnoses for Current Problem List

1		4
2		5
3		6

TB Status:  no signs  suspected  diagnosed  on treatment  completed treatment  
*If diagnosed/on treatment specify*  new onset  recurrent/relapse  defaulter  tx failure

## PLAN

ARV Plan		Reason (tick all applicable)	
<input type="checkbox"/> Continue current			
<input type="checkbox"/> No ARV's		<input type="checkbox"/> no indication <input type="checkbox"/> indicated, but <input type="checkbox"/> defer until TB treatment <input type="checkbox"/> patient refusal <input type="checkbox"/> on hold for toxicity wash-out <input type="checkbox"/> adherence concerns <input type="checkbox"/> stock out <input type="checkbox"/> no available active drugs <input type="checkbox"/> supporter pending <input type="checkbox"/> counselling ongoing	
<input type="checkbox"/> Start initial regimen <input type="checkbox"/> Re-start  <input type="checkbox"/> Book		<input type="checkbox"/> Clinical <input type="checkbox"/> CD4(____) <input type="checkbox"/> TLC(____) <input type="checkbox"/> pMTCT <input type="checkbox"/> PEP <input type="checkbox"/> Other:	
<input type="checkbox"/> Switch  <input type="checkbox"/> Stop		<b>Failure:</b> <input type="checkbox"/> clinical failure <input type="checkbox"/> immunologic failure <input type="checkbox"/> virologic failure <b>Toxicity:</b> <input type="checkbox"/> anemia/neutropenia <input type="checkbox"/> nausea/vomiting <input type="checkbox"/> diarrhoea <input type="checkbox"/> liver toxicity <input type="checkbox"/> peripheral neuropathy <input type="checkbox"/> sleep disturbance <input type="checkbox"/> lipodystrophy <input type="checkbox"/> dizziness <input type="checkbox"/> rash <b>Misc:</b> <input type="checkbox"/> poor adherence <input type="checkbox"/> pregnancy <input type="checkbox"/> stock out <input type="checkbox"/> new TB tx <input type="checkbox"/> finished pMTCT <input type="checkbox"/> Other, specify:	
ARV Regimen	<input type="checkbox"/> AZT (zidovudine) <input type="checkbox"/> CBV (AZT/3TC) <input type="checkbox"/> NVP (nevirapine) <input type="checkbox"/> Atripla (TFD/FTC/EFV) <input type="checkbox"/> 3TC (lamivudine) <input type="checkbox"/> ABC (abacavir) <input type="checkbox"/> EFV (efavirenz) <input type="checkbox"/> Other: <input type="checkbox"/> D4T 30 (stavudine) <input type="checkbox"/> TDF (tenofovir) <input type="checkbox"/> Kaletra (lopinavir or Atova) <input type="checkbox"/> <input type="checkbox"/> DDI (didanosine) <input type="checkbox"/> Truvada (TFD/FTC) <input type="checkbox"/> Triomune 30 (NVP/D4T/3TC)		
Provider	<input type="checkbox"/> MOH <input type="checkbox"/> MJAP <input type="checkbox"/> TREAT <input type="checkbox"/> FTF <input type="checkbox"/> TASO <input type="checkbox"/> Other:		

Counseling Plan

 None  First Pre ART  Second Pre ART  Adherence/ongoing  Psychosocial  Other

OI Plan

 PCP  none  septrin proph  dapsone proph  septrin tx  other:  stop (Why?:  improvement  toxicity)

 TB  none  SRHZE  RHZE  EH  RHE  RH  INH  other:  stop

 CCM  none  diflucan proph  diflucan tx  other:  stop (Why?:  improvement  toxicity)

Other Medications:	1.	2.
	3.	4.
	5.	6.
Tests ordered:	<input type="checkbox"/> None <input type="checkbox"/> CD4 <input type="checkbox"/> CBC <input type="checkbox"/> Viral load <input type="checkbox"/> creatinine <input type="checkbox"/> ALT/AST/ALP <input type="checkbox"/> CXR <input type="checkbox"/> sputum AFB <input type="checkbox"/> urine HCG <input type="checkbox"/> urinalysis <input type="checkbox"/> RPR/VDRL <input type="checkbox"/> stool <input type="checkbox"/> lipid profile <input type="checkbox"/> Others:	

Transferred out:  no  yes, to:Referred:  no  yes, to:Admission:  none  medical ward  TB  OBS/GYN  psychiatry  emergency  surgical

Other Comments:

Next scheduled appointment date: / / Provider name:

requirement intended to mandate the inclusion of Mbarara faculty in foreign-funded research projects.<sup>7</sup> Some of the other doctors felt envious of Atuhaire, whose close involvement with the study provided him with some extra income as well as valuable professional development opportunities (including a six-week clinical research training course in the United States, and tuition for the MPH program at Makerere). If they were going to be doing what felt like extra work for the research project, they wanted to be compensated for it too.

## **Discomfort**

My own anthropological research was not exempt from this politics of compensation. I experienced these dynamics firsthand in the summer of 2009, when I returned to Mbarara to observe Beale's research operation and conduct follow-up interviews with doctors. Prior to my visit I had been in touch with Dr. Mary Balenzi, the Wellness Clinic's director, about my project and received her permission to approach the clinic doctors about being interviewed for my research. Shortly before I arrived, she sent me an email alerting me to a possible problem: she had informed the doctors of my plans, she said, and a number of them had objected, arguing that they should be paid for the interviews. In the United States, given available funds, this would not have been a problem, as it is common practice to provide study participants with reimbursement for their time. In Uganda, however, ethical regulations prohibit payment for research participation. In the context of Uganda's widespread poverty, offering research subjects payment for enrolling in medical studies is viewed as potentially coercive and antithetical to the bioethical principles of patient autonomy and voluntary consent (see Loue, Okello, and Kawuma 1996; Loue and Okello 2000). Such compensation was thus not a component of my research proposal (nor my budget). At the same time, I was also aware that it was a rule that was often bent by providing study participants small amounts of food or other staple goods, money for transportation to the study site, or air time for their mobile phones (Geissler 2011).

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7. Dr. Atuhaire was also my local IRB applicant.

When Dr. Balenzi sat down with me in her office shortly after my arrival in Mbarara in the summer of 2009, she was apologetic about the reaction of her colleagues. The doctors, she said, were “uncomfortable” with being interviewed without compensation, as they felt that they could otherwise use that time for other things, such as seeing private patients—a common way in which public sector doctors (including herself) supplemented their low government salaries. This kind of demand was new: “It is the beginning of people expressing discomfort,” she told me. Indeed, when I had interviewed her and other doctors in Mbarara four years earlier, it had not arisen as a concern. It was not my project alone that generated these feelings, she reassured me, and told me of a Ugandan PhD student from Kampala who had recently asked her to bring some surveys back to the Mbarara doctors for his research. The surveys were thick, she said, and the doctors had protested that they should be compensated for the time spent completing them.

Cognizant of Ugandan regulatory prohibitions against paying research participants, but also aware that small tokens of thanks were not uncommon, Balenzi and I embarked on a careful conversation about what might be appropriate. I suggested the possibility of phone cards for air time on the mobile networks, knowing that Beale’s earlier research in Kampala had offered this to clinicians as a way of thanking them for referring their patients to his study. She warned me that there was a risk of insulting people by offering too little, especially the senior doctors who were also lecturers in the university. Offering 5, 10, or even 20 thousand shillings’ worth of airtime (about US\$10) to a senior lecturer could be “embarrassing,” she cautioned me. Then, in a moment of frankness about the racial politics of global health research, she added, “Maybe it would be ok if you were a black.” But as a white person, she told me, I would have to offer more.

Our conversation concluded with Dr. Balenzi offering to check with the Dean about whether such compensation was even permissible under the university’s rules. We did not hear back from him, but in the end, I was able to interview a number of doctors without offering them any recompense other than my profuse thanks. Those who ignored or put off my requests, I speculate, were those who wanted to be paid or who were otherwise too busy to grant my request. What the situation made clear was that my own anthropological

research was shot through with postcolonial power dynamics just as much as Beale's was.

## **Gratitude**

In retrospect, Dr. Balenzi's assertion that "it is the beginning of people expressing discomfort" indicates that my visit in 2009 occurred at a time when the moral economy of international research in Mbarara was shifting. When I had conducted my initial interviews with doctors there in 2005, no one mentioned compensation. Beale's project was still small and relatively new. When seeking interviews with doctors, I found that mentioning Beale's name opened doors for me. This openness was probably due not only to positive feelings about the American research presence, but also favorable feelings about American programs in general. This was in part because the initiation of Beale's research project corresponded nearly exactly with the arrival and expansion of free HIV treatment at the clinic, much of it American-funded. Beginning in late 2004, PEPFAR dollars became increasingly visible at the clinic, not only in the form of ARVs and other drugs, but also computers, laboratory equipment, and new clinical staff paid for by the program. At the same time, Beale's fledgling research study was beginning to enroll more and more of the clinic's patients, and was further augmenting patient care by offering free CD4 counts and viral loads (tests which at the time were often otherwise unavailable).

The Wellness Clinic doctors, who for years had been helplessly watching their patients die for lack of money to buy ARVs, were filled with gratitude for the influx of American resources that suddenly made it possible for them to practice effective HIV medicine. Not only could they now give their patients drugs that would restore them to relative health, but they could also monitor their immunological progress using CD4 tests. For doctors accustomed to working conditions in which even basic antibiotics and simple laboratory tests were often unavailable, it was a chance to finally practice "real" medicine (Wendland 2010). In addition, those doctors who had been hired into newly created PEPFAR-funded positions actually owed their livelihoods to American funding. Thus, on the ground, it was often difficult to tell the difference between American research money and American treatment money. This was driven home for me during a 2005

interview with one of the Wellness Clinic doctors, when she thanked me—even though she was taking time out of her busy schedule to help me with my research—thinking that as an American I might have connections to PEPFAR:

Maybe what I need to say is to thank God for everybody who is trying to help find knowledge about our clinic or about our patients. Not only here but maybe Africa as a whole. And trying to help our patients. Our brothers, our sisters, our family. I know, because I've seen this work [is] very rewarding. When you see a patient comes in and you know they can't afford the drugs, and then they just have to pick them [up for] free from the pharmacy at the counter, and then they go home and come back happy, you know. Then at least they have some energy to make money and pay school fees for their siblings or for their daughters or something like that. I find it very rewarding and I think I need to say thank you. *Maybe you might not be directly in touch with the people who are concerned, but at least if you are, you're able to tell them thank you for the very good work they are doing here. We appreciate it.* [emphasis added]

Thus, in 2005, the dominant sentiment attached to the influx of American funding—both for treatment and research—seemed to be one of gratitude. Americans were welcomed as generous donors, and Ugandan doctors saw their clinics and patients as grateful recipients. Indeed, it was this same moral economy of assistance and gratitude that led Dr. Beale to envision his research database as a “donation” to the clinic. By 2009, this gratitude was still present, but it was tempered with a wary self-protectiveness.

In addition to the added employment, buildings, and technological infrastructure that Beale's grants supported, the fiscal power of American research had also become visible in the changing circumstances of its employees. In 2009, Dr. Atuhairé was studying for his master of public health degree courtesy of a scholarship from Beale's project, and his wife had left her job as a schoolteacher to become the project manager of Beale's largest study, a job at which she excelled. The couple, who had been renting a house near campus in 2005, now owned land and were building a house there for themselves and their two young daughters. They drove themselves to work and their elder daughter to school in a Pajero jeep, a step up from the ubiquitous Toyota Corollas driven by most car-owning Ugandans. Ozo-bia, who was paid on an American salary scale, had built herself a picturesque

home surrounded by bougainvillea bushes on a hillside overlooking the campus. My friend and colleague Idah Mukyala, who had relocated to Mbarara from Kampala in order to continue working for Beale, was earning enough as the coordinator of several smaller projects to pay a younger cousin's school fees and buy herself a modest secondhand car over the Internet. Given this, it is easy to see why doctors would resent being asked to give their time to research (either by being interviewed, or by filling out "clinical encounter forms") without some form of compensation. Even the chair of the Department of Medicine at the time, a British expatriate doctor, seemed wary of research work that did not pay. Following a lecture by Dr. Norman Musinguzi, a respiratory specialist within the department, he asked the doctor whether he was a principal investigator on the U.S.-funded HIV prevention study he had described in his lecture. The exchange continued as follows:

Musinguzi: I am a consulting physician.

Chair: You help them if they have problems?

Musinguzi: Yes, I help them.

Chair: [protectively] They are paying you something?

Musinguzi: Yes, they are paying me something small.

Chair: Good!

Thus in 2009, as in 2005, on the ground it remained difficult to distinguish between the American dollars brought in by research and those brought in by PEPFAR. But unlike a few years earlier, by 2009 the most palpable sentiment was not one of gratitude but one of guarded self-protection. The longer-term consequences of the influx of American money for AIDS were becoming increasingly visible. These included an internal brain drain of doctors and others out of the public sector to work at better-paid jobs in AIDS research or NGOs, sudden unemployment or cessation of services when a hoped-for foreign grant never materialized, a growing disparity between the state-of-the-art care available at the Wellness Clinic and the lack of even the most basic supplies on the hospital wards, and rising concerns that the world economic crisis and changing global health priorities would temper American largesse and end the era of unlimited ARV treatment slots (which they eventually did; Garrett 2007; McNeil 2010). When I told Idah Mukyala about the doctors' insistence that I pay them for interviews,

she told me it was because they could now see that there was a lot of money in research. The doctors wouldn't understand or believe me if I tried to explain that my budget was small, she said, because people think *all* research projects have a lot of money.<sup>8</sup> She told me that it used to be enough to simply offer doctors air time, as she had done when working on Beale's study in Kampala. But now they wanted more—especially, she said, “these PEPFAR doctors,” who were accustomed to the higher pay offered by the American treatment program.

## Inclusion

This shift from gratitude to self-protection has something important to tell us about the postcolonial power dynamics of global health science. Warwick Anderson describes encountering a “postcolonial melancholy” upon visiting Carleton Gadjusek's former kuru research site in Papua New Guinea. At the height of Gadjusek's activities in the 1960s, foreign scientists and the local Fore people enjoyed a fragile but mutually beneficial moral economy, in which the reciprocal exchange of blood and tissue samples for “cargo” (goods) was embedded within social relations of trust and mutual obligation (Anderson 2008). Years later, things had changed. “When I was there in 2003,” Anderson writes, “everybody was talking about compensation:”

A sort of postcolonial melancholy pervaded conversations, a sense that as individuals and as a people they were unfairly excluded from globalization and its presumed rewards. . . . Kuru research once led development of the region. . . . White men came and went, got *bigpela* prizes and perhaps plenty of money, and left the Fore people with demands unmet and expectations dashed. Now everyone wanted more compensation, especially some of Carleton's former assistants. (Anderson 2008, 215)

In Uganda, too, requests for compensation seemed to stem not only from economic motivations, but from a disappointment with—or a desire to be recognized by—global science. AIDS had placed Uganda at the center of

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8. My research was supported by travel funds from a postdoctoral fellowship, which paid for little more than my airfare.

global health science, but too often Ugandan scientists remained at the periphery, “excluded from globalization and its presumed rewards,” to reiterate Anderson’s words. This disenchantment grew more acute as evidence of the economic wealth connected with American research (sometimes elided with American treatment programs) became increasingly visible.

However, what I learned from the doctors who were willing to be interviewed was that money was only part of the picture. Also at stake for these doctors was the issue of *inclusion* in international science, not just in the form of monetary compensation, but as intellectual peers and collaborators. In the sketches that follow, I summarize what some of the Mbarara doctors told me of their feelings about working with foreign researchers, the impact of international research on the clinic, and their own scientific interests and ambitions.

Dr. Douglas Mutungi

*“People I think only wanted to be a part of the process.”*

I interviewed Dr. Douglas Mutungi in one of the minimalist examination rooms in the Wellness Clinic, where he was a full-time clinician supported by PEPFAR. The room contained little other than a wooden desk, which we sat on opposite sides of, and a simple exam table spread with a green sheet marked with the acronym of one of PEPFAR’s local partner organizations. Outside, patients gathered on the wooden benches lining each side of the hallway, as they did every morning, waiting to be called for their appointments. When I asked him about the presence of international research at the clinic, he responded with a complaint. The studies were present, he said, but as a clinician he was rarely informed of their plans or activities: “Sometimes you find people telling you they are carrying out a study when you are seated in the clinic and you didn’t know what is taking place. They are carrying out a study they never sensitized me about.” At times, he would call a patient in to be examined only to find that they had already been summoned for a research appointment, “and I am not even aware of what the project is doing about that person!”

Dr. Mutungi’s complaint about international research had to do with inclusion, not money. It was this lack of inclusion that he saw behind his

colleagues' insistence on compensation from me and other foreign researchers:

Like when you had come, Dr. Mary [Balenzi] told me about you and said that people were not cooperating. And I told her that probably the reason is that people come in and ask for information and then come back to tell us what they are finding out, when we don't actually know what has been happening. Maybe that would be the reason why people are not cooperating. It's not you alone [laughs]. There are a number of people who have come here and [the reaction is], "Ah, these people are wasting our time after all. What are they doing? We don't even know." Not that really what people wanted was to be compensated, but people I think only wanted to be part of the process.

Later in the interview, he expressed similar feelings in stronger terms. Most of the HIV clinic doctors were unhappy with the American project, he said. They felt that the research project simply took data out of the charts they wrote up, but didn't keep them informed of the progress or findings of the research on a regular basis. The clinicians didn't feel included, he asserted, and that is why they expressed annoyance to Dr. Balenzi in response to my own requests for interviews.

When I asked about his own research aspirations, Dr. Mutungi described himself to me as "very much interested" in conducting research, and said that he was particularly keen on monitoring the toxicities of antiretroviral drugs, which could include liver and kidney problems, metabolic disorders, nerve damage, and skin conditions. As a clinic doctor, he had no worries about finding adequate numbers of research subjects, telling me, "I won't find difficulties in finding the study subjects since I'm all day dealing with patients." (In this way, aspiring Ugandan researchers may also benefit from the same surfeit of patients that attracts Northern scientists.) However, he thought it was unlikely that he could find adequate laboratory facilities to do the kind of study he wanted to pursue—one that included pharmacokinetic measures of drug levels, and not simply clinical observation of drug side effects. In addition, his appointment as a full-time clinician left him no time to engage in research. Lastly, he would only be able to do research if he were able to obtain funding, which was highly competitive and required finding a senior researcher from abroad who was willing to partner with him, as there were no local sources of scientific funding available.

Dr. Felix Musoke

*“It seems you must have contacts.”*

Dr. Felix Musoke received his bachelor’s-level medical degree in Kampala, and in 2009 was in his final year of postgraduate study at the MUST medical school (roughly equivalent to a master’s degree in the United States). His clinical duties were primarily on the hospital’s inpatient wards, but he also rotated through the various clinics, including the HIV clinic. As a postgraduate student he was expected to conduct independent research. Musoke was interested in blood glucose levels in patients with sepsis, and was studying whether patients’ glucose levels upon admission to the hospital had any relation to whether they survived or died. This was a question that had been studied in the “developed world,” he told me, “but unfortunately when I did the literature search this study has not been done anywhere in sub-Saharan Africa.” It was important, he thought, to see how things might be different in a “tropical set-up” and “in a place where we don’t have access to intensive care units or to drugs as often as may be necessary.”

Dr. Musoke was paying his own way through graduate school, and had no university scholarships or outside sponsorship to support his educational expenses. Students in his situation were often forced to self-fund their own research projects. Musoke, however, had a stroke of luck. At the time that he was presenting his research proposal, a professor from the University of Virginia was visiting MUST from the United States. The visitor had an interest in sepsis, and asked Musoke to forward him his proposal. The University of Virginia, it turned out, had a partnership with Pfizer Pharmaceuticals to sponsor promising research proposals from Africa. The American professor passed Musoke’s proposal on to the Pfizer program, and Pfizer agreed to fund his research. Dr. Musoke saw himself as lucky. “It seems you should have contacts,” he told me, “with people who are willing to link you with people who are willing to help you. Because really, if this gentleman had not come in at that particular time, I don’t think I would have got sponsorship for my research. If he hadn’t come, I was going to put out most aspects of my study because there was no financing. So that’s the setback, from an African perspective.”

Dr. Julius Katabira

*“You need to be attached to someone.”*

At the time I spoke with Julius Katabira, he had been out of work for six months. The two international studies he had been coordinating had ended. Another one was likely to start soon, and Beale’s team was prepping him to manage it, but nothing would be certain until the funding came through. In the meantime, Dr. Katabira was working one day a week at the Wellness Clinic. Although he could have made additional money seeing private patients, he chose not to, telling me that he disliked private practice. Fortunately, his wife had steady work as the laboratory coordinator for Beale’s projects, so the couple was able to financially weather his break in employment. And, as he had hoped, the expected funding materialized soon after, and Katabira was hired to oversee a new project testing the use of an electronic pill case to measure patients’ adherence to medication.

Dr. Katabira had studied medicine in Mbarara, and then spent a year abroad getting a postgraduate degree in global health in the United Kingdom. After spending some time working in drug regulation and then on a malaria research project, he had begun working as the local coordinator of several projects under Dr. Beale’s research umbrella. He was glad to be working in Mbarara rather than in Kampala, and saw Beale as a valuable mentor. “Because I have been working with him, we have been talking and discussing things I’m interested in,” he told me. “And I think the idea is that I help him with his work while I learn and also try to do my own things.” Katabira was interested in conducting research aimed at improving patient care. “I’m really interested in seeing things work, and really seeing things change for the patients,” he told me. Under Beale’s mentorship, and with access to the database the research team had built, he wrote an article demonstrating the need for outreach to the significant numbers of patients who waited to seek HIV care until their disease was quite advanced—making ARV treatment less likely to succeed. The article was subsequently published in a top-flight international journal, with Dr. Katabira as first author.

Katabira felt strongly that he would not have gotten the same professional opportunities had he been working in Kampala, where there was an entrenched group of older Ugandan researchers with international connections

and few chances for junior investigators to lead studies or author publications. “That’s one of the reasons I like it here,” he told me. “If I was in Kampala, I wouldn’t have written anything or done anything. They will pay you more money, for sure. But you won’t get anything apart from the money. If you look at the people in Kampala, in Mulago, they are the same people who were there before we were born! And there is no one really coming up. They are not mentoring other people, bringing up other people.”

Mentorship was critical, not only for the grant writing and research skills it offered, but because it was a means of linking into the international scientific networks through which funding and opportunities flowed. To be a successful researcher, Katabira said, “First you need a lot of money, then you need a certain kind of experience and education, and then you need to know people. You need to be attached to someone.” For him, Beale had been that person.

Dr. Kizza Mayanja

*“You have to dance to the other person’s tune.”*

Dr. Kizza Mayanja was junior faculty within the Mbarara medical school. He had finished his undergraduate medical degree at MUST several years earlier, and then completed a master’s degree in infectious disease and clinical biology in the United Kingdom. In his clinical work, he primarily cared for patients with tuberculosis and meningitis, and these diseases were also the focus of his research inquiries. Most of his patients were hospitalized with AIDS on the inpatient wards. Several years earlier, Dr. Mayanja and a colleague at Mbarara medical school realized that the hospital had no protocol for managing patients with cryptococcal meningitis (“crypto”)—a common opportunistic infection that comes with AIDS—even though mortality rates from the disease were very high. They teamed up with a visiting lecturer from the United Kingdom and wrote a “small proposal” which they then forwarded to the visitor’s colleagues at St. George’s Hospital in London. They were then connected with a cryptococcus researcher at the hospital’s affiliated medical school, and he helped them secure funding for their initial study.

Since then, Mayanja and his colleague at Mbarara medical school had been testing a variety of different treatments for crypto in an effort to find

one that was both effective and affordable given the hospital's minimal budget. The study had been very successful not only at finding alternate treatment options, but also at garnering scientific respect and ongoing support from international funders. Their results had been published in a prestigious international medical journal. Nonetheless, even with this success, Dr. Mayanja felt that his research options were constrained. The crypto study had succeeded in part because it fell within the donors' interest areas: AIDS, TB, and malaria. It was much harder to find support for other areas of research. "I mean, I wanted to look at campylobacter, OK, in this local population here," he told me.<sup>9</sup> "But you can't do that because no one will fund such research. You need specific culture techniques, specific cells, which we don't have here. And no one can give you a fund to even set up a lab that will look at campylobacter, because it isn't a priority."

There were other challenges that came with foreign funding as well. "You have to dance to the other person's tune," he told me. "If they want something done, it has to be done their way, not your way." Also, foreign researchers typically shipped the specimens they collected out of Uganda for analysis. Sometimes these samples would be used for additional research later on, "and we never get to be acknowledged as a part of those researches," he told me. In addition, international research funding was fickle, and studies could sometimes end with little notice due to economic constraints at the funding institution. Nonetheless, Dr. Mayanja's overall sentiment about international research was positive. "The benefits are there," he asserted. "I mean, we've been able to have our infrastructure upgraded, we've gotten very good collaborations, we've written papers. Our patients get drugs—some of these drugs are very expensive! We've actually benefited in that way."

Dr. Norman Musinguzi

*"HIV money has somehow killed our health care system."*

I first met Dr. Norman Musinguzi in 2005, when he was studying for his postgraduate medical degree at MUST. By 2009 he was faculty in internal

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9. Campylobacter is a microbe often carried by chickens, and is a major cause of diarrheal disease in Uganda.

medicine, where he taught medical students and saw patients on the hospital wards. In addition, he was “lead clinician” on a U.S.-designed HIV-prevention study located at a rural hospital about an hour away from Mbarara. The project, which was unconnected to Dr. Beale, was funded by the Bill and Melinda Gates Foundation and overseen by the University of Washington. When I asked him what this position involved, he replied that the work consisted primarily of examining patients and filling out “CRFs” or “case report forms”:

We just fill forms, case report forms, which have a lot of information about patients, about social demographics, about examination findings, about history, about everything. There are like ten case report forms every time a patient visits. That’s what we fill. We data-fax it to the University of Washington. So we do a lot of data collection, including blood. We fill what we have found in blood, then we fax it also.

The study Dr. Musinguzi describes was actually at the cutting edge of HIV science, examining the possibility that antiretroviral drugs might work to *prevent* HIV infection, rather than only treat it. The findings of other, similar studies were considered landmark upon publication (McNeil 2011a). But for Musinguzi, the work was largely administrative.

In truth, Dr. Musinguzi’s primary motivation for commuting forty miles to work on this project was not scientific, but financial. As a doctor who was paid through the Ministry of Health, he simply did not earn enough through clinical and teaching work alone, and research was a way to “make ends meet.” Given his choice, Musinguzi would have preferred to work as a full-time clinician, specializing in respiratory disease. But, he told me, “I think the biggest barrier that I’ve faced is that if I decide to become a [full time] respiratory physician, how will I survive? OK, I’m interested in respiratory—so what? If I am interested, how will I survive from this?” As a Ministry of Health employee, Dr. Musinguzi’s salary was low, but he had job security and possibilities for promotion over time. Leaving government employment for full-time research work, he argued, was a poor career option. “If you leave the Ministry of Health,” he told me, “you are not promoted. You remain a researcher for two years, and then the project ends, and you are not anyone.”

Dr. Musinguzi did have an intellectual interest in research, particularly in research that focused on the respiratory infections he was most interested in clinically. But he was truly a clinician at heart. When I asked him about his own research interests, he told me that while he would be interested in doing research on “TB, pneumonia, cryptococcal diseases in the lung,” his “first calling” was really as a clinician. “My first calling, if they give me a lot of money—not a lot, but enough money—is that I sit in a ward and see patients.” In other words, in his mind, research work was a good means by which to earn enough money to survive, but he preferred caring for patients over studying them.

Musinguzi spoke pointedly about the impact of the HIV epidemic and foreign aid on Uganda’s health care system. “I believe,” he told me, “that HIV money and research money has somehow also killed our health system.” When I asked him to explain he continued, “If you pay a medical officer<sup>10</sup> more than a professor, what do you expect? It has reduced the level, the involvement of the Ministry of Health.” He went on to tell me that even Ministry of Health doctors with the title of “senior consultant”—the highest rung on the Ministry’s promotion scale—earned less than medical officers working in research or under PEPFAR. As a junior professor with many steps left to go before earning the title of “senior consultant,” this was disheartening for a doctor like Musinguzi, who found himself surrounded by doctors with less training and experience who nonetheless earned higher pay because they worked for foreign research projects or a U.S.-funded treatment program.

Dr. Musinguzi wished that the World Health Organization or African governments would step in and require that international funding be divided up equally among those working in research and in patient care. “They should be getting the same amount of money,” he argued. “I don’t know how it can be done, but I think where there’s a will there’s always a way.” He continued:

There can be a way that government can rearrange this, even in Africa as a whole. To make sure these groups which are coming here, funding HIV, funding research, put their money for salaries in one basket so it could be

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10. A medical officer is a clinician with an undergraduate degree in medicine.

equally distributed. And people in hospitals would be happy, people in health clinics would be happy, people in research would be happy—everyone would be happy. And everyone would now be ready to settle down and do what he does best, and things would be even much better.

Instead, what was happening was what Laurie Garrett and others have described as “internal brain drain”—the abandonment of the public sector health system by doctors and other health care workers in favor of the higher salaries offered by research and foreign NGOs (Garrett 2007). Or, in Dr. Musinguzi’s words, “the Ministry of Health people get so demoralized they end up leaving the hospital to go and look for more money.”

Dr. Fredrick Muyenje

*“We say HIV opened Uganda’s doors.”*

Dr. Frederick Muyenje was one of the most promising young researchers within the Mbarara medical school, and also the one with the most American contacts. After attending medical school in Uganda, he had been accepted into a very selective NIH-funded program that supported his doctoral studies in epidemiology at a prestigious U.S. university. Upon returning to Uganda in 2007, he was hired as faculty within MUST’s School of Public Health, a position that freed him from any clinical duties and allowed him to focus exclusively on teaching and research. At the time we spoke, he was studying obstacles to HIV treatment in a nearby rural district, where long distances and high transportation costs often prevented poor patients from making monthly clinic visits to pick up their antiretroviral medications. With his American PhD advisor, he had applied for and received funding to test a mobile pharmacy that would move around the district, allowing patients to “walk, a five- or ten-minute walk, as opposed to a two-hour travel” to the district hospital. The idea had originated in his dissertation research and was now being implemented, with early reports of success. Dr. Muyenje was pleased with the results, but worried about the sustainability of the program once his research funding ended. He also worried about patients’ ability to genuinely consent to research, given the extreme shortcomings of their existing health care options. “Viral load testing became available for the first time [in the district] due to my research,” he told

me. As a result, “I in fact felt guilty consenting patients. Because when we told them we were going to provide a test that was unavailable, that was almost coercion.” Nonetheless, he saw that patient care had benefited from the presence of his project.

Dr. Muyenje also had several exciting prospects for new research projects in his future. He was one of two local faculty who had been accepted into a new professional development program that Dr. Beale had initiated through his home university. Called the International Scholars Initiative, the five-year program provided research training, mentorship, and funding support to promising African health professionals. Through the initiative, Muyenje was working closely with Beale on a grant application for a new study of physician retention that would examine how many graduates of Mbarara’s medical school had left the country to practice elsewhere.

Dr. Muyenje felt that the training and mentorship he received through both his Ph.D. and the Scholars Initiative were invaluable in developing his research pursuits. It was through these experiences that he had learned the art of grant writing and been introduced to the U.S. “culture of publication,” in which scholars’ success is often judged by the number of articles they have listed on PubMed. In Uganda, he told me, “We haven’t entered into the culture of publication. People do good things and they just have them on their shelves. It’s only recently that universities are starting to count how many manuscripts you’ve written and published.” Muyenje particularly valued the fact that he had been afforded the opportunity to work on research proposals from the very beginning. “I don’t really like it when somebody comes over [to Uganda] for a collaborating research [project] and he comes with a written proposal,” he told me. “I like it if somebody comes with an idea and says, ‘OK, I have this idea, how can we work on this?’ You see? Then we work together on developing the proposal. Then I take part in that, and take part in everything. But if you come and you say, ‘OK, I have this idea and this is my proposal, so are you interested or not—?’ Well, you are holding the money!”

Of all the doctors I met in Mbarara, Muyenje was perhaps the best example of a success story from a “development” or “capacity-building” perspective. He had gone to the United States for his Ph.D., but had returned to Uganda to work. His connections with American institutions had allowed him to initiate research projects that were both locally relevant and internationally recognized. The mentorship he received was giving him a growing ability to successfully navigate the world of foreign research funding.

He was on his way to becoming a leader in the field of global health. All of this was made possible because of AIDS, and the way that Uganda's epidemic in particular had drawn foreign resources into his country:

I think overall we've benefited from the international collaborations, and we are happy that they've happened. You know, we say HIV opened Uganda's doors to a lot of international organizations. If it wasn't because of HIV maybe not many people would have come here. I would maybe not have participated in that training program, an international training program, because it's the AIDS international training program. It's a bad thing that it happened to Uganda but I think it has also exposed the country to certain things that maybe we would never have seen.

Thus, for Dr. Muyenje, not unlike for Dr. Beale, AIDS in Uganda represented both a tragedy and an opportunity.

## **Collaboration**

The obstacles of time, funding, and infrastructure were faced by all the aspiring physician-researchers I spoke with in Mbarara, but they were not insurmountable. As their perspectives show, some doctors were building very promising research careers for themselves on topics that were of great personal interest to them. Others felt forced to do research on AIDS, rather than a topic of their choice, because of donor priorities. Some, like Dr. Mutungi, saw too many barriers to pursuing research and stuck to clinical work, but resented being "out of the loop" when it came to research happening within their own clinic. Still others preferred to work primarily as clinicians, and took supplementary positions in research simply to make ends meet. In other words, the relationships that doctors had to research (and its international networks) were diverse.

In her study of medical education in Malawi, Claire Wendland describes Malawian doctors-in-training as having both a "desire and distaste" for international research work (Wendland 2010, 167). The doctors I spoke with in Uganda were similarly ambivalent: they were grateful for the opportunities and resources that research brought, but also frustrated by the way in which foreign (usually American) control governed their involvement, often

requiring them to “dance to the other person’s tune,” in Kizza Mayanja’s phrasing. What their perspectives have in common is a desire for *inclusion*: to be a part of the research discussion, rather than just instruments in the logistical execution of science.

This was a lesson that Beale’s team learned through trial and error over the course of the development of the clinic database. For the first several years of the database’s existence, the research team faced discontent from many doctors who resented the extra paperwork the project caused them, and were unconvinced by the Americans’ insistence that the database was benefitting clinical care. As Eve Ozobia told me, the clinicians’ reaction was, “You’re asking us to do research, and you’re not paying us.” It was not until the database software was updated to allow the production of a “patient summary sheet”—a one-page print-out of all a patient’s relevant clinical information from previous visits—that doctors began to experience the database as useful to their clinical practice. Dr. Balenzi, the clinic director, explained, “If you have a summary of the latest information about the patient in terms of the CD4, Hb [hemoglobin], clinical stage, drugs given, it helps the clinician not waste too much time looking through the file from the beginning” in order to search for it. Other doctors also spoke favorably of the summary sheet, which by 2009 had become integral to their clinical practice. In retrospect, Ozobia told me that if she had to go through the process over again, she would make sure the patient summary sheet was operational from the start:

We implemented this database and two years later the summary sheet section started working. And this was the time when the clinicians were saying, “This is a research tool. What are we getting out of this?” They didn’t see the relevance. And if I were to do this over again, I would not implement the clinic database until that summary sheet is available. Because the clinicians needed to see the relevance.

In addition to the patient summary sheets, the data team began generating weekly and monthly reports showing how many patients had been seen and how many were scheduled to come. These reports became a key tool in the weekly clinicians’ meetings, providing doctors with both a tangible record of the work they had done and a means by which to anticipate and strategize for heavily scheduled clinic days. Moreover, the researchers began

including input from more doctors (beyond just Atuhaire) as they continually revised and updated the information the database was designed to collect. One doctor, for example, was interested in learning about rates of circumcision, which had recently been shown to reduce HIV risk in men, so the team added a question about it to the clinical encounter form. All of these steps eventually helped win the clinicians over, giving them a stake in the “donation” they had formerly viewed with resentment.

Similarly, the aspiring researchers I interviewed spoke favorably about international research projects in which they felt they had been genuinely included. For Felix Musoke and Kizza Mayanja, fortuitous connections with international colleagues had allowed them to pursue self-initiated research projects by linking them with funding sources not available locally. Their experiences demonstrate the importance of “contacts,” to use Musoke’s word, to the success of Ugandan research endeavors. As Julius Katabira told me, it was necessary to “be attached to someone” in order to succeed in the research world. Katabira viewed his own attachment to Beale as a two-way street: he helped Beale run his Mbarara-based studies, and in return Beale mentored him in his own efforts to analyze and publish data collected by the research. For Dr. Muyenje, too, his contacts with both Beale and his U.S. dissertation advisor had been key in opening up research opportunities for him.

Of course, this is nothing new in science. Both “contacts” and mentorship are essential to the success of researchers’ careers within the United States as well. In the United States, as in Uganda, junior researchers advance by linking themselves to more established scientists, who have the standing to win grants and get published in top journals. What is different in the cases I describe in this chapter is that the transnational nature of these relationships—and specifically the fact that they are between researchers in a very wealthy country and researchers in a very poor country—embeds them in postcolonial power dynamics steeped in the politics of global health philanthropy. For this reason, actions that might be unremarkable or even expected within the United States—for example, Beale’s assumption of ownership over the clinic database he funded, or my interviewees’ expectation that they would be compensated for their time—become caught up in a politics of assistance and autonomy that positions Americans as donors and Ugandans as dependent aid recipients or targets of development. This dynamic is further exacerbated by the lack of local funding opportunities in

Uganda, which frequently forces aspiring Ugandan researchers to fund their studies out of their own pockets, and makes linkage to U.S. and European projects an obligatory passage point for Ugandans wishing to conduct ongoing research (Latour 1987). In such a situation, it becomes very challenging to forge relationships that are collaborative. Nonetheless, as I think some of the stories above show, it is certainly not impossible.

In her critique of medical humanitarianism in France, Miriam Ticktin argues that humanitarianism depoliticizes its targets. “The subjects of humanitarianism,” she writes, “forever miss the jump to full citizenship” in that they “must remain subjects of benevolence, not of full rights” (Ticktin 2006, 129). Though Ticktin’s subject matter (immigration law) differs from mine, her argument is useful here. In envisioning their research in a humanitarian register (as aid), American scientists diminish the possibility of relating to their African counterparts as colleagues. As Mahmood Mamdani has observed, this reduction of collaboration to assistance serves to foster a “consultancy culture” at African universities that discourages the development of independent inquiry and expertise (Mamdani 2011). Furthermore, this humanitarian framing of global health science misrecognizes the value of transnational medical research, which is as much or more about forging mutually beneficial social relationships as it is about providing lifesaving care (Stewart and Sewankambo 2010; Geissler et al. 2008). This is true not only for African research subjects, but for African medical professionals as well. For both patients and professionals, the value of international research lies not just in “mere material benefits or means of survival” but also in “long-term relations and new kinds of belonging” (Geissler 2011, 60). In this register, the social relations of global health science—being “attached to someone,” in the words of Dr. Katabira—are about a desire for social collectivity and membership in a scientific community. Similarly, the doctors’ desire to be compensated for their time spent being interviewed for my research should be read not as self-interest or greed, but as a moral call for social inclusion in a transnational scientific collective and its attendant economy.

Ticktin’s insight into the power dynamic of humanitarianism is remarkably resonant with Eve Ozobia’s assertion that “If you’re giving me a hand-out, you don’t see me as an equal.” For her part, Ozobia was adamant about the need to avoid this dynamic in the future by formalizing any new research agreements with the Immune Wellness Clinic, rather than relying on the

informal processes that had led to the initial development of the database (and the subsequent conflicts over it):

Now what I tell Jason [Beale] is, if we are to ever embark on an institutional collaboration—I don't want to do anything without several meetings, without written documents, without an MOU [memorandum of understanding]. Not just an MOU but a written *plan*, up front, signed by everybody, so that we don't get into the kind of mess that we got into with the clinic database.

It was Ozobia's opinion that this kind of formalization would allow for open negotiation of research terms between all parties, and codify agreements in written documents so as to avert future confusion or disagreements. In her view, the informal way in which the database was initiated would never have taken place in a U.S. context, where all the issues around ownership and control would have been negotiated up front. Significantly, it is just this kind of negotiation that Dr. Muyenje described as critical to meaningful participation and inclusion in research. He resented foreign researchers who appeared with their proposals in hand, looking for local doctors to implement a scientific project they had already designed. What he enjoyed was when researchers approached him as a colleague—someone to bounce an idea off of—and worked with him collaboratively in crafting the shape and focus of the research. He wanted to be included as an architect of global health science, rather than simply an administrative conduit or local stepping stone.