# **POPULATIONS AT RISK**

# AMPATH: Living Proof that No One Has to Die from HIV

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BACKGROUND AND OBJECTIVE: The HIV/AIDS epidemic in sub-Saharan Africa is decimating populations, deteriorating economies, deepening poverty, and destabilizing traditional social orders. The advent of the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) made significant supplemental resources available to sub-Saharan national programs for the prevention and treatment of HIV/AIDS, but few programs have demonstrated the capacity to use these resources to increase rapidly in size. In this context, AMPATH, a collaboration of Indiana University School of Medicine, the Moi University School of Medicine, and the Moi Teaching and Referral Hospital in Eldoret, Kenya, is a stunning exception. This report summarizes findings from an assessment of AMPATH staff perceptions of how and why this has happened.

**PARTICIPANTS AND APPROACH:** Semistructured, indepth, individual interviews of 26 AMPATH workers were conducted and recorded. Field notes from these interviews were generated by independent reviewers and subjected to close-reading qualitative analysis for themes.

**RESULTS:** The themes identified were as follows: creating effectively, connecting with others, making a difference, serving those in great need, providing comprehensive care to restore healthy lives, and growing as a person and a professional.

**CONCLUSION:** Inspired personnel are among the critical assets of an effective program. Among the reasons for success of this HIV/AIDS program are a set of work values and motivations that would be helpful in any setting, but perhaps nowhere more critical than in the grueling work of making a complex program work spectacularly well in the challenging setting of a resource-poor country. Sometimes, even in the face of long odds, the human spirit prevails.

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I live in the village that my clinic serves and know many of the people who come to the clinic. When they first come they are weak and often think they are in a hopeless situation. Watching them get first medicines, then get food for themselves and their families, gain strength, and become themselves again is inspiring and gives me hope that *no one has to die* of HIV. [Clinical Officer]

**F** or the past decade, HIV/AIDS has been decimating populations in sub-Saharan Africa while virtually all attempts to control the pandemic have failed. With the advent of highly active antiretroviral therapy in the mid-1990s, the number of deaths from HIV in the United States began to fall precipitously, but in sub-Saharan Africa the morbidity and mortality from HIV continued virtually unabated. In some parts of Africa, the prevalence of HIV in populations of economically productive adults is nearing 30%, antenatal clinics swell with HIV-infected women oblivious to their HIV status, and the ranks of orphans increase at a frightening rate as parents die without access to treatment. The international community has mobilized billions of dollars to help Africa respond to its HIV/AIDS problem, but there are limited examples of large-scale success.

The purpose of this report is to describe staff work dynamics in a system of HIV/AIDS care that has arisen in response to the daunting set of sub-Saharan HIV challenges, made its services accessible to an estimated population of two million persons in western Kenya, and demonstrated an exceptional record of successful program decentralization and growth in enrollment. This system, called *AMPATH*, the Academic Model for the *P*revention and *T*reatment of *HIV/AIDS*, was founded in 2001 with private philanthropic support and has subsequently developed into one of the highest-performing HIV/AIDS control systems in sub-Saharan Africa.

### **ORGANIZATION OF AMPATH**

The history, organizational structure, and health programs of AMPATH have been described in a recent publication. <sup>5</sup> AMPATH emphasizes regional Kenyan leadership and a diverse consortium of providers. <sup>6,7</sup> Founded upon a 17-year collaboration between Indiana University School of Medicine and Moi University in Kenya, AMPATH *leads with care* but leverages and hosts activities of all academic missions—clinical care, teaching, and research. The directors of AMPATH are the

Director of Moi Teaching and Referral Hospital and the Dean of Moi University Faculty of Health Sciences. One General Internist from Indiana University (JM) has served on-site in Kenya as coordinator of AMPATH clinical activities since the program's inception.

AMPATH operates HIV/AIDS care clinics and screening programs in the city of Eldoret at Moi Teaching and Referral Hospital (Kenya's second national referral hospital) and in a network of 18 other district hospitals and rural health clinics. Currently, it delivers care to more than 52,000 patients (of the estimated 200,000 HIV-infected persons in its service area), has nearly half of these patients on antiretroviral therapy (ART), and is enrolling more than 2,000 new patients per month. AMPATH mainly employs teams of Kenyan clinical officers (akin to physicians' assistants in the U.S.), nurses, and nutritionists who work within facilities owned and operated by the Kenya Ministry of Health. These teams are formally supervised by medical doctors, but the bulk of the antiretroviral therapy is prescribed and monitored by clinical officers using standardized clinical algorithms.<sup>8</sup>

Experienced observers of global HIV programs, including leadership in USAID, Kenyan Ministry of Health, WHO, and major philanthropies<sup>9</sup> consider AMPATH's record of enrollment growth in response to population need to be "best in class" among PEPFAR and other programs. In addition to remarkable growth, AMPATH's patient retention, adherence, and restoration of immune competence among patients meeting criteria for ART have also been favorable. <sup>10</sup> Interest in understanding the determinants of this success moved the principals of the Purpleville Foundation (PVF), a Canadian private family foundation with a record of commitments to global health, to request and sponsor an evaluation.

#### AMPATH EVALUATION—A FIRST STEP

In January 2006, work was initiated for the larger AMPATH evaluation. The initial qualitative field work was focused on staff dynamics that supported the program's robust performance. How the program had been able to perform at such a high level and, in particular, what has permitted this performance to be sustained in a social environment often marked by organizational failure (and even corruption) was not self-evident. In effect, the qualitative evaluation sought to answer the question, "What makes AMPATH tick?"

#### **METHODS**

In January of 2006, one of the authors (TI) conducted 26 semistructured interviews with consenting AMPATH program personnel and closely related others. The general form of the interview was derived from the organizational development method of "appreciative inquiry" (AI). 11,12 AI is an organizational development method that employs interviewing and storytelling to draw out the best of an organization's past experience. It is a process designed to:

- facilitate the discovery of factors that give life to an organization;
- change the nature of conversations in an organization;
- stimulate the emergence of an organization's collective "future vision"; and
- set the stage for future action.

The assumptions of AI are two: (1) something is working well for every person or group in an organization and (2) looking at what works well and doing more of it is more motivating and energizing than looking for what does not work and trying to fix it. In this setting, AI interview approaches that have been widely used in industry and academe were adapted to serve as the basis for exploring AMPATH performance from the diverse perspectives of a sample of AMPATH personnel. The actual interview protocol, in outline form, is available from the authors. This study's activities were approved by the Moi IREC (Moi University's NIH-approved Institutional Review Board [IRB]) and Indiana University's IRB.

AMPATH personnel interviewees were drawn from a strategic sample of personnel, including: occupants of leadership, administrative, and line positions. No person declined to be interviewed, although certain program personnel were in the field and unavailable during the interview period. Interviews were conducted at 3 program sites over a period of 2 weeks. All interviews were audiotaped and extensive field notes were taken. Interviews were approximately 60 minutes in length (ranging from 50 minutes to 85 minutes) and were conducted in office settings. Audiotapes of 2 interviews were technically flawed—one because of background noise and the second because the digital recorder exhausted available memory in midinterview.

The procedures followed by the analysis team are wellaccepted qualitative research methods in the tradition of crystallization/immersion described by Crabtree and Miller. 13 The recorded interviews and field notes were reviewed for "themes" within and across question responses by Inui. Twenty of the interview recordings were also reviewed by at least 1 other individual from the analyst group that included John Sidle, Richard Frankel, and Tadeo Muriuki. Each of these reviewers listened to the recording of the interview and independently recorded "field notes" for comparison with Inui's original notes. These independent analysts also extracted and compared themes. Themes independently identified from paired field notes revealed an extraordinarily high degree of concurrence between reviewers. Of all themes identified by either reviewer in an analyst pair, 90.1% were identified by both members. These themes are listed in the accompanying table, grouped by analyst consensus into 6 domains, shown as headers within the table. After consensus themes were codified, narratives from the interviews were identified as illustrative of the themes. Condensed versions of these stories were developed (to shorten them and preserve appropriate degrees of confidentiality) and were reviewed by the analysts to ensure that the meaning and natural language of each story were preserved. The condensed stories are presented to illuminate the themes.

### **CREATING EFFECTIVELY**

Putting patients first

From the beginning we have tried to put patient priorities and patient treatment activities first in order of importance. Unless we succeeded with patients, nothing else we might say would convince anybody to trust us. When we did succeed with patients, many were astonished and wanted to help. [Physician]

#### Working between organizations

It has been helpful for AMPATH to work "between organizations" like the School of Medicine and the Moi Teaching and Referral Hospital. When one organization's policy is a barrier, the other can sometimes create a more flexible environment. In the space between organizations nobody is really "in charge" and the program can make progress rapidly. [Hospital Director]

#### Providing transportation

In the beginning there was one driver, one car, many trips, and many people to transport. Although the work days were long, we somehow made it work. Now there are twenty cars and twenty drivers, twelve sites, a very large number of daily trips, and even more personnel than I could have imagined. Somehow we still make it work. You learn how to recognize other peoples' strengths and to rely upon them. [Driver]

A number of personnel believe that having an opportunity to be innovative and creative in their work is highly effective in growing and improving the operational efficiency of the program. More than that, seeing such innovation be successful and sustainable is inspiring. Virtually all AMPATH employees said something about the importance of participating in "something that really works," whatever risks and personal investment are required. In the beginning it was not clear that taking care of patients with AIDS would be beneficial at all. Seeing these individuals improve and participating in growing the program that helps them is thrilling for AMPATH personnel. Indeed, 1 interviewee expressed the opinion that—in some deeply ironic way—"HIV might be good for Kenya." In a society with so much chaos, she ventured, where it is so very difficult for anything to really work, seeing an HIV program begin and succeed is "an important lesson for us all."

# CONNECTING WITH OTHERS—THE AMPATH TEAM, PATIENTS. AND OTHERS

#### Teamwork pays off

In a village one morning I was surprised to see that colleagues from several different AMPATH programs had, apparently by chance, all arrived there on the same day to pursue their different activities. For my part, I was to explain to people in the village a new form of nutrition—a powder that didn't look like food at all. Because we had all come together, an impromptu large village gathering formed around us and gave us a chance to work together as a team. It was exciting and got the message to the people about why the different parts of the AMPATH program are each important and how we work as a team. [Nutritionist, Program Leader]

#### Leaving my wife in labor

This work is demanding and requires total commitment. The day came when I was supposed to go to work in clinic, but my wife was at home in labor with our second child. I was uncertain what to do. She was healthy, and I thought she would have a successful labor. My patients in clinic were often severely ill and needed me to be

there, so I left her at home and went to the clinic. Twenty minutes into the clinic work there was a knock at the office door and Joe Mamlin was there, saying "Go home to your wife!" I did, and we successfully delivered the new baby—a boy named Joe Mamlin. [Clinical Officer]

#### Avoiding a crisis

When I came back from my maternity leave, I was proud that the pharmacy was working beautifully-my colleagues had successfully taken over my duties in my absence. When I reviewed the supply of medicines in the store room, however, I was stunned to realize that we were going to run out of medicine for our patients in about six weeks! I could not rapidly increase our supply from abroad because orders for new medicines often take a long time to be filled. I called a number of pharmacists I knew in HIV/AIDS programs in Kenya, asking whether they could loan me a small supply of antiretroviral drugs for a short period of time. Every single one of them helped, and with a little bit from here and there we made it through without putting any patient at risk. When my big supply came in I repaid the other pharmacists. Pulling together, acting in trust and faith, we avoided the crisis. [Pharmacy Director]

Everyone among the AMPATH interviewees emphasized the importance of strong relationships with one another and with patients and their families. Watching patients recover gives hope to all. Seeing the extraordinary commitment of the programs' founders—perhaps notably the IUSM anchor physician Joe Mamlin's example—has been an inspiration, but the stories of how various AMPATH personnel work together as a team, recognize and celebrate their interdependence and teamwork also abound.

#### MAKING A DIFFERENCE

#### Coming back

One of the most challenging patients I've ever cared for was pregnant, HIV positive, and developed head and neck cancer. When I first saw her in clinic I thought she would die before we could get her to the hospital. Putting her in the car, we drove to the hospital, delivered a healthy baby after spontaneous labor, started her on chemotherapy, and—once regression of her tumor permitted swallowing—started her on ARV's, I thought she had truly come back from the dead. She remains tumor-free to today. I love seeing her and her healthy child in clinic. [Physician]

#### Presenting at a national conference

I was pleased, but somewhat surprised, to be asked to represent the AMPATH program at a gathering of the national leadership and officials in the Ministry of Health in Nairobi. It was in the early days of AMPATH and I did not consider myself to be a major figure or leading expert in the care of patients with HIV. I presented the approach we had developed at AMPATH, describing what we were doing as a doctor might—using cases—and was gratified to see how excited others became at our success. I think it was understood that

we were truly pioneers and had found a way forward that worked. Now we are regularly consulted on policy and program approaches. We are known for making something work. [Physician]

Reports of seeing people who "come back from the dead" are strong part of the narrative fabric of AMPATH. Beyond this "medical miracle" there is the sense that the emergence of AMPATH as a successful program has been a "pathfinder" development for the institutions involved in its founding, including Moi University School of Medicine, Moi Teaching and Referral Hospital, and Indiana University School of Medicine (as well as Brown University and other institutions from the northern hemisphere involved in AMPATH activities). Many feel that by its operation and success, the program is making a contribution to national and international policy as well as to the health of vulnerable populations.

#### SERVING THOSE IN GREAT NEED

#### Advocating for a patient

In the early days of AMPATH treatment, we had too few antiretroviral drugs to treat the many patients who actually needed them. I was working in the clinic every day and noticed one woman who came back and back begging for medicines, asking whether just a few pills might be available for her. Finally the day came in which we had a treatment slot for one more patient. I described this woman, her many visits to the clinic, and how I was sure she would completely adhere to all our requirements if she were given a chance to take the ARVs. When the team decided that she could now be treated, she could not stop crying—from happiness and relief. She is one of our best patients and takes wonderful care of her family. [Nurse]

#### Magic

I work in a number of locations that others in AMPATH may not see. Because I hear who is sick, hiding, and not coming at all to our clinics, I sometimes visit them in their homes to help them decide to get care. Some of them think there is no recovery from HIV. Others don't want neighbors or other people in the village to know they are sick. Slowly, we are making progress even with these hard-to-reach patients and their neighbors. When I finally talked one man out of his house and, after treatment, he was restored to total health, his neighbor said to me, "What do you people do over there—magic?" [Director, Outreach Service]

The philosophic foundations of the program are easily identified in the interviews. Program personnel, from top to bottom, feel "called" by a service ideology. They particularly recognize the need to respond to the most vulnerable populations, including the sickest and poorest individuals in western Kenya, children, orphans, widows, and others. There is an explicit, shared belief in the need to put these individuals and their care first among all priorities.

# PROVIDING COMPREHENSIVE CARE TO RESTORE HEALTHY LIVES

#### Getting tested

I saw a patient in clinic with abdominal pain and had to transport her to a hospital on an emergency basis in my car. She turned out to have a pelvic inflammatory disease and almost died from this, but she also had HIV when she was tested. When she recovered she brought her daughters to clinic for testing and more recently has brought other women to the clinic to be certain they are checked for HIV. I think she wants all women in the village to stay healthy. [Clinical Officer]

#### How far can he go?

I took care of a patient in our clinic whom I saw for a long time before he was eligible to start on antiretroviral drugs. Once he began to take the medicines, he regained his health and didn't need to come in to the clinic as often, or to see me when he came. One day, when he was in clinic, he saw me and said, "Now I am too well for you to talk to me anymore, but do I have to be sick for you to say hello?" I felt sad about this and when it occurred to me that I needed help at home on my farm I asked him to come and do this work. Now he lives on my farm and looks after the animals. He is almost becoming a member of my family. He has come a long way, but I am interested to see how far he can go! [Clinical Officer]

AMPATH workers are proud of treating the whole person and attending to nutritional and income security as well as medical care. They are acutely aware that PEPFAR support for drugs will end and that patients must be ready to be self-supporting. They recognize the importance of this matter and are eager to work on prevention, behavior change, and employment as well as medical care.

# GROWING AS A PERSON AND AS A PROFESSIONAL

 $\label{thm:equivalence} \textit{Having the confidence of others}$ 

When we first started to do research, it was decided that a special office was important to provide standard administrative procedures and support services for research. I had some relevant experience, but not a great deal of it. When I sat with the two senior directors they asked, "Are you ready to take this challenge?" I was, and it felt good to have their confidence from the beginning. [Administrator]

Personal and professional growth is a significant part of work motivation and satisfaction among AMPATH workers. They have created a community of trust and teamwork, within which each person's new skills, knowledge, and capacities serve everyone else. At every turn, they are eager to get and give training. The program environment supports this use of expertise, new and old, to the fullest, and provides resources for training and innovation.

## **DISCUSSION**

This study has limitations that are important to cite. It was undertaken because AMPATH is a remarkable case which, if explored, might have heuristic value for other programs. Like all case reports it has unknown generalizability. Although we used our best efforts to triangulate data, all qualitative methods are subject to "observer bias." The study concentrates on worker performance dynamics and isolates these from other determinants of program performance.

There are, of course, many explanations for AMPATH's success. Some of the most important are the international organizational cooperation that undergirds AMPATH and the program's systemic approach to HIV prevention and treatment—a holistic, biopsychosocial approach to health care that includes prevention, medical care, nutrition, psychosocial support, and income security. Clearly, the availability of PEPFAR funds and other resources (e.g., volunteered effort, food, land, and institutional infrastructure) have been critical to the capacity of the program to initiate, sustain, and expand its efforts.

Like all high-performing programs, however, AMPATH must operate, grow, and innovate through the efforts of its inspired workers. Rising to the challenge of Kenya's HIV epidemic requires shared, sustainable staff commitment to a holistic vision of health, the belief that their work will succeed in spite of daunting circumstances, and efficient and effective use of resources, even in the face of daily tribulations. The odds are stacked against any such effort succeeding. Kenya, like many other developing countries suffers not only from the spread and adverse impact of HIV, but from substantial and entrenched health problems attributable to malaria, tuberculosis, malnutrition, poverty, unemployment, social violence, ineffective governance, untrustworthy institutions, ossified bureaucracies, low educational attainment, gender inequities, tribalism, and limited development of transportation infrastructure. The people of Kenya, including the AMPATH workers, know all of this.

The AI method does not highlight these negative contexts. As an organizational development and research method, AI focuses instead on "positive" stories because these success narratives show the way forward in spite of many challenges. Whereas they do not "pathologize" organizations, people, or social orders, AI narratives are not naïve. The stories collected for this study could also be read to reveal the program's challenges. The "Working between organizations" story is remarkable precisely because several bureaucracies did not reduce AMPATH to a "least common denominator" organization, paralyzing it by requiring compliance with all their policies. "Putting patients first" reveals how AMPATH secured trust, a critical but scarce resource at the beginning of program operations. "Providing transportation" reveals the lack of basic infrastructure, including daily staff transportation to and from decentralized clinical sites. "Teamwork pays off" documents successful teamwork in spite of the risk for interdisciplinary conflict and chaos. "Patients give and get hope" simultaneously highlights the generally hopeless state of HIV-positive patients before the emergence of an aggressive ART program and how staff are inspired by patients (avoiding burnout). "Avoiding a crisis" documents the resiliency of a

staff network, but also the tenuousness of the drug delivery supply chain. Other challenges visible in the stories include a background of folk beliefs that attribute HIV/AIDS to witch-craft, the risk of unemployment for HIV-positive persons, the need for a larger skilled workforce. AI does not neglect challenges and barriers, instead, it shows how people in effective programs have found ways to overcome them.

Against all these odds, the AMPATH workers know that they have made something work—and have done this together. From the highest levels of leadership to the critically important support staff, everyone within the program feels him or herself to be a vital participant in the work of the program, someone without whom AMPATH could not succeed. These individuals are spurred on by the daily experience of making a difference to individuals, their region, their country, and the world. In a highly challenging environment, they have created a trustworthy community of work and action. In an impoverished society, they have found a richness of spirit. Unlike mythical Camelot, AMPATH is a hardworking, sleeves-rolled-up enterprise marked by flexibility, innovation, and quick response to need. It succeeds because it serves. It inspires because it expresses in the daily round of intense AMPATH activities the core aspiration of humankind to help one another, especially the most vulnerable among us, whatever the challenges.

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#### **APPENDIX**

AMPATH Staff Interview Themes

"Creating effectively"

New challenges, new opportunities

Program innovation

Being flexible

Making something really work

Making "long shots" pay off, taking risks

Using the advantages of working between organizations instead of within them

Sharing credit for our achievements with others (e.g., the Ministry of Health)  $\,$ 

Investing in training, education, counseling

Successful advocacy for patients and program

"Connecting with others'

Networking, liaising with community, including rural locations

Forming strong relationships to patients

Taking patients into our lives

Teamwork, trusting others, relying on others, partnering with other disciplines

Seeing other committed people work

The force of Joe Mamlin's example, determination, confidence,

Good, supportive working environment

"Making a difference"

#### (continued)

Seeing people brought "back from the dead'

Growing a large program

Answering national-level questions

Being supported with what's needed (various resources)

Responding to big needs

"Serving those in great need"

Believing in the potential of humankind

Serving the most needy, the most vulnerable

Treating children

Putting patients and their care first

"Providing comprehensive care to restore healthy lives"

Treating the whole person, being patient-centered

Working on prevention, behavior change

Fostering hope, recovery, independence

Providing psychosocial support, nutrition and income security

"Growing as a person and a professional"

Finding work

Being trusted with big responsibilities

Getting training, new skills

Having and using relevant expertise to the fullest

Experiencing pride of accomplishment

Being collaborative, truthful, totally committed, competent,

confident, efficient

Becoming good at working with other people

Being in a good work environment, supportive and trustworthy

Being in a transformative community of care

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