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Michael David Arenson Date

Paying Attention to “Water”: A Pragmatic Ethics Argument for Returning Results from HIV Tests Performed During Population-Based Surveys in Sub-Saharan Africa

By

Michael David Arenson
Master of Arts

Bioethics

Kathy Kinlaw, M.Div.
Advisor

John Banja, Ph.D.
Committee Member

Drue Barrett, Ph.D.
Committee Member

Ronald Bayer, Ph.D.
Committee Member

Accepted:

Lisa A. Tedesco, Ph.D.
Dean of the James T. Laney School of Graduate Studies

Date

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Michael David Arenson
B.S., University of Minnesota, 2010

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Abstract

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This thesis argues for the development of a new HIV surveillance approach that better accounts for the current landscape of the HIV epidemic in sub-Saharan Africa. Today, one major driver of the HIV epidemic worldwide are people that do not know their HIV status. The method of surveillance commonly used in sub-Saharan Africa, called Unlinked Anonymous Testing (UAT), tests participants for HIV but does not return their results. Instead a referral voucher is provided for free Voluntary Counseling and Testing (VCT) where one can get counseled, tested for HIV (again), and if eligible, receive treatment. Simply referring survey participants to VCT, however, is ethically inadequate because of the barriers to VCT services (e.g. stigma). Instead, it is argued, one ethical approach would be to link the HIV tests performed during population-based surveys with home-based VCT. After many ethics consultations in the past, UAT was defended as the most ethical form of HIV surveillance. However as circumstances have shifted in sub-Saharan Africa, so have the ethical implications of not returning HIV test results obtained during population-based surveys.

When viewed through a pragmatic ethics lens, specifically through that of D. Micah Hester's *Community as Healing* [1], an argument is made that UAT has become an old habit (i.e. a habituation). In order to create new habits of surveillance, I argue, public health must pay more attention to the "softer," more intangible dimensions of the HIV epidemic in sub-Saharan Africa (i.e. behaviors and attitudes), and more broadly, to the ethics of public health. By doing so, public health creates new – and as Hester describes it – "intelligent" habits of HIV surveillance that better balance the population's need for accurate public health data with each community member's moral claim to information that could benefit their health (i.e. results of their HIV test) among other things (e.g. equitable access to VCT). Thus, Community as Healing accounts for public health's primary purpose of protecting populations, in addition to its ultimate goal of healing each individual within the population.

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Acknowledgements

It dawned on me one day during the early part of the process of writing this thesis that I have been drawn to the study of ethics since an early age. In preparing for my Bar Mitzvah, the synagogue had Saturday morning classes, or "rotations", that taught the 5th, 6th, and 7th grade students the prayers, how to read Torah trope, and Jewish ethics taught by Mr. Joel Green. In all there were about 8 or 10 principles that we learned, and the culmination of our ethics training was a mock trial in which the biblical figure Abraham was prosecuted. A redacted version of the story of Abraham goes like this:

Abraham was accused of the crime of *unethically* sending Abraham and his wife, Sarah's servant, Hagar and her son Ishmael (the son of Abraham), away into the desert to fend for themselves. I happened to have been chosen to play the role of Abraham, and as such I had to know the ethical principles inside and out; I had to be prepared to defend myself against the prosecution's relentless bombasts, and be ready to spin whatever principle they threw at me in a positive light. For example, if the prosecution said I did not act ethically because I violated the principle "Love your neighbor as yourself", I reminded them that in this situation I had two neighbors, Hagar and Sarah, and the latter was my wife. When deciding which "neighbor's" well being to honor, I naturally had to choose my wife's well being over my servant's. I guess I wasn't that great, because the jury found me guilty of being unethical.

I remember looking forward to that trial very much, and not just because studying Hebrew prayers and Torah trope was so dry. I remember one principle in particular: Do not put a stumbling block before the blind (in Hebrew: *lifnei iver*). It is a figurative expression prohibiting against misleading people, particularly when giving advice. In the case where the recipient of advice is unaware of the accuracy of advice, he or she would *stumble* if the advice were harmful or otherwise damaging. Amazingly, 10-12 years later I'm studying the same principle in the context of HIV surveillance in sub-Saharan Africa. As I hope to elucidate in the following pages, while in theory the surveillance method used to gather data by public health to track and plan intervention strategies against the HIV epidemic is ethical, in practice there are fatal stumbling blocks that public health has not accounted for: stigma; cultural practices of sex and marriage; intimate partner violence and the social status of women; inadequate state resources; and the implicit responsibility of low- and middle-income countries to prove that international funds are being used most effectively, to name a few.

I wish to acknowledge a number of very special people. First, I would like to express the deepest gratitude to all of my Faculty Thesis Committee members: Kathy Kinlaw, John Banja, Drue Barrett, and Ron Bayer. I do not know how I got so lucky to meet you all, let alone have the ability to draw on your time, energy, patience, flexibility, care, and of course, expertise. Second, for many of these same reasons, I would also like to thank Drue Barrett (again), Leonard Ortmann and Lindsay Feldman from the Public Health Ethics committee at the Centers for Disease Control and Prevention (CDC), and Mark White from the Centers for

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Also, I would like to thank everyone at the Center for Ethics for inviting me to be a member of your family. You all have made such a big impact on my life in so many ways, and words cannot express how thankful I am for you! As the story goes, if you teach a man how to fish, you feed him for a lifetime; while perhaps the only thing you did *not* teach me was how to cook, you did feed me for four semesters, and so I thank you for that as well.

Of all of the people at the Center for Ethics, however, I need to thank Kathy Kinlaw in particular for being my advisor "to the third power": In addition to serving as the chair of my faculty thesis advisory committee, she served as my academic advisor and the Public Health Ethics Club advisor, which she encouraged me to co-found. Needless to say, Kathy, I associate my awesome Emory experience with you more than anyone else. I cannot thank you enough for all of the time and energy you have invested in me over these past two years.

Last, but most importantly, I would like to thank Mom, Dad, Greg, and Haley, as well as my grandparents, Pokky, Bubbe and Zaddie. All I can say is thank you for *everything*. I owe you all more than I could begin to describe, and I love you all very, very much. And thank you also to Dani for making my life so colorful; always, in all ways, love…

Michael

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ABBREVIATIONS AND DEFINITIONS

ANC – Antenatal Care Clinic

CDC – U.S. Centers for Disease Control and Prevention

HTC – HIV Testing and Counseling

KAIS – Kenya AIDS Indicator Survey (population-based surveillance survey conducted in 2007)

OPRR - Office for Protection from Research Risks

PEPFAR - The US President's Emergency Plan for AIDS Relief (PEPFAR) was announced by President George W. Bush in 2003. As a result, in its first five years more than 2 million people were provided treatment, and more than 10 million people were given care, including more than 4 million orphans and other vulnerable children. Treatment was also provided in prevention of mother-to-child services during nearly 16 million pregnancies. In 2008 the second phase of PEPFAR began, with the aim of working through partner governments to support a sustainable, integrated, and country-led response to HIV. See www.pepfar.gov.

PHS – U.S. Public Health Service

PMTCT – Prevention-of-Mother-to-Child-Transmission Programs (housed in ANC)

UAT – Unlinked Anonymous Testing

UNAIDS - The Joint United Nations Programme on HIV/AIDS

VCT – Voluntary Counseling and Testing (one of many models of HTC)

WHO – World Health Organization

CHAPTER 1: SWIMMING IN PUBLIC HEALTH WATER

Two fish are swimming together in the ocean when they pass an older, wiser fish going in the opposite direction. “Morning, boys! How’s the water?” the wise fish asks. After exchanging brief pleasantries they swim on. A few minutes pass, then one of the two friends turns to the other and asks, “What the hell is water?”[2]

David Foster Wallace, prodigious author, began his 2005 Kenyon commencement address with a version of this tale. “The point of the fish story,” Foster said, “is merely that the most obvious, important realities are often the ones that are hardest to see and talk about.” ‘Water’ is woven inextricably throughout all of our lives yet we are unaware of it because it’s always there. We find water in all of human activity, including the thoughts, feelings and actions of people both affected by HIV as well as those working to eliminate it. In this case, water is the role human behavior plays in public health and the social connection we all share as a result of living in communities.

I spent a semester researching the ethics of HIV surveillance practices in sub-Saharan Africa at the U.S. Centers for Disease Control and Prevention (CDC). What I expected would be a short and simple ethical analysis turned into a report for CDC and this thesis. While there are ethical issues in HIV surveillance around the world, I am most familiar with sub-Saharan Africa and therefore focus primarily on that region. However, the ethical approach I use (in chapter 4) can – I believe – be applied to other cases of HIV surveillance globally. In addition, sub-Saharan Africa is also the region that bears the greatest burden of HIV, and as such, the habits that I propose public health develop in this region would likely have the biggest impact if implemented.

At its core HIV surveillance in sub-Saharan Africa has everything to do with “water,” because at their core public health and HIV expose us to the subtle, yet most important parts of human behavior. They remind us that humans are social animals, situated within and developing out of communities. This is not apparent to us all of the time, and we often forget how much we are products of the communities we come from and are apart of. When it does become apparent, though – when we do realize how interconnected we all are – humans can do great things. For example, raise millions of dollars for cancer research, provide emergency financial, medical, and humanitarian aid to people whose lives have been destroyed by natural-disaster, and eradicate diseases such as smallpox and (hopefully, soon) polio. But as we become more aware of water, we are required to change old habits and think intelligently about our actions. When our understanding of the facts changes, our understanding of how we address them does too.

I do not mean to intimate that I am the wise old fish (it is truthfully, quite the opposite). My only purpose is to contribute in some way to solving the following problem: the number of cases of HIV, globally, continues to increase and has increased each year since HIV was discovered in 1981. Put more concretely, in 2010, an estimated 2.7 million people were infected with HIV, and approximately 1.8 million deaths were due to AIDS (see Figure 1). At the end of 2010 an estimated 34 million people were living with HIV worldwide. This 17%

increase from 2001 is due in large part to greatly expanded access to antiretroviral treatment (ARV).[3]

Until an effective vaccine is created, the burden of HIV will continue to increase. In the mean time, other preventive measures must be taken. One major driver of the epidemic exists when people do not know their HIV status.[4] The number of people who do not know their HIV status in six sub-Saharan Africa is estimated to be between 30% (Kenya) and 70% (Congo).[4] When people do know their status, however, they change their behavior in ways that significantly decrease chances of passing on the virus.[3] One of the most efficient ways of decreasing incidence, therefore, is improving people's knowledge of their own HIV status.

Currently many people are tested for HIV surveillance purposes, however the method of surveillance most often used in sub-Saharan Africa precludes individuals from receiving their HIV test result. This is in part done because surveillance is generally not used for clinical benefit, but instead for monitoring and planning purposes of public health activities or programs. Often, however, an HIV test performed for surveillance purposes is the only test an individual will receive in many years, or provides the most convenient opportunity to learn of their HIV status. As such, efforts in Africa are missing a tremendous opportunity to inform those who participate in epidemiological research in Sub-Saharan Africa of their HIV serostatus. I aim to contribute to public health's awareness of the "water it swims in" when it comes to HIV surveillance in Sub-Saharan Africa. My ultimate conclusion is that before HIV burden can be decreased – or at the very least, in order to accelerate the elimination of HIV and thus save more lives

– public health must develop an HIV surveillance approach that not only performs quality epidemiological research, but also, when circumstances dictate, effectively returns HIV test results to participants.

CHAPTER 2: SURVEILLANCE AS “WATER”

June 5, 2011 marked the 30th anniversary of the first report of Acquired Immune Deficiency Syndrome (AIDS) in Morbidity and Mortality Weekly Reports (MMWR).[5] Over the past 30 years, the HIV/AIDS epidemic has taken more than 25 million lives worldwide and more than 60 million people have become infected.[6] Some estimates list total lives lost due to AIDS at 30 million.[7] Each day, more than 7000 people around the world are newly infected with HIV, including 1000 children.[6] According to a UNAIDS report [4], 1.8 million people died as a result of AIDS in 2010, and 6.7 million people were put on HIV antiretroviral therapy, including close to half a million children.

But as these bleak statistics are cited, attention must be given to the first example of water public health swims in, namely surveillance. Surveillance is defined by the Centers for Disease Control and Prevention (CDC) as, “the ongoing systematic collection, analysis, and interpretation of health data for purposes of improving health and safety.”[8] Surveillance is critical to evaluating existing public health programs, tracking trends in the spread of HIV/AIDS, and is largely considered a “foundation of the public health response to the HIV pandemic.”[9] Surveillance further helps public health stakeholders plan and implement public health programs and strategies. The method that has historically been used for HIV surveillance, however, has been the subject of a long, at times rancorous debate.

Controversy Surrounding Unlinked Anonymous Testing (UAT)

The method of HIV surveillance employed at the beginning of the epidemic, called Unlinked Anonymous Testing (UAT), was developed in response to three main issues. All three were ethically charged in-and-of themselves, but HIV surveillance brought all of them to a head. The first issue was the stigma surrounding AIDS along with the complete lack of therapeutic prospects for HIV-infected individuals. Second was the debate of whether surveillance was human subjects research, and therefore requiring informed consent from all participants. And third, without a clear answer on the 'surveillance as research or non-research' distinction, public health was trying to develop a surveillance method that acted in accordance with the part of the U.S. Code of Federal Regulations that protected human subjects in research (which will be referred to as 45CFR46, for reasons made clear below).

In the 1970's, the U.S. government had passed and promulgated federal research legislation and guidelines that built on the Nuremburg Code of 1947 and Declaration of Helsinki of 1964. The latter two were created in response to the unethical use of humans in research performed by the Nazi regime as well as America's own Public Health Service (PHS) during what is known today as the Tuskegee Syphilis Experiments.[1] The capstone of those efforts was Title 45, Part 46 of the Code of Federal Regulations (45CFR46), which lays the legal

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[1] The technical name for the Tuskegee Syphilis Experiments is the U.S. Public Health Service Syphilis Study.

groundwork for protecting human subjects in research. Ultimately what the creation of these regulations did was prioritize the rights of the individual over that of the society (i.e. privacy, freedom and confidentiality).[10] According to 45CFR46, in order to perform research on a human subject, their explicit consent must be obtained first and they must be made reasonably aware of the risks of participating in said epidemiological research.

In 1981, the U.S. Department of Health and Human Services (DHHS) explicitly exempted epidemiological research involving *already existing* data from informed consent requirements, provided the risk to subjects was minimal, the research did not record data in a way that was individually identifiable, and the research could not otherwise be conducted.[11] In other words, if research data was completely unlinked from any and all identifiable information (i.e. the person the data described could not be identified), the requirement to obtain informed consent from the subject could be waived.

Coincidentally, in 1981, a pattern of opportunistic infections began to manifest among homosexual men. Public health quickly realized that it could not rely on anecdotal evidence to track this new disease, but instead needed a system for collecting data and tracking trends. When the Centers for Disease Control (CDC)[2] began to plan for large-scale epidemiological studies around this time, it struggled with the type of surveillance it would use. It was afraid of two possible

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[2] The Centers for Disease Control (CDC) changed its name to Centers for Disease Control and Prevention in 1992. See in Bibliography: CDC 1992, *Announcement of CDC Name Change*.

situations called “selection bias” or “participation bias,” both of which would lead to inaccurate data. Selection bias exists when the person administering the surveillance test *selects* the participant in some biased way (whether consciously or not), while participation bias occurs when the participant does or does not get tested for some reason that leads to skewed data.

In the case of AIDS and HIV, the reason a person might not have taken part in a surveillance test was because of stigma. Stigma is a common theme in the story of HIV/AIDS. In many ways, the current controversy surrounding HIV surveillance stems from the stigma HIV-infected individuals – and those assumed to be HIV-infected even if they were not – received in the 1980’s and 1990’s. Stigma and myths about AIDS were so high that, for example, people were afraid of touching someone infected with HIV, even though HIV was passed through more intimate avenues (i.e. blood transfusion or sexual intercourse). Thus, creating the surveillance system for HIV required practitioners to be aware of the psychosocial consequences of simply being identified as *potentially* HIV-positive.

Due to 45CFR46, public health became more aware of ethical obligations to promote an individual’s ability to make autonomous choices and protect them from harmful medical and research practices. This meant an individual needed to be fully aware of the potential benefits and risks of participating in research so that they could not be conscripted into participating in research that they did not want to be a part of. As a result, obtaining individual’s informed consent, as well as maintaining privacy and confidentiality in medicine and research started to become standard ethical norms. This presented a problem for the CDC, however, when they began HIV surveillance. They feared that consenting individuals in order to collect information about their HIV-status would deter many people from participating in surveillance surveys. Who would participate in surveillance if doing so meant that they would be identified as *potentially* HIV-infected? The CDC was concerned that the participant's fear of experiencing stigma would lead to participation bias. As a result of the pervasive stigma – and reflective of the trend of the times to treat HIV as exceptional – obtaining an individual's consent to be tested for HIV surveillance – which, if not kept confidential could lead to psychosocial devastation for anyone suspected to be HIV-positive – was decidedly too risky.

As a result, in 1988 the CDC adopted Unlinked Anonymous Testing (UAT) as a method for HIV surveillance.[13] The process of UAT has changed over time, as will be described further on, but in its original form UAT described the screening of left over blood taken for purposes *other* than HIV surveillance, such as routine syphilis testing, and striped the specimen of all personal identifiers. Since no personal identifiers were collected, it could be carried out without requesting the consent of the patient. This also makes it cheaper, more efficient (at collecting data), and logistically simpler than non-blinded surveys. Ethically, blinded surveys ensure the participant cannot be identified, and thus issues of privacy and confidentiality are not raised.[14]

However the benefits of UAT were also the characteristics that were most open to criticism. The practice of completely unlinking the data precluded the individual from ever receiving his or her test result, and therefore from knowing whether he or she was HIV-positive. Unless he or she were to get tested a second time – which was unlikely due to the risk of stigma – they would not be aware of their HIV status, which increased the likelihood that they unknowingly would transmit the virus to other sexual partners, or in the case of pregnant women, to their babies. By not returning results public health was withholding valuable information that a pregnant women could utilize to take precautions to avoid transmitting HIV to her baby. In sum, UAT protected individuals from the social and psychological risks of being identified as HIV infected, as well as guarded the data from selection and participation bias. However it also precluded the individual from ever knowing their HIV status. Little did stakeholders know in the late 1980's and early 1990's that the same ethical argument would continue for the next thirty years.

Global Response to UAT

A variety of different perspectives greeted the implementation of UAT around the world. Public health decision makers in the United States, Great Britain, and the Netherlands came to very different perspectives on the same issue. In America, there was very little resistance by all stakeholders, including activists. In fact, it was largely supported; A working group comprised of philosophers, lawyers, social scientists, public health officials, gay rights advocates, and representatives of civil liberties organizations at the Hastings Center – a medical ethics research institute – raised no objections to blinded seroprevalance surveys.[14] Notably, neither the gay rights advocates nor the civil liberties organization's representatives took exception with blinded surveys because both were particularly sensitive to the possibility of putting individuals at risk of having their privacy violated. In addition to widespread political support, many states took swift legislative and administrative action in support of blinded surveys as well by enacting exemptions for blinded studies in their consent laws.[15]

A different landscape took shape in Great Britain. Unlike America, where primary stakeholders in public health's response to HIV/AIDS not only embraced blinded studies, but had been their biggest proponents, the English counterparts resisted on the grounds that doing so conscripted people into research activities. "I know that is an unhappy position for those who have to make policy," said Professor Ian Kennedy of the Centre of Medical Law and Ethics at Kings College in 1987, "but it is after all the heritage that we have acquired from Nuremberg and afterwards…" In addition, those who opposed blinded surveys argued that blinded surveys would perform bad science; by only collecting the most bare demographic facts (so as to avoid identification), the most important information about the spread of HIV would remain unanswered (i.e. HIV transmission between high-risk groups to the general population).[15] As such, in May 1987 the Social Services Committee issued a report stating on scientific and ethical grounds, that it was "unable to recommend the general use of anonymized screening at this stage."[16]

The report was quickly rebuked by prominent figures in the medical research community.[15] They argued that Great Britain's ability to track trends in the spread of HIV would falter. In response, the Minister of Health called for further debate and formal comment. Within six months of discussions, and in light of an increasing body of evidence on the social utility of blinded surveys, some of their biggest opponents reversed their positions. As a result, blinded surveys would be incorporated into Great Britain's HIV surveillance programs. But in response to those who continued to object, the program called for the public to be made aware that blood taken for routine medical procedures might be used for anonymous HIV testing, and that their right to refuse such testing would be respected if expressed in a 'spontaneous refusal'.[15]

Around the time that Great Britain had come to this decision, the Netherlands still had not been able to answer the question of whether to conduct anonymous HIV seroprevalence studies.[15] Despite ten months of debate by the Dutch Health Council's Standing Committee on AIDS, and its eventual recommendation to proceed with blinded surveys in February 1989, there remained a considerable amount of dissent among public and governmental figures. For example, the Dutch Secretary of Health hesitated to accept the recommendations, and expressed caution of that the Committee's recommendations should be implemented.[17] Nonetheless, there was enough professional and popular support for blinded surveys that parliament finally endorsed them. When a new government administration took office after national elections in September 1989, however, the issue of blinded studies was revisited and reversed. This protracted disagreement likely arose because of a pattern of Dutch public health policy that traditionally rejected compulsory measures as overly coercive and unwarranted. Physicians, for example, were not required by law to report cases of AIDS. Thus, as Ron Bayer wrote in 1990, the debate surrounding blinded surveys in the Netherlands led to, "a confrontation between the need to obtain critically important data bearing on the public health and a public health tradition which favors voluntary compliance to obtain reliable data from medical practitioners."[15]

Improved Therapeutic Prospects and Concern Over UAT in America

In the 1990's, therapeutic prospects for those infected with HIV improved dramatically. In 1994 a clinical trial showed that Zidovudine (AZT) could prevent mother-to-child transmission of HIV by two-thirds, which contributed even more to the unfavorable stance towards UAT.[18]

Learning that individuals were tested and not given their results, an assemblywoman in the New York State Legislature named Nettie Mayersohn introduced legislation in 1993-1994 that would require the State Department of Health to notify parents if their infant showed positive results on the HIV test performed anonymously.[19] This might be considered the moment when the debate became as polarizing as it did. In response, the New York State Assembly asked the Governor's AIDS Advisory Council to study the issue. The advisory council, after months of deliberation and hearings, recommended a policy of "mandatory counseling and strongly encouraged voluntary testing for all pregnant and postpartum women,"[20] in addition to other measures to strengthen counseling, testing and services for care. Pediatricians in particular, however, were obstinate. One group of pediatricians argued that the policy was "insufficient to offer the protection which every infant deserves" and that voluntary testing had an "unacceptably high failure rate."[21] Given the amount of dissent previously observed, it is perhaps unsurprising that other groups and individuals in Great Britain and the Netherlands also took exception with the continuation of blinded surveys.[19]

In 1995, the CDC stopped funding of UAT in the United States. It is unclear whether this was done at the time for ethical or political reasons, or both.[3] In accordance with a 1988 policy from the Office for Protection from Research Risks (OPRR),[4] which states, "when HIV testing is conducted or supported by PHS, individuals whose test results are *associated with personal identifiers* must be informed of their own test results and provided with the opportunity to receive appropriate counseling [emphasis mine]." Since UAT was discontinued, surveys were no longer blinded and participants were thus identifiable. Due to this link between individuals and their sensitive information, and in accordance with OPRR's policy, people attending HIV sentinel sites – which are clinics or other healthcare satellite sites where surveillance for monitoring HIV infection trends in population groups takes place[22] – had to be informed their blood would be tested for HIV *and* that they would be informed of their test results. The report states, "Individuals may not be given the option "not to know" the result, either at the time of consenting to be tested or thereafter."[23] This was problematic for surveillance because of the increased risk of selection and participation bias. Nonetheless, OPRR's policy implicitly

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[3] Over time, the author has heard from people at CDC expressing multiple, sometimes conflicting stories of why CDC discontinued UAT in 1995.

[4] OPRR is now referred to as Office for Human Research Protections (OHRP).

made the decision that requiring informed consent for testing, providing counseling, and informing participants of their results was more important than collecting the most accurate surveillance data possible via UAT.

From an ethical perspective, on the one hand OPRR was respecting each participant's autonomous choice by providing informed consent as well as counseling. But on the other hand, OPRR tied relatively large preconditions to the consent as well; in order to get tested, an individual must agree to receive his or her result. By not allowing the individual to choose not to know his or her result, OPRR paradoxically took some of the autonomous choice away from the individual. It is important to note that the policy is not overly rigid, however, and *does* provide relevant exceptions when individuals would not be required to have their test results returned. Exceptions to the policy include, (1) compelling and immediate reasons that justify not informing a particular individual, (2) designing a protocol that collected data on subjects who "would be expected to refuse to learn their HIV antibody results" and (3) foreign sites where cultural norms, health resource capabilities and official health policies need to be considered.[23] In the first case, the policy allows for an IRB to be notified after the fact, whereas for the latter two, approval from necessary IRB's must be acquired ahead of time.

Nonetheless, by making the default option to inform participants of their results, the policy potentially eliminated people who wanted to participate in a practice for the common good, but were afraid of stigma, intimate partner violence, or of knowing their own result. Furthermore, when someone does find out they are HIV-positive, there are many challenges and consequences tied to that knowledge, such as how they disclose their status to loved ones and friends.[24] By only allowing limited exceptions for individuals to have the option to ‘not know’, OPRR limited participant’s autonomy and, paradoxically, opened their own study up to more participation bias. In this light, it is questionable whether the OPRR policy’s benefit to the public’s health by requiring participants to agree to know their result was big enough to ethically justify limiting their autonomy. Nonetheless, informed consent became a necessary part of the process of conducting epidemiological research at a time when heavy criticism of blinded surveys existed in America.

This policy also applied to all intramural and extramural activities funded by PHS, “including both research and health services activities, domestic and foreign.” Pertaining to foreign sites, the same OPRR report states, activities “should be carefully evaluated to account for cultural norms, the health resource capabilities and official health policies of the host country. If a research protocol review is involved, the reviewing IRB must consider if any modification to the policy is significantly justified by the risk/benefit evaluation of the research.”[23] Despite CDC discontinuing UAT in 1995 domestically, and despite OPRR’s guidelines stating results must be returned given the presence of any identifiers, UAT continues to be funded in sub-Saharan Africa and other middle- and low-income countries by the U.S. under the third OPRR exception. “If CDC continues to perform unlinked anonymous testing without informed consent in these settings,” Terence Chorba, MD, MPH of CDC wrote in 2008, “then CDC’s domestic and international practices are in conflict.”[25] In the cases where exceptions were granted, ethical questions that arise regard whether these exceptions continue to be ethically justified given the shift in therapeutic prospects for HIV-infected individuals and the relatively improved social acceptability of being HIV-infected.

Treatment, human resources in healthcare, and other resources are limited in many countries hit hardest by HIV, and stigma remains high. Thus, ethically speaking, the obligation of public health to protect individual’s privacy and confidentiality to avoid any leak of sensitive information and subsequent psychosocial harm remains important. In this way these countries resemble the U.S. during the 1980’s and early 1990’s when therapeutic options were limited and stigma discouraged people from participating in HIV-related interventions. For these reasons the use of UAT historically has been in resource-constrained countries (often low- and middle-income countries). However, other characteristics of the situation are not the same, and continuing to use UAT (and thus not returning results) raises ethical questions. For example, treatment *does* exist now, prevention options (biomedical and behavioral) are greatly expanded, and transmission is most common in sub-Saharan Africa in heterosexual encounters which creates the possibility of vertical (mother to child) transmission. Whereas in the past a case for the use of UAT could be made on ethical grounds, the case is weaker as time goes by. The issue continues to cause moral distress within CDC: how ethical is it to prohibit UAT domestically yet fund UAT abroad? The answer becomes even more complex when framed within the context of a changing landscape of available HIV treatment.

Surveillance: Research vs. Non-Research

At the same time as this debate was going on, and despite the comprehensiveness of the 45CFR46 in protecting human subjects in medical research, it was unclear if surveillance even could be considered, by definition, public health *practice* or *research*. If it was research, it would have to be regulated as such in accordance with 45CFR46, and consent of participants would have to be obtained for any surveillance activities. The federal code was created to protect *each individual* from doing anything they did not want to, or were not informed enough to do. But surveillance can be mandated by state or federal law, and as such has the power to compel individuals to do or not do things for the common good. Thus, surveillance is founded upon almost entirely different ethical grounds. As Fairchild and Bayer note, in public health it is an ethical mandate to "undertake surveillance that enhances the well-being of populations."[26] For example, those who have active TB are reported to state health departments and legally detained and isolated if they pose a great enough risk to others (i.e. by not complying with their treatment regimen). In sum, despite using methods that acutely align with research, surveillance is an ethical obligation that, paradoxically, would be considered ethically unacceptable if categorized as research.

Even the *Belmont Report* created in 1979 stated, "The distinction between research and practice is blurred partly because both often occur together."[10] Robert Levine, who drafted the first definition of research for the group that created the Belmont Report (The National Commission for the Protection of

Human Subjects of Biomedical and Behavioral Research), argued that the difference between practice and research was *intent* to generate new knowledge. But it was difficult to measure intent, and in the end the Belmont Report adopted the word *design*.[10] In 1996, CDC created its first guidelines that stated surveillance was public health practice, not research because of intent: “The intent of research is to contribute to or generate generalizable knowledge; the intent of public health practice is to conduct programs to prevent disease and injury and improve the health of communities.”[27]

The CDC submitted its guidelines to OPRR for approval, but at the same time, and in contradiction to the CDC guidelines, OPRR was also promoting the notion with its own reports that surveillance was research.[10] The conflicting message was not simply a semantic issue. In response to OPRR, CDC emphasized the implications of calling surveillance research; “There are 2,088 health departments and over 100 surveillance systems. If all surveillance activities were research, it might mean each local health department would have to form institutional review boards (IRBs) and secure [special CDC assurances that human subjects were being protected] for each system. Whether the surveillance system is mandated by state law is irrelevant. If the research activity is federally funded, it requires assurance of human subject protection.”[28] If surveillance were considered research, the CDC said, “people with TB could prevent their names from being reported to the health department or refuse to provide information about their contacts.”[29]

In the end, OPRR did not put up much of a fight: “the bottom line is that OPRR is prepared to live with a certain amount of ambiguity as long as we are convinced that CDC is making a genuine effort to define these distinctions in a reasonable manner, that the definitions are not being abused, and that CDC has an effective gatekeeper…to ensure consistency in its decision-making."[30] The back-and-forth between CDC and OPRR exemplifies the difficulty in defining surveillance as public health *practice* or epidemiological *research*. The definition one uses has serious ethical implications for HIV surveillance in sub-Saharan Africa; if it is research then it falls under the purview of 45CFR46, and informed consent must be obtained. If it is practice, then it can be used by public health *primarily* to evaluate and implement better public health programs. This does not necessarily free public health practice from the ethical obligation to obtain informed consent. In the context of public health practice, as Kahn and Mastroianni put it, informed consent can "assure understanding and protect the right of self-determination of individuals from whom samples and/or information is ought."[31] In the latter context, it can be described as a means to a greater end. Much depends on what the *intent* for surveillance is, and as will be argued in chapter four, the intent for surveillance ought to be less of a means and more of an end in-and-of itself.

The Conversation on the Ethics of HIV Surveillance Practices in sub-Saharan Africa

There are currently two main types of HIV surveillance carried out in low- and middle-income countries like sub-Saharan Africa. The first is performed passively by sentinel – or satellite – hospitals and clinics, and for this reason is called sentinel surveillance. Sentinel surveillance is most often performed with left over blood from attendees at Antenatal Care Clinics (ANC) – which provide routine healthcare to pregnant women. It is collected for purposes other than HIV testing, such as a routine syphilis test. After any identifiers are stripped from the left-over blood sample, it is sent to a laboratory to discern HIV serostatus, and then the result is sent to public health and governmental agencies for statistical analysis. As mentioned above, performing surveillance in accordance with the U.S. Code of Federal Regulations becomes a condition tied to any American dollar used to pay for surveillance on human subjects. But because the blood sample is unlinked from any identifiers, consent does not need to be obtained. As such, sentinel surveillance (see Figure 2) is sometimes referred to as UAT *without* consent.

This can lead to confusion because UAT originally meant that surveillance was performed without the knowledge of the individual, and therefore without their consent. But today, surveillance practices have changed outside of the U.S. while old language has remained. This is because consent must be obtained when performing the second type of surveillance called “Population-Based Surveys” and for this reason has been called UAT *with* consent.

Population-based surveys require public health and/or the government to take a more involved, *active* approach, as seen in Figure 2. It requires public health to go out into the community and test the population for HIV. For this reason, this second method is called population-based surveys, and it is a way to test persons residing in statistically representative communities or households. Since public health is approaching community members, it must obtain the community member’s consent before they can take their blood and test them for HIV.

Despite obtaining consent, the large majority of population-based surveys still do not return HIV test results. This second method of HIV surveillance borrows the same mentality that led to the first method of UAT in sentinel sites, namely that returning results to participants would decrease the number of people that agreed to be tested. In the past, this made some people uneasy as well, and over time it was agreed that the only way not returning HIV test results from population-based surveys could be done ethically was by referring participants to voluntary counseling and testing (VCT). As will be described in greater detail in chapter 3, VCT is often a building in a permanent location, but sometimes a mobile clinic that sets up near villages or goes to people’s homes that provides HIV testing, counseling, and treatment. Often by participating in a population-based survey, the participant will receive a voucher for free HIV testing, and if the test is positive, free counseling and treatment. But until recently, test results were never returned. As such, the practice of UAT has shifted away from “unlinked”, or even “anonymous” and has now come to signify a surveillance practice that does not return test results, or “avoids selection and participation bias” (See Table 1, [32]).

In recent years, there have been increasing concerns in some countries about the use of these strategies.[33-35] The principal concern is that UAT can lead to missed opportunities for referring patients/clients to both treatment and prevention services. The most common types of these services are voluntary counseling and testing (VCT), and prevention-from-mother-to-child-transmission programs (PMTCT). Whereas in the past most ANC did not perform HIV testing for screening purposes, many now house PMTCT programs where the pregnant women can learn their HIV status and receive treatment for both herself and her child, decreasing vertical (mother to child) transmission.[36] As a result of improved therapeutic and prevention options for HIV-positive individuals in sub-Saharan Africa, the ethical debate between the need for accurate data versus the value of returning test results to individuals continues.

Early in the AIDS epidemic, stigma was high and treatment was not available, and furthermore it was unclear whether human subjects regulations even applied to surveillance. This led to the conclusion that the need for accurate data outweighed the individual's need to know his/her HIV-status. Today, proponents of UAT utilize several justifications. One argument is that there is a difference between "surveillance" and "screening." Surveillance is meant to measure the prevalence of HIV and monitor trends on a population level, while screening activities aim to diagnosis and treat individuals at an early stage of their disease, or prevent it altogether, and as such has a clinical focus (see Table 2). In 2003, a UNAIDS working group on the issue supported these distinctions: "Inadequate prevention, treatment and support services in many countries are often a result of limited resources (human and financial) and inadequate infrastructure. These services are important and should be offered, but generally not through surveillance activities, given that the objectives of the two activities (i.e. voluntary counselling and testing, and surveillance) are different."[33] Surveillance is, therefore, admittedly used as a means to the ends that public health seeks, namely by monitoring and evaluating screening services that already exist.

Second, proponents argue that referring participants to VCT after performing a test for a population-based survey allows for the highest quality of care for HIV-positive individuals. (Mark White, personal communication, 2011) Referring to VCT ensures privacy, confidentiality and availability of qualified counselors. The diagnostic ability of the HIV test is also improved in VCT settings, thus giving a slightly more accurate HIV diagnosis. And in addition, by visiting VCT individuals are able to receive ART during their visit if they are HIV-positive *and* they are eligible to receive treatment. One is eligible for treatment if their disease has progressed to a specified stage agreed upon by international public health agencies (e.g. WHO).

In my personal opinion, another not-so-obvious concern of those who argue against returning results is the fear of losing funding. A condition for countries receiving US funds for any HIV-related program or intervention is that they show that the money is being used wisely. The best way to do this is by gathering accurate data. Despite being ethically questionable, UAT provides the best guarantee for accuracy because bias is much less of a concern. As a result, anyone that argues for returning results puts countries that are responsible for showing accurate results in a bind. Introducing the *risk* of bias that returning results does might be unacceptable for some countries because they are not willing to risk loosing funding.

But performing UAT passively (without consent) and actively without returning test results is problematic. UAT does not allow the individual to know their HIV serostatus, which might encourage them to seek treatment and counseling and/or change behavior.[37] This is a particularly strong argument in the context of antenatal care clinics where pregnant women could take measures to protect not only themselves, but also their unborn babies. So whose wishes should be honored? Those in favor of using the strict definition of “surveillance” whereby data is collected for planning and evaluation purposes only, or those who might sacrifice the data’s accuracy in order to gain the benefit of returning the results of tests performed for HIV surveillance to participants? Thee question is not a new one, rather a fairly common ethical tension found in public health; one where the values of the individual differ from the values of the community as a whole.

Public Health Ethics

Public health ethics often weighs the individual’s values against the greater public’s values. In other words, being a part of a community of many people sometimes requires that individual’s liberty, privacy, and/or autonomy must be limited in a way so that all community members may have a chance to flourish.[38, 39] A policy or program that limits an individual’s liberty must weigh the burdens and benefits of honoring the needs of the greater public more; otherwise some populations within the community may be treated unjustly.[40] For example, President Barack Obama reformed healthcare so that each American was required by law to purchase health insurance. Otherwise, the logic goes, it would be unfair to the community that had to pay for an individual who doesn't buy health insurance and then cannot afford his or her medical bills.[5] [41]

Most relevant to the issue at hand is an individual's claim to their own test results, to information about themselves, to privacy, confidentiality and treatment. Of course, this assumes that information collected about an individual belongs to them. But harkening back to the 'surveillance as research or non-research' debate, it is unclear what surveillance is, and therefore unclear whether information collected for surveillance should be used as a part of public health practice or research (with all its individual protections). Nevertheless, these things are critical to getting tested and treated for HIV, and as such, limiting an individual's access to these goods for the benefit of the greater public must be justified. Treating the individual with dignity, treating them justly, and preserving their liberty, therefore, may be weighed against public health values of maximizing good and minimizing harm to all people within the community. The

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[5] In a speech to congress in 2009, Barack Obama said, "The problem is, such irresponsible behavior costs all the rest of us money. If there are affordable options and people still don't sign up for health insurance, it means we pay for these people's expensive emergency room visits. If some businesses don't provide workers health care, it forces the rest of us to pick up the tab when their workers get sick, and gives those businesses an unfair advantage over their competitors. And unless everybody does their part, many of the insurance reforms we seek -- especially requiring insurance companies to cover preexisting conditions -- just can't be achieved."

challenge for public health institutions and coordinators, then, is to serve two "masters": the public's values and the individual's values.

Accurate and precise data must be collected to perform public health duties. It would be unethical for public health institutions and employees to carry out public health initiatives without good data. Doing so would be a waste of energy, time, and already limited resources. Yet the surveillance method that has been deemed ethical in the past (UAT) precludes the individual from obtaining their test result, which in the present day, is necessary for that individual to get counseled and/or treated. And so the public health ethics question is, "do we value the public's or the individual's values more?" Often this question is misunderstood as a technical or structural problem. Some say that the theory is sound, and the problem is simply putting it into practice. But can a theory be a good one if it has not – and likely will not – ever be able to be put into practice?

Alternative avenues, such as vouchers for free voluntary counseling and testing (VCT) sites, have been developed that allow individuals to get tested and learn their HIV status that theoretically mitigate this moral tension. But what this line of logic seems to neglect (discussed more in chapter 3) is that many people don't take advantage of VCT because of various barriers such as stigma, fear of knowing the result, and distance to VCT site. This is therefore the key question that I aim to explore; *given the barriers to testing that exist in practice, are we comfortable with the level of access to counseling, testing and treatment that a voucher for free VCT provides?* Or would returning the results of the test performed for surveillance purposes give the individual a valuable "resource" that they can then leverage to help themselves and others in their community prevent the spread of HIV.

It should be noted, the values of individuals and the public are not always mutually exclusive in the case of HIV surveillance, and do not always conflict. For example, decreasing stigma in the community toward HIV/AIDS benefits the individual psychologically and emotionally, as well as benefits the community by decreasing a significant barrier to getting tested for HIV for either surveillance or personal reasons. As such, in the case of HIV surveillance, one is left with a tangle of values that are sometimes compatible and sometimes not. In order to aid practitioners in creating policies and programs that reflect all of these ethical considerations the Public Health Leadership Society developed twelve principles that condense many of the common values of individuals and the public alike (often referred to as the Public Health Code of Ethics).[42] These principles were later adopted by the American Public Health Association (APHA). In a similar manner as a yardstick, or a scale that measure's a person's body weight, the Public Health Code of Ethics principles act as a standard of ethical measurement for an issue.

Meetings have been convened almost annually by major public health institutions such as CDC, WHO, and UNAIDS to discuss the ethics behind UAT in developing countries. One of the most recent meetings was the Columbia Consult in February 2008, in which a group of community members, ethicists, and public health experts were asked whether it is ethically acceptable to collect samples and test for HIV without informing individuals of their test results in both passive and active HIV surveillance in low- and middle-income countries.[43] The Public

Health Code of Ethics principles were employed by some of the leading ethicists who attended the Columbia Consult, and provide a broad idea of the aim of public health ethics. As discussed above, however, ethics is based in circumstance, and the circumstances in sub-Saharan Africa where UAT is employed are extremely varied from country to country, and even regionally.

Columbia Consultation in Response to Debate Over Ethics of HIV Surveillance

The Columbia Consult issued two recommendations, one for each method of surveillance. The group of experts that gathered at the Columbia Consult eventually came to similar conclusions regarding each of the two types of HIV surveillance. For passive surveillance they concluded,

> "UAT for HIV can be ethically justified in some countries but (perhaps increasingly) not in others. The ethical justification depends on facts and circumstances that can change, and must be reviewed periodically to determine whether they no longer warrant testing without providing results to the individuals tested."[43]

An example of a country where UAT was permissible in 2008 is Sudan. Sudan had the highest official HIV prevalence in the Middle East and North Africa region. As a result of the "One Country-Two Systems" plan due to civil war, there is little coordination between the North and South Governments. This political unrest, along with high stigma, lack of resources, lack of quality Prevention-of-Mother-to-Child Transmission (PMTCT) programs (which are housed within ANC sites), slow government public health prevention response, and little to no educational opportunities on HIV infection, led the ethicists to conclude that circumstances such as those found in Sudan may mean that the practicality of UAT can be ethically justified.[43] Even in places like Sudan, however, UAT must be conducted ethically. In the past, for example, syphilis tests have been performed simply to facilitate HIV testing. In this case, the primary purpose for collecting blood becomes the HIV test, and is performed without the knowledge or consent of the patient.[44] Where UAT is found to be acceptable, there are ways to ensure that it is carried out ethically. For example, using a multifaceted approach that includes local capacity building, community engagement, and increased access to HIV and STI testing.[44]

Evidence exists that collecting data from pregnant women who have participated in PMTCT programs (designed specifically for testing for HIV-infection) can provide an accurate enough picture of the trends of the HIV epidemic in specific regions, and might therefore replace UAT in those areas. However, in only select countries such as Thailand, where the nationwide PMTCT coverage and a very high acceptance of HIV testing[45], can PMTCT data accurately reflect the nature of the epidemic in that country. For other countries where the resources are available but not always accessible to the greater public, such as Botswana[43], a value judgment must be made: Should using UAT to gather accurate data for HIV surveillance take precedence over the treatment of individuals? And if there is no possibility of treatment for economic reasons, is UAT permissible then?

The evolution of the ethical debate has shifted the weight in the past thirty years from the community to the individual. The need for informed consent as well as the right of each individual to access information critical to their well-being have emerged as the strongest arguments for the shift. It is morally problematic if public health has the resources to take action but does not do so in the name of collecting the best data possible. Even when resources are scarce, public health is still ethically mandated to carry out surveillance. "When some or all of these [PMTCT] programs are established in the country," remarked the ethicists at the Columbia Consult, "and there is adequate uptake, thereby enabling those tested to receive appropriate services based on their knowledge of their HIV status, it is unethical to continue UAT for the purpose of surveillance."[43]

The strongest support for the continuation of UAT without consent is made regarding the technical limitations of data in health services such as PMTCT. However, the ethicists came to the conclusion that due to the increased availability of counseling and treatment, the increasing awareness of and education about HIV infection, and the improved ability of sentinel surveillance sites such as PMTCT to provide an *adequate* picture of the trends in HIV infection, UAT must no longer be the default surveillance option. Instead, the ethicists concluded, the burden of proof should lie on those that would argue for the use of UAT in specific circumstances (i.e. Sudan). Furthermore, if UAT were found to be permissible, communities should be informed that such surveillance is being carried out (so that community members may choose for themselves if they wish to participate), the results of the surveillance activities must be made public afterward while being sensitive to the fact that high prevalence communities may experience increased stigma, and the necessity for its continued use should be periodically reviewed as circumstances shift and PMTCT surveillance becomes favorable.[43]

The second recommendation focused on active surveillance performed in population-based surveys. Historically ethical consults have concluded that UAT was permissible in population-based surveys as long as participants were able to access VCT or PMTCT as well. After a test is performed for the purposes of the survey, people are provided a referral to a VCT site where they are encouraged to be tested a second time and, in theory, with greater access to counseling and testing. Those that support referral to VCT argue that the results of the test might also be kept more confidential, since homes where surveys are carried out are often small and crowded leaving little room for privacy.[9]

However, it is now well documented that significant barriers to VCT exist. These include stigma, fear of receiving an HIV-positive status, lack of confidentiality, long distances to VCT sites, and long delays in returning HIV test results[46], in addition to low perceived risk for HIV infection and lack of access to free testing[47], shortage of counselors[48], and general negative perceptions of test services[49], which may be because HIV-infected persons also continue to receive late diagnoses.[50] These barriers may be more challenging for many women, who may feel powerless to discuss condom use, HIV testing, and infidelity with their male partners.[51] Women must often times ask their husbands for the money to attend ANC, and may also fear physical and sexual violence[52], although there may not be as strong of a link between intimate partner violence (IPV) and HIV in developing countries as there once was.[53] Although simply providing a voucher for free VCT theoretically ameliorates these barriers, in practice the barriers are insurmountable for many. Ignoring these circumstances would be unethical, and the ethicists at the Columbia Consult therefore concluded that "[n]o ethical justification exists for obtaining samples from individuals with their consent for the purpose of surveillance, and testing the samples for HIV without offering to provide the test results to the individuals tested."[43]

Conclusion

At the beginning of the HIV epidemic there was widespread fear and stigma. So the method chosen for surveillance was unlinked anonymous testing (UAT). The benefit of UAT was that people were tested anonymously. Public health could track the progression of HIV without harming those that had HIV. There was no treatment available. This coupled with the negative social effects of being recognized as HIV positive led to the environment in which UAT was created.

But the strength of UAT has now become its weakness. Anonymous testing and unlinking the results also precludes the individual from knowing their result and taking the steps toward counseling and treatment. Without knowing their status, it is more difficult to get individuals to change risky behavior. This debate has affected parties on either side. Some became so upset that they thought about leaving the field of surveillance, or retiring all together. (Mark White, personal communication, 2011) But this only exemplifies how truly critical quality surveillance is for public health. It is precisely because of the important role HIV surveillance plays in combating the HIV epidemic that this debate has been so charged. If it weren't important, it wouldn't be worth arguing about.

Today, the intensity of the argument has subsided. Despite repeated recommendations from public health experts, community members and ethicists alike at meetings like the Columbia Consult, population-based surveys continue to be conducted without returning HIV test results. In the chapters that follow, an argument is made for returning population-based survey (active surveillance) results based on the importance of knowing one's HIV status, the effect it has on behavior change, and a pragmatic ethics understanding of community and how it can be used to heal its community members. It begins with a call for a collective feeling of a sense of urgency – a call for action. If we wait for the next population-based survey cycle five years from now, or wait for a vaccine to be created, or continue to perform HIV surveillance with the same old habits we have been for thirty years, too many more will die.

CHAPTER 3: RETURNING RESULTS AS "WATER"

The Columbia Consult provided the theoretical foundation for the ethical analysis of UAT. The recommendations of those ethicists that attended the Columbia Consult clearly state that active UAT – most often performed through population-based surveys with informed consent – cannot be ethically justified in any context. Yet the majority of population-based surveys around the world, let alone in sub-Saharan Africa, continue not to return results.

In contrast, the recommendation for sentinel surveillance (passive UAT) states clearly that a case can be made – although increasingly less – that situations may exist where its use can be ethically justified. After the Columbia Consult, confusion still surrounded how to define when passive UAT was ethically acceptable. Some of the Columbia Consult participants reconvened in Geneva a year later to continue discussing and ideally settle the issue. (Ron Bayer, personal communication, 2011) They focused on a new approach to sentinel (passive) surveillance, namely using Prevention-of-Mother-To-Child-Transmission (PMTCT) programs housed in antenatal care clinics (ANC) as sources of data. The purpose of PMTCT programs is primarily to test, counsel, treat, and prevent the vertical transmission of HIV, and as such, data can be collected without dealing with the ethically challenging issue of returning results. Pregnant women are a stable population that require routine care, and thus attend sentinel surveillance sites regularly. In addition, data collected from PMTCT can provide relatively accurate estimates of the prevalence of HIV in the broader population. In order to completely phase out passive UAT and solely use data accumulated from PMTCT attendees, however, PMTCT uptake must be close to 90%.[43]

In the end, attendees in Geneva concluded that, where PMTCT programs or stand-alone testing services were available in less than 75% of ANC sites, and where uptake of testing in these clinics was less than 90%, a waiver should be submitted to conduct UAT surveillance. (Ron Bayer, personal communication, 2011) Although availability of PMTCT is increasing, it is still not enough in every country to completely eliminate passive UAT. In 2012, coverage of PMTCT programs ranges from less than 10% to greater than 80% in sub-Saharan Africa.[54] Thus, some countries and sub-regions that do not have enough access to PMTCT may still be able to claim the need for passive (sentinel) UAT.

For active surveillance, providing a voucher for free voluntary counseling and testing (VCT) has not improved VCT uptake significantly. Thus, one ethical question that must be asked in sub-Saharan Africa is what level of access to HIV testing, counseling and treatment services should public health be comfortable with? And is it morally acceptable to refer people to VCT knowing that, on average, more than half of them will not take advantage of it? Some say this problem is a technical matter, but it is not. It also involves access inequality and resource allocation, and as such it is an ethical one. In the chapter to come, I argue that access to VCT and other HIV testing and counseling services (HTC) is inadequate when one considers the importance of the services provided by HTC and the utility it provides public health to act as a bridge between prevention, treatment and surveillance practices.

Another consideration that must be weighed is the prevalence of disease in the general population. Epidemic can be described in three ways: generalized, concentrated and low states.[55] According to UNAIDS[56], a generalized epidemic is an epidemic that is self-sustaining through heterosexual transmission and the prevalence of HIV exceeds 1% in pregnant women attending ANC. Alternatively, in a concentrated epidemic HIV prevalence in one or more high-risk sub-populations is greater than 5%, but is not well established (prevalence less than 1%) in the general population. A low level epidemic is one where HIV prevalence has not consistently exceeded 1% in the general population nationally, nor 5% in any subpopulation.

I argue only for returning results in generalized epidemics in sub-Saharan Africa, although returning results could be warranted in other generalized epidemics around the world. Ultimately public health must do what brings about the greatest good for the greatest amount of people, and investing a large amount of resources into implementing the return of results for a relatively small number of people would be difficult to ethically justify at this point. It is worth noting, however, that some concentrated epidemics have prevalence rates as high or higher than some generalized epidemics. As such an argument for returning results on a smaller scale – perhaps with the majority of oversight and funding from municipalities instead of international public health organizations and high-income countries – might be able to be made in the future. It is also worth noting that the definition of the epidemic categories above has been scrutinized because it does not account for important factors (i.e. transmission-dynamics).[57]

Sense of Urgency

June 5, 2011 marked the 30th anniversary of the first report of Acquired Immune Deficiency Syndrome (AIDS) in Morbidity and Mortality Weekly Reports (MMWR)[5]. Significant successes have been achieved, and there is a sense of momentum building. Increased access to efficacious biomedical interventions, promising vaccine and gene-therapy research, and improved understanding of the preventative effects of behavior change all hold promise for new, more effective solutions to the same 30-year-old problem. These promising new strategies have led public health officials and organizations (i.e WHO, CDC, UNAIDS), to envision a world free of HIV.

In 2009, Kevin De Cock and colleagues published a landmark challenge to the global community. Based on mathematical modeling, the *Lancet* article proposed the possibility of eradicating HIV in nations heavily burdened by the disease by repeated, universal testing and the provision of ART to all infected persons.[58] The World Health Organization (WHO) echoed De Cock's challenge in 2010 in their *HIV/AIDS Strategy 2011-2015,* in which they speak of, "a world free of new HIV infections and where people living with HIV enjoy long healthy lives."*[59]* The vision of the WHO strategically aligned its plan with the vision of the Joint United Nations Programme on HIV/AIDS (UNAIDS)[60] which aims, "[t]o get to zero new infections, zero AIDS-related deaths and zero discrimination."

The driving force behind these audacious strategic plans and models have been the sixth of eight total Millennium Development Goals the United Nations adopted in 2002, which aims to, “[h]alt and begin to reverse, by 2015, the spread of HIV/AIDS, and achieve, by 2010, universal access to treatment for HIV/AIDS for all those who need it.” Unfortunately, universal access to treatment still has not been achieved, and it seems the world is still far enough away from reversing the spread of HIV/AIDS, that the year 2015 will come and go as well without its deadline met. In light of this, the 2011 UNAIDS *World AIDS Report* poignantly states, “[t]he world faces a clear choice: maintain current efforts and make incremental progress, or invest smartly and achieve rapid success in the AIDS response.”[3]

And so, the picture I hope to paint is one of a sense of urgency. While efforts toward the eradication of HIV have been tireless and admirable, UNAIDS still sees a need for increased effort. Continuing to approach the problem the way it always has been approached will not lead to the “rapid success” called for. Rapid success means solving problems creatively, and creating new habits in the process. I propose that one creative, smart investment is returning population-based survey results to HIV surveillance participants through home-based HIV Counseling and Testing (HTC). Uptake of HCT services are too low, yet are crucial to preventing the further spread of HIV. Returning results and providing home-based HTC in one package is an effective way to obtain accurate data while simultaneously providing individuals with the critical opportunity to get tested for HIV and receive counseling. Furthermore, returning results has shown to provide enough motivation for people to overcome barriers to treatment, and seek out HCT.

The Utility of HIV Testing and Counseling (HTC)

Although sub-Saharan Africa has only 12% of the world's total population, it carries about 68% - or two thirds – of the world's HIV burden.[3] South Africa has more people living with HIV (an estimated 5.6 million) than any other country in the world. Since the peak of the epidemic in 1997, the total number of new HIV infections by 2010 in the region has declined by more than 26%, from 2.6 million to 1.9 million. Despite these gains, the region accounted for 70% of all new HIV infections globally in 2010. At least one million lives have been lost each year in sub-Saharan Africa due to AIDS since 1998.

A challenge to decreasing the prevalence of HIV in sub-Saharan Africa is getting people to increase their uptake (consumption) of HTC. The primary purpose of HTC is to benefit the individuals that utilize its services. There are three main components to HTC: Testing, Counseling, and Treatment. Each can have therapeutic benefits for HIV-positive individuals, or have preventative benefits for HIV-negative individuals. As seen in Figure 3, there are many forms of HTC, including VCT, PMTCT programs, and home-based VCT. Although the primary purpose of HTC is to benefit the individual, HTC can also be utilized as a surveillance access point (see Figure 4). As such, HTC is a tool with tremendous utility that can be used for treatment, prevention, and surveillance.

But uptake of HTC is incredibly low. In 2010 in sub-Saharan Africa, out of every 1000 people, only 82 tests were performed. In fact, this number is likely inflated because it includes people who tested multiple times.[4] The percentage of people living with HIV who had *ever* received an HIV test *and their test results* between 2007-2009 ranged from 30% in the Congo to 70% in Kenya.

Testing and counseling provide an individual with two valuable resources: knowledge of their HIV status and education. These resources can be leveraged to *overcome barriers* to treatment, or further testing and counseling. Thus increasing uptake of HTC is an important step toward increasing the percentage of people that get tested for HIV each year. However, a catch-22 exists for the current HTC model; one must overcome barriers to testing and counseling *before* they receive their test or are counseled. As such, individuals have trouble accessing HTC. Instead, returning results could be paired with home-based HTC, which provides testing and counseling to the individual in the home.

Neither returning results from population-based surveys, *nor* home-based HTC is a new idea, and both have been tried before. But the combination of the two has not been tried. I turn next to discussing how each of these have been implemented in the past next. First, I will discuss the most recent and comprehensive example of returning results from population-based surveys performed in Kenya.

Kenya AIDS Indicator Survey (KAIS)

In 2007, Kenya conducted a population-based survey called the Kenya AIDS Indicator Survey (KAIS).[61] Of all the data, the most noteworthy is the following: "In total, 83.6% of HIV - infected adults aged 15-64 years were unaware of their HIV infection because they had never been tested, had been tested but never received a test result, or believed themselves to be uninfected based on their last test. Based on these findings, in 2007, an estimated 1.1 million HIV-infected adults nationwide were unaware of their HIV status, including an estimated 700,000 women and 400,000 men."[61, p. 83] (see figure 5) Of respondents who had never been tested for HIV, 47.2% reported that they had not sought testing because their risk perception for HIV-infection is poor.[61, p. 65] But this is a problem, because "[k]nowledge of HIV and perceptions of risk for HIV infection are essential for making *behavioral choices that reduce risk of acquiring and transmitting HIV* [emphasis mine]." This is the line of logic Kenya employed when they decided to return results from the KAIS in 2007. After participating in the survey, individuals received a voucher listing two sites – one nearby their home, and one further away – to choose to attend to receive the results of their test. They were instructed to wait six weeks before their test could be analyzed and processed.

The outcome of returning results is staggering. Nearly half (45.6%) of all KAIS participants who completed an interview and provided a blood sample travelled to select health facilities to receive their test results. This means that the promise of knowing their result was worth overcoming all of the barriers to VCT.

Furthermore, more than one third (35.8%) of HIV-infected participants who had never tested or who believed themselves to be uninfected learned that they were HIV-infected during the 2007 KAIS. And participants in rural areas were twice as likely to return to receive their test results (52.5%) compared to those in urban areas (24.5%). What this shows is that returning results provides a unique access point to VCT and other HIV counseling and testing services for a lot of different types of people (i.e. people who perceive themselves at low risk, or living in rural areas that lack a significant amount of HTC services).

An estimated one-half of participants, however, did not return to receive their test results. They hypothesize that this is because of barriers that made it difficult to attend either site for their results, and because of the six weeks participants had to wait. Thus, the study concludes, "[f]or future population-based surveys, *methods to return a greater proportion of HIV and other test results should be explored* [emphasis mine]. The use of health facilities to return test results, for example, is logistically challenging and may delay participants from receiving test results in a timely manner. Future surveys should explore how to return test results to participants efficiently and quickly."

The following chapter, therefore, makes two main arguments. First, that returning results has a tangible impact on the fight against HIV and second, that in order to return a greater proportion of results, home-based HTC should be leveraged. Of all of the participants of KAIS nationally, a total of 83.5% agreed that they would be willing to be tested for HIV at home, which was similar across sex, age, wealth and rural/urban residence. Home-based HTC is the logical next-step for returning results.

Home-Based VCT

There are three conditions, often referred to as the ‘3 Cs’, that must be guaranteed for any person that takes an HIV test, and have been advocated for since the HIV test became available in 1985.[62] Testing of individuals must be *confidential*, be accompanied by *counseling*, and only be conducted with informed *consent*, meaning that it is both informed and voluntary. The 3 C’s are not always easy to guarantee, however. If an individual wants to know his or her status, there are a large number of HTC models that someone can choose from. There are pros and cons for each one. For example, community-based models has been proven to increase uptake because they are more accessible for the participant [63, 64], but there is also a greater chance that the participant will be seen by a community member at a VCT site, for example, and subsequently be the source of gossip and stigma. It is very difficult to maintain confidentiality and privacy as well when, for example, someone is diagnosed as HIV-positive and is then taken to the only room in a small VCT site where ART is prescribed (thus identifying that person as HIV-positive).

Home-based VCT aims to increase access to HIV testing while reducing the stigma associated with HIV testing in facility settings[65, 66]. Evidence suggests that the strategy is cost effective, increases testing uptake[67-69] and reduces the inequities in access of existing testing services.[70] This is particularly true for women, where home-based VCT decreases what is described as the “male advantage” in uptake of VCT.[46, 66, 68] Inconvenience, fear of stigmatization, and emotional vulnerability of receiving results from public facilities are common explanations for the relative popularity of home-based VCT. In addition, a variety of tests, from finger pricks to mouth swabs, can now produce results in 1–20 minutes and can be administered in the home. The cost of a test is less than one dollar, which makes returning test results performed for HIV surveillance both in sentinel clinics and out in the field during population-based surveys more feasible.

One concern with home-based VCT is that confidentiality would be harder to maintain because people in low- and middle-income countries often live in small homes with large families. When confidentiality is not maintained, consequences could include intimate partner violence and stigma. Other concerns are whether the common, or "lay" administer of population-based surveys would adequately be able to provide proper pre- and post-test counseling. Or in the case that an experienced HIV counselor could accompany the surveillance team, if there would be enough counselors to effectively provide counseling to each survey participant. To be sure, human resources are limited in many regions of sub-Saharan Africa, but creative methods have been proposed and used to accommodate this shortage, such as employing retired nurses or training lay counselors.[71]

However, to return to the example of the KAIS, 91.5% of people surveyed were willing to care for an HIV-infected family member.[61, p. 11] Thus, it is highly likely that home-based testing would be accepted. It may be likely that this trend could be found in other countries as well, although willingness would need to be assessed. Furthermore, home-based VCT would allow for an individual to learn of their HIV status in twenty minutes or less. This is a considerable benefit when compared to, for example, the KAIS where individuals were promised that their results would be returned, however, due to post-election violence results were not returned.[6] Edwin Cameron, Justice of the Constitutional Court in South Africa, is an advocate for home testing and has said that knowing your HIV status “simply ought to be a part of life.” He has said that people have a right to access accurate tests and use them in the privacy of their own home, and that though it won’t solve every problem of accessing treatment and care or negotiating safe sex, it is “a simple and affordable way to take the first step.”[3]

A tremendous example of the efficacy of home-based VCT is found in Kenya. As is the case in sub-Saharan Africa as a whole, people in Kenya continue to access HIV care relatively late in their stage of disease, which decreases the potential benefits of ART. To address this issue, The Academic Model Providing Access to Healthcare (AMPATH) developed a community-based door-to-door HIV testing and counseling service that offers testing and counseling to everyone 13 years or older. In addition, testing and counseling is also offered to children younger than 13 years whose mothers have died, have unknown vital status, are living with HIV or have unknown HIV status. Since 2008, more than 350,000 people have received testing and counseling through AMPATH. Importantly, 83% of the adults and 86% of the children found to be living with HIV were newly identified cases. According to one study, compared to other HIV testing and

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[6] Participants were extremely displeased when they did not receive their results to a point that the principle investigator’s life was threatened and his cellular phone number had to be changed multiple times. (Mark White, personal communication, Spring 2011)

counseling approaches, HIV-positive individuals who took advantage of home-based VCT in Kenya have significantly higher median CD4 cell counts when entering HIV care, thus helping solve the problem of late-stage entry. Furthermore, the same study found that a higher proportion of people entering care and receiving treatment that were tested using home-based VCT were members of HIV serodiscordant couples, or were pregnant, both of which could benefit from treatment and prevention interventions tailored to their specific needs. “This implies that antiretroviral therapy can be initiated in a timely manner,” UNAIDS says, “In this context, strengthening links between testing and care services is essential to facilitate access and effective follow-up.”

All 3 C’s can be met using home-based HTC. And as the AMPATH model shows, providing HIV tests door-to-door in a community is largely accepted (AMPATH had greater than 98% uptake as of 2011 [72]), which is exactly what a population-based survey does. It follows then, that one benefit of home-based HTC is it provides a method to return results from population-based surveys. Linking the two brings the “testing” part of HTC to the participant while, at the same time eliminates barriers to testing. By doing so, testing and counseling can reach people who would not otherwise get tested (i.e. people that perceive themselves at low-risk of being infected).

Behavior as “Water”

Public health often forgets that to any biomedical intervention, there is a behavioral component. One example is condom usage, which is only effective if a person can consistently use condoms in different circumstances. The same goes for taking ART. The medicine is only effective if the person is compliant with his or her therapy schedule. Compliance is dictated by one's attitudes toward, and responsibility taken for his or her own health. Even in the case of a medical intervention such as circumcision, convincing young men to undergo the procedure requires significant behavioral and attitude shifts to make it an effective prevention approach.

The behavioral component is important to keep in mind when planning public health programs. In the case of PMTCT programs, for example, and the behaviors required to prevent mother-to-child (or vertical) transmission, providers must routinely offer testing, women must accept testing, HIV+ women must accept and be compliant with ART, HIV+ women must travel to and deliver in a health facility, health providers must administer intrapartum treatment, and the mother must agree to give post partum ART to her infant.[73] "Almost all biomedical interventions require actions (behaviors) on the part of the person." Martha Rogers, a doctor and professor in the Emory University School of Nursing says, "Failure to consider these behavioral issues will likely result in lower impact of the intervention program."[73]

Recognizing the role behavior and behavior change plays in decreasing the HIV epidemic, international public health agencies have begun to promote behavior change programs and other related efforts. The Global HIV Prevention Working Group, a panel of over 50 leading public health experts, clinicians, biomedical and behavioral researchers, advocates, and people affected by HIV/AIDS was convened by the Bill & Melinda Gates Foundation and the Henry

J. Kaiser Family Foundation. In 2008 the panel drafted a report titled "Behavior Change and HIV Prevention: (Re)Considerations for the 21st Century" which stated, "Based on a comprehensive review of hundreds of studies of behavior change for HIV prevention, we find that the evidence base for behavioral HIV prevention is robust, with multiple studies documenting the effectiveness of interventions in numerous settings, among diverse populations, and throughout the course of the epidemic."[74]

Without behavior change in Zimbabwe, new HIV infections (incidence) would have remained twice as high as current levels, which would have resulted in an additional 35,000 new infections annually.[3] A similar story can be seen in urban areas of Malawi, where behavior change has avoided about 15,000 new infections annually.[75] Examples of behavior changes that prevent HIV infection are increasing utilization of condoms, decreasing sexual partners, or delayed age of first sex.[3] In the last year, UNAIDS reports that the percentage of young men with multiple partners has decreased significantly in 11 of the 19 countries with sufficient data, and decreased in six countries among women., In a study of seventeen countries with sufficient data male participants in seven countries and female participants in five countries indicated increased condom use (during their last instance of intercourse). The percentage of young men and women who have had sex before their 15th birthday decreased significantly in eight of the 18 countries with sufficient data. Many of these behavior changes are particularly exciting because they are a form of HIV prevention that need *no treatment* or significant investment in biomedical resources, which is attractive to resource constrained countries such as those found in sub-Saharan Africa.

In addition to the beneficial effects behavior change has on individual lives, it also improves communities as well, as collective behavior change leads to social change. As more and more people change their risky behavior, social norms shift.[3] For example, a community-based approach pairing HIV and violence prevention programming is a way to engage men to challenge dangerous gender norms.[3] This example is an increasingly important one since a recent report suggesting that nearly one in seven cases of young women acquiring HIV could have been prevented if the women had not been subjected to intimate partner violence.[76]

Changing harmful or risky behavior starts with knowing one's status. Yet many people are unaware of their HIV status. When they do know their status, however, protective and preventative behavior and attitude change is observed in both HIV-positive and HIV-negative individuals (as will be described next). Thus, getting tested for HIV and knowing the result has broad effects. The knowledge provides each individual with a "resource" that allows them to make further autonomous, *informed* decisions about their health and support-services. As such, the dignity of each individual is respected. But in addition to this, behavior change has significant practical applications as well.

The "T" in HTC: Testing for the Purpose of Improving HIV Status Awareness

Although the "T" in HTC stands for HIV "testing", in truth testing alone does very little. In fact, testing is all UAT does, which is the foundation of the issue at hand. The importance of the HIV test is that it is the key step to making the individual aware of the result of that test. This solves one of the biggest challenges facing public health and the fight against HIV, namely, increasing people's awareness of their own HIV status.

There are a number of reasons why so few people know their correct HIV status. In some cases, people may believe that they are at low-risk of being HIV infected, and therefore see no reason to seek counseling and treatment. Or alternatively, many individuals who know they are at *high risk* of being infected may not take part in HTC programs because they fear their result will not be kept confidential, which may lead to stigma, intimate partner violence, or other barriers to testing described in the last chapter.

Public health has tried many strategies for increasing people's awareness of their HIV status. Some examples are scaling up "Know Your Status" campaigns, home-based HTC, and routine (opt-out) testing.[60] Although some of these initiatives are controversial, it cannot be denied that they have had a large impact on the number of people that know their status. One such impact from testing (and counseling, described in the next section) is behavior change. In a meta-analysis of 27 published studies assessing sexual behavior before and after counseling and testing it was shown that HIV-positive participants and HIV-serodiscordant couples reduced unprotected intercourse and increased condom use after counseling and testing more than HIV-negative and untested participants.[77] In other words, knowing the result of their HIV test (regardless of whether they tested negative or positive) led to protective behavior changes.

One demographic that drives the HIV epidemic in sub-Saharan Africa are discordant couples, couples whose HIV statuses do not match (i.e. one partner is positive and the other is negative). In one study performed in 1986, Dr. Susan Allen, one of the world's preeminent advocates for couples-based voluntary testing and counseling (CVCT), and her team requested permission to return results to ANC (antenatal care) visitors. After 18 months, The Ministry of Health of Rwanda agreed. During the study Dr. Allen offered HIV test results to 1461 women and only 3 refused. Women even asked if their husbands could be tested, and one-third of their husbands were tested. In the two years of follow-up after the study, condom use increased. Of those that opted to receive their result, 55% of HIV-positive individuals reported their condom use increased, and 23% of HIV-negative individuals increased condom use. In comparison, of those who did not want their results returned, only 28% of HIV-positive individuals and 13% of HIV-negative people increased their condom use.[78] While someone can change their behavior without knowing their HIV-status – after all, individuals that did not receive their result increased condom use – the effect is much more significant when individuals do know their HIV status.

Nevertheless, barriers are still in place to testing. In order to increase the amount of people that correctly know their status, more people will have to get tested. This means that either barriers to testing sites must be decreased or eliminated, or the HIV test will have to come to the people. For those who have been tested during a population-based survey, they have already taken and sustained the physical discomfort of the HIV test performed for surveillance purposes. Since the average person living in sub-Saharan Africa survives on just slightly more than $3 a day ($1,176 per year[79]), they often cannot afford the money or the time to go attend, for example, VCT. Furthermore, even if they were to decide to get retested, they would have to come back days or weeks later for their results.

This is one reason why UAT is problematic in the context of sub-Saharan Africa. The HIV surveillance test turns into two trips to a VCT site that may be far away , and that puts the participant at risk of becoming the target of rumors and stigma. In the face of such obstacles, testing may never occur. In regions where uptake of VCT and other testing and counseling services are low, someone is missing out on one of their only opportunities to learn of their correct HIV status when their HIV surveillance test is not returned. Furthermore, testing twice is not the most efficient use of already scarce resources.

Counseling as Education

According to UNAIDS/WHO Policy Statement on HIV Testing, all individuals must receive the 3 C's with each test. One of the three C's is counseling. For HIV tests performed for population-based surveys, individuals are tested but are not currently counseled. This is because they do not receive their results. Instead, participants are given a free voucher to get tested at a VCT site after the test performed for the survey. While the test is important so that individuals can learn of their HIV status, counseling is just as important because it is a form of education about the disease. Knowledge about HIV is lacking in sub-Saharan Africa, particularly in women [80], which is the gender demographic that shoulders the greatest HIV burden in this region. Currently, except for the KAIS, participants of population-based surveys cannot access either testing or counseling if they do not overcome the barriers to VCT. But if home-based VCT were integrated into the process of returning results from population-based surveys, participants – which often number in the tens of thousands – would have access to counseling (education).

Counseling performed for the purposes of HTC encompass pre-test counseling and post-test counseling. Pre-testing counseling may be provided either on an individual basis or in group settings with individual post-test counseling (also called "follow-up"). The benefit of this model is that pre-test counseling can ensure that the participant getting tested is that much more able to give informed consent. Informed consent is another one of the 3 C's, and as such, providing counseling not only increases access to education about the disease, but leads to the fulfillment of a second "C".

Once pre-test counseling and true informed consent is ensured, UNAIDS/WHO encourages the use of rapid tests so that results are provided in a timely fashion and can be followed up immediately with post-test counseling.[62] Regardless of whether a person tests negative or positive, post-test counseling (education) can help that individual stop the spread of HIV. Furthermore, since rapid tests are already encouraged, why not move the rapid test from the clinic to the home? The push for home-based VCT has begun independently of the call for returning test results performed for surveillance purposes. However, the two could form a perfect partnership and eliminate many of the barriers to testing and increasing general knowledge of people's HIV status. This is not to downplay the challenges. Confidentiality in the home can be difficult to maintain, and requires more human resources. But models for home-based VCT exist that have been successful, so it seems to follow that it would continue to be successful in the context of HIV surveillance.

Evidence shows that motivation for uptake of VCT is driven by knowledge and education. (Mark White, personal communication, 2011) In other words, the more people learn about the disease, the more likely they are to overcome barriers to counseling and testing. This can have a positive impact on HIV when, for example, individuals find it easier to get counseled and tested multiple times as, the Nelson Mandela Foundation suggests.

Pitfalls of Using Treatment as Prevention and The Softer Side of HIV Prevention

When someone becomes infected with the virus, it takes approximately three months for the virus to replicate enough to be able to infect another person. In the meantime, the virus is attacking cells (called CD4 cells) in the body's immune system that are usually responsible for fighting off infections. The virus is so harmful because it attacks the body's defense system, opening the door to other opportunistic infections. When a person's CD4 cells decrease to a certain point, they are categorized (medically) as having AIDS.[81] Antiretroviral therapy, or ART (usually a combination of three drugs) helps an HIV-infected individual by decreasing their viral load (or the amount of virus that can be detected in a person's body) and keeping their CD4 cells at healthy levels. When a person's viral load decreases, so too does their chances of passing on the virus to another person. As such, ART decreases individual's viral load to negligible levels and thus saves them from acquiring AIDS and decreases the chance of infecting others.

The evidence for the efficacy of ART is strong. For example, in a randomized, placebo-controlled trial involving 3381 heterosexual African couples, antiretroviral therapy was shown to reduce the risk of HIV transmission from an HIV-infected partner to the other non-infected partner by 92%.[82] Where ART has been implemented, the prevalence of HIV has substantially and rapidly decreased in communities in America.[83] However, the best evidence for using treatment as prevention comes from the United States National Institutes of Health in May 2011 in a trial involving 1,763 HIV-discordant couples, which showed that those who started ART immediately after receiving their diagnosis significantly lowered the risk of HIV transmission to their sexual partners, compared to those who started treatment at a later stage in their disease progression.[84] The results showed a 96% reduction in risk of transmission, which was considered so effective that results were released early and the trial, originally set to end in 2015, was closed.

These promising results led to the great push for universal access[7] to antiretroviral therapy and using treatment *as* a prevention strategy. The greatest increase in antiretroviral therapy coverage has occurred in sub-Saharan Africa,

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[7] Universal access is defined by UNAIDS as providing antiretroviral therapy to at least 80% of the people eligible for treatment.

with 20% more people having access in 2010 than in 2009, alone, from 3,911,000 to about 5,064,000.[3] By December 2010, Botswana, Namibia and Rwanda (all with generalized epidemics), had achieved universal access to antiretroviral therapy, and Swaziland and Zambia (also with generalized epidemics), had estimated coverage levels between 70% and 79%. Receiving treatment has also been shown to lead to behavior changes as well. For example, when someone does know their status and subsequently receives ART, significant reduction in unprotected sex following treatment has been observed.[85]

But using treatment as prevention has its pitfalls. First, access to treatment is limited. Until access to treatment is improved, using treatment as prevention cannot be leveraged. In 2010 in sub-Saharan Africa, only half (49%) of those needing treatment received it.[4] For those that do receive ART, data on the proportion of people who remain on antiretroviral therapy over time in low- and middle-income countries indicate that significant attrition (discontinuation of treatment regimen) occurs within the first year of starting therapy. The average retention rate a year after initiating ART was 81% (92 reporting countries), 75% at 24 months (73 countries) and 67% at 60 months (46 countries).[86] In addition, HIV drug resistance is becoming a concern [4], which counteracts ART and bumps up an individual's viral load (making them more likely to transmit).

From strictly an epidemic point of view, as more people live longer due to ART, they also have more time to infect other people. Yes, ART decreases the chances of transmission while they are alive, but not so much that they cannot infect other people. For an individual that dies due to AIDS, their viral load goes to zero. But the more treatment prolongs an HIV-infected person's life, the longer their viral load remains in the population, and the more opportunities they have to infect someone else. For many people on treatment in low- or middle-income countries, the chances of transmitting the virus increase over time; the level of their viral load fluctuates because of various issues such as noncompliance with their treatment, lack of access to more treatment, and HIV drug resistance.[87] Thus, for every person placed on ART in 2009, an estimated four to six others acquire HIV.[86]

To be completely clear, this is not an argument to let all HIV-infected people die. To do so would be ethically unjustifiable. But, it is important to understand that treatment as prevention is not the only answer. HIV prevention, namely increasing people's awareness of their status, education, and encouraging behavior change is important. Individuals cannot even be eligible to receive treatment unless they know their status and receive counseling. And since barriers to testing and counseling are high and coverage of ART is low, returning results becomes ever more important. Thus, given the problems with using treatment as prevention, and *if our ultimate goal is to eliminate new HIV infections in sub-Saharan Africa, then what access level to HTC is acceptable for each person in the present?*

Whereas an individual would have to overcome barriers in order to receive all three services (testing, counseling, and treatment), returning results allows an individual to receive the intrinsic benefits of testing and counseling without having to worry about all of the barriers to HTC (see Table 3). There is no magic bullet, but returning results addresses the realities of the sub-Saharan African environment, as well as many of the challenges public health experts have identified in the fight against HIV in sub-Saharan Africa.

Conclusion

"It is increasingly recognized," UNAIDS states in a 2011 progress report, "that voluntary testing and counseling and provider-initiated testing and counseling *must be complemented by alternative approaches to more rapidly expand the availability and uptake of HIV testing and counseling* [emphasis mine]."[4] An updated HIV testing and counseling framework is currently being developed to assist countries in developing an appropriate and effective combination of HIV testing and counseling approaches to maximize coverage and impact.[4] Several countries have already introduced many new approaches, which include public campaigns, mobile testing, workplace testing and home- and school-based testing. Returning results from HIV tests performed during population-based surveys needs to be a part of this discussion.

With population based surveys, the test comes to the people that need it most, yet because of UAT the results of that test have been kept a secret because of the notion that doing so improves the accuracy of the data. Vouchers for free VCT are provided as a part of population-based surveys to make it easier for people to overcome barriers to VCT. But the reality is that the barriers are often too great. Although in theory providing a voucher ameliorated these barriers, in practice the barriers are insurmountable for many.

This is unfortunate because VCT, along with other HIV testing and counseling programs (or HTC), provides a participant with a unique opportunity to learn of their HIV status and receive education. As a recent UNAIDS report published on World AIDS Day states, “HIV testing must become simple and as ubiquitous as home-based pregnancy test kits. This will drive down the high costs of maintaining dedicated HIV testing and counseling centers as well as empowering individuals to access HIV treatment and care services in a timely and confidential manner.”[3] Referral to VCT during population-based surveys is also unfortunate because individuals are already getting tested for surveillance purposes. In areas of serious resource constraints such as sub-Saharan Africa, it would seem efforts should be made to “stretch” the utility of one test as far as possible. It is proposed here that one such “stretch” method is home-based HTC.

Home-based VCT has been widely accepted when it has been used, and has proven to conveniently provide timely, accurate results. Furthemore, many of the barriers to testing can be ameliorated, if not eliminated, by performing HTC in the home.[3] Pairing home-based VCT with returned results from population-based surveys could provide valuable services to both HIV-positive and negative individuals, and also act as a bridge between prevention and treatment programs. For those that are positive, they are able to receive counseling, testing, and treatment (one must know one’s status in order to receive treatment). For those that are negative, they learn of their result, and become educated (through counseling) on how to avoid getting infected themselves. Simply put, testing in the home during population-based surveys could lead to behavior changes that benefit individuals and communities, augment other “harder” biomedical interventions, and increase the amount of counseling and testing uptake.

Treatment can be used as prevention, but there remain challenges to doing so. Even when someone does receive treatment, one’s behavior and attitude toward it will dictate how effective it will be. I have termed behavior and attitude change as the “softer” side of public health because they are less tangible. Public health cannot directly buy, build, touch, or easily evaluate “soft” prevention methods, but they are just as important as the “hard”, tangible biomedical interventions. Thus, approaches that leverage the “soft” side of the HIV epidemic, such as “know-your-status” campaigns, community-based programs that change social norms, and returning results (through home-based HTC) must also be used.

Chapter 4: Community as Healing and Healing the Community

In the last chapter, I argued for returning HIV test results from population-based surveys to participants in sub-Saharan Africa. The argument for returning results from population-based surveys is that the benefits and burdens the individual receives from returned results via home-based HTC outweighs the benefit and burdens of collecting top-notch surveillance for society. This is primarily an ethical argument, and not merely a structural or technical issue as has been argued in by some[8]. Whereas the more concrete science and facts were presented in the last chapter, this chapter aims to develop the ethical dimensions of the above argument. And at the same time, this chapter takes a step back and asks if the facts as they have been presented make a good ethical argument to return results.

To make this ethical analysis I will use D. Micah Hester's application of Pragmatism – his moral theory of choice – to bioethics and the doctor-patient relationship.[1] His analysis yields a conception of medical ethics as the obligation to make each patient a part of the medical community in order to heal them. Or in other words, medicine ought to use "Community as Healing." What Community as Healing means exactly will be explained below, but the conclusions arrived upon after applying "Community as Healing" to HIV surveillance in sub-Saharan Africa are four-fold: First, that population-based

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[8] This has been intimated by a couple of people at the CDC to the author personally, either at CDC or as a guest lecturer in class at Emory University.

surveys have become a habituation (which is an old, rigid potentially dangerous habit); Second, Hester's argument contributes to the idea that ethics and public health practice mutually benefit by incorporating ethics into the decision making process, as opposed to the oversight of public health. Third, that a community becomes a separate entity from the individuals that make up that community, and in so far as that community can be considered an organism with its own characteristics and values, it is public health's job to protect and promote its health just as a doctor does with his or her patient. And fourth, that public health practices (i.e. surveillance) used as means to a greater end (i.e. preventing the spread of HIV infection) must incorporate aspects of the greater ends being sought, such as increased access to counseling and testing).

Pragmatism is a philosophical movement that values practice (what we collectively learn over time about morality) over traditional moral theory. Compared to traditional theories of morality and ethics, pragmatism rejects certain epistemological assumptions about the nature of truth, objectivity, and rationality. For pragmatists, the only theory employed is that morality arises out of the natural world as it is commonly *experienced* with our five senses. In contrast, traditional approaches to philosophy try to deduce the nature of morality by using abstract, *a priori* evidence (which are moral concepts assumed to be universal). But, it is important to note, traditional moral theories have a place in pragmatism because they were created and influenced over time by the *experiences* of people, despite their ultimate conclusions being misplaced in pragmatists eyes. They are misplaced because pragmatism falls under the broader philosophical category of "naturalism," which is the position that the nature of *right* and *wrong* – and *truth*, in general – can only be found in the natural world and natural sciences. As such, naturalists hold that morality can be deduced by the scientific process and not from a higher power or *a priori* moral principles whose source resides in a separate metaphysical realm. As described further below, naturalism has become a more justifiable position with scientific evidence from modern research in fields such as social and moral psychology.

Furthermore, pragmatists are more interested in the *process* of inquiry than the answers to classic philosophical questions, i.e. what is "good" or what can be considered "the good life." They are concerned with resolving moral conflicts and reaching their ends. The way they reach their ends is by doing what is most agreeable to everyone over time. When their ends are met, new questions and moral conflicts arise as a result, which starts the process over of meeting their new ends. Thus, as a process-driven method, pragmatism is about experimenting and *doing* rather than studying and *thinking* about issues. It therefore has a predeliction for taking moral action, but they *take action* in the spirit of *fallibility*, which is the notion that some of our beliefs may not be true. As *fallibilists,* our ability to understand right and wrong is therefore based on our incomplete understanding of the truth, and as such, the more perspectives we take into account in moral decision making, the more ethical our actions are. Thus, a pragmatist as a fallible individual experiments and takes action keeping in mind the wants, needs, and values of others.

One might question whether this is just moral commonsense; how is the above all that helpful? The answer, I hope, will be drawn out over the course of this chapter, but an initial response might be that, if pragmatism is just moral commonsense, this could be described as a *good* thing. If all of humanity could act with moral commonsense, we would more or less agree and effectively take action in addressing common problems. But pragmatism is not simply moral commonsense, because this implies there is a moral viewpoint that is *commonly* understood and agreed upon, and this agreement is questionable. Furthermore, what is moral commonsense today might be moral *non*sense in the future, as moral norms and social contexts shift over time. Pragmatism, in contrast, holds none of these views. Pragmatists understand that humans are fallible, and therefore cannot count any viewpoint as common. And as a process-driven method, it accounts for shifts in moral norms as opposed to traditional theories (such as utilitarianism or Kantianism) that describe morality as static and unchanging.

Good ethics begins with good facts. If the facts change, so does the ethics. Ethics is therefore wrapped around, and infused within the continuous stream of facts that emerge from any given context. Pragmatism does not divorce ethics from reality by citing some abstract, *a priori* truth, but instead grounds ethics in reality. Thus, systems and infrastructure – particularly when viewed through the eye of pragmatism – are ethics issues. And when those systems and infrastructure problems are fixed, new – and different – ethical conflicts emerge, for example, ethical tangles may remain with confidentiality, consent, resource allocation, and distributive justice.

Pragmatism Justified

There exist other frameworks specifically designed for public health ethics, and others that were designed for traditional bioethics and medical ethics yet translate to the public health context (i.e. principlism). Pragmatism is employed here, however, not so much because these alternative approaches to ethical analysis have shortcomings – although I will present some criticisms of them – rather pragmatism is suited particularly well to answer ethical questions regarding HIV surveillance in sub-Saharan Africa.

Pragmatism was created by Americans and developed primarily in response to both general medical practices of the West and specific medical encounters in the United States.[1] Pragmatism reflects the American spirit; as McGee notes, "Rooted in American culture, tied to American ideas about social and scientific progress and about health and disease, in many ways pragmatism is American's philosophy."[88] While it was by no means created strictly for Americans, American ideology naturally influences the lens through which pragmatism views the world.

Many of the prominent players in the story and history of HIV surveillance worked in America and American agencies such as the CDC. And America continues to globally impact the HIV/AIDS scene today through the President's Emergency Plan for AIDS Relief (PEPFAR) signed into law by President George W. Bush in 2003.[89] In particular, 11 out of the 15 "focus countries" that receive that lion's share of the funding are sub-Saharan African countries.[90] Since much of the funding to fight HIV in sub-Saharan Africa comes from America, funding is therefore tied to American rules and regulations which, as described in the first chapter, have had a profound influence on the way HIV surveillance has been performed in sub-Saharan Africa to date. As another example, despite criticism[91] funds from PEPFAR must be used in part for abstinence-only education as a prevention method. While this no-doubt reflects a certain religious perspective, it also reflects American political motivations at the time.[92] As such, an ethics approach that can account for American ideals (or ideology) is important.

Furthermore, and perhaps reflecting the American "melting pot" culture as well as the sentiment of public health, pragmatism embraces pluralism, which claims that there are multiple considerations that go into making ethical decisions and not just one priority (e.g. one must do their duty for Kantians). Even if one might not share similar perspectives or values, a pragmatist must, at the very least, listen to others; Pragmatism, like public health, therefore preaches tolerance. It holds no moral theory as better than any other, rather all moral theories contribute to, as Hugh LaFollette describes it, the "arena of ideas."[93] As such, although it is a method of philosophy borne out of the American tradition, it is well suited to adjudicate moral problems across cultures where moral norms and values likely differ. And, at the same time it reflects the modern times better than other theories created during the enlightenment or before.

Third, pragmatism is a type of "naturalism", which grounds philosophical investigation in empiricism. Pragmatists (as naturalists) reject not only the *a priori* metaphysical questions that traditional moral theories discuss, but also the abstraction from the experience acquired in actual moral action. Morality, a pragmatist would say, resides in the world as we experience it with our five senses. This is perhaps one reason why pragmatism has not been adopted largely by traditional philosophy in that it rejects many of traditional philosophies foundational claims. But, as Hester writes, “The pragmatist tradition…is uniquely suited to approach contemporary ethical issues since pragmatists have always emphasized the integration of theory and practice and the relevance of philosophy to living.”[1, p. 4] Theory cannot be divorced from practice in public health, because theory regarding what is and is not ethical has developed and changed over time as a result of practice. For example we know now that slavery is grossly unethical, but in the past it was not viewed universally as unethical. As time passes, our practice informs moral theory and *vice versa*. As such, pragmatists promote the use of the scientific method. As Johnathan Moreno says, “The philosophic naturalist stresses the method of science rather than the content of science.” In other words, although the scientific method is most often applied to the “hard” sciences, hard science is not, by itself, the only way to examine our experiences of the natural world. Instead art, for example, is an alternative inquiry into the nature of our experiences. Anything humans experience in the natural world informs our conceptions of what is and is not moral over time. Morality, in the form of naturalism, is a *process*, and as time passes, we collectively get closer to understanding what is and is not ethical.

Additionally, the method of pragmatism is teleological (end-oriented). The method by which those ends are achieved is the scientific method – making an educated hypothesis and testing philosophic ideas by trial and error over time. “Pragmatists are driven not by principle, but by the desire to achieve their ends.

Hence pragmatists have little interest in abstraction, idealization, nitpicking argument…; they have no time for these because they are fixed on practical tasks."[94] Pragmatism aligns with public health practitioner's motivations and intuitions about morality: morality is in the *doing*, not armchair philosophizing. As such it suits the consequentialist nature of public health. That is, public health actions are often judged according to whether *outcomes* promote the greatest good for the greatest number of people.

Moral and Social Psychology

The final, but perhaps most compelling reason to use pragmatism, is modern research into moral and social psychology. As mentioned, pragmatism is a type of naturalism, and modern research in moral and social psychology is suggesting the naturalists had it right. Although it is debated, evidence strongly suggests that our brains are wired to create morality. In other words, morality may be an evolutionary trait that some animals (not just humans) have developed over time in various capacities to get along with each in order to build communities. More has been written about this research elsewhere than can be discussed here.[95-98] But briefly, the first thing moral psychology teaches us is that humans are affectively (emotionally) driven. We believe reason tells us why an act is wrong, when research suggests that it is our emotional response to something that we try to rationalize post-hoc.[99] Hume noted long ago that reason is indeed slave to the passions, and Blaise Pascal said, "The heart has reasons the head knows not of."[98][9] The role of emotion challenges the notion that morality stems from our ability to reason, as Immanuel Kant's prominent moral theory suggests.

Charles Darwin suggested that our brains did not evolve to selfishly separate us from one another as unlinked individuals, but instead to form groups with one another.[100][10] To do so, however, requires that we be able to work together without killing each other. As such, Emile Durkheim's definition of morality is particularly helpful, namely that morality arises out of our complex social interactions. In other words, morality binds us to one another and helps us build community, and in so doing create groups whose properties are greater than the sum of its parts.[101]

Jonathan Haidt, a research psychologist from the University of Virginia draws on Darwin and Durkehim when he defines morality as, "interlocking sets of values, practices, institutions, and evolved psychological mechanisms that work together to suppress or regulate selfishness and make social life possible."[96] According to Haidt and colleagues, these mechanisms – or the way humans develop their morals – comes from six psychological "moral

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[9] Quoted in David Brooks, 2012.

[10] Darwin wrote, "[A]ny animal whatever, endowed with well marked social instincts…would inevitably acquire a moral sense or conscience, as soon as its intellectual powers had become as well, or nearly as well developed, as in man. For, firstly, the social instincts lead an animal to take pleasure in the society of its fellows, to feel a certain amount of sympathy with them, and to perform various services for them." (Darwin 1875)

foundations".[102] Like an equalizer used to record music, each foundation can be amplified or muffled depending on the culture one grows up in. But cultures and communities have developed many different moral environments over time, and unsurprisingly have come to value very different things. In sum, research in moral and social psychology illustrates that morality is found in the "natural" world, and is therefore a naturalism. According to Haidt, morality is a neurological, psychological, and cultural mechanism that has evolved to link us with other people so that our communities can thrive.[96]

Criticisms of Frameworks

As mentioned, it is not that principles and frameworks do not account for American ideals, naturalism, pluralism, or consequentialism, but pragmatism accounts for it better. There are also valid criticisms of principlism and public health ethics frameworks. In 1979, the first edition of a landmark work, *The Principles of Biomedical Ethics*, authored by Tom Beauchamp and James Childress, became one of the most important basic texts for medical ethics.[1] The authors argue for four foundational principles: respect for autonomy (acknowledging the right to act and make choices based on personal values and beliefs), nonmaleficence (avoiding harm to patients), beneficence (doing good, or benefitting patients), and justice. Beauchamp and Childress' principles – called principlism by some – are the cornerstone of what I will call traditional bioethics (patient-centered, clinical ethics). Principalism is considered a "mid-level" approach to moral theory, because it takes moral norms called *considered moral* *judgments* and considers how they cohere with higher level moral theories developed over time (see Figure 6). They borrow a method developed by John Rawls called “reflective equilibrium”. As Beauchamp and Childress describe it, “The goal of reflective equilibrium is to match, prune, and adjust considered judgments and their specifications to render them coherent with the premises of our most general moral commitments.”[103, p. 382]

Over time, Beauchamp and Childress have been very responsive to their critics, and by their latest edition (6 ed. 2009), they had broadened their focus and application of their principles to global level health issues, effectively making it applicable to the field of public health. It is perhaps unsurprising, then, that the development of public health ethics frameworks beginning around 2000, use a similar method as Beauchamp and Childress’ principles. They take the considered moral judgments that public health stakeholders most often hold and try to make them cohere with the applicable theories of morality (i.e. rights-based approaches). These frameworks, like principlism, provide a list of various ethical considerations for public health practitioners. For example, Nancy Kass’ framework emphasizes the importance of considering the goals of a program, its effectiveness, known or potential burdens, minimizing burdens, fair implementation, and a fair balance of benefits and burdens.[104] Or, another helpful framework by James Childress and colleagues not only outlines important moral considerations of public health (i.e. respecting autonomous choices and actions), but also provides five conditions that should be used to adjudicate when those considerations can be “overridden”.[11] [38] These include the program or policy’s effectiveness, proportionality of benefits and burdens, necessity, least restrictive infringement, and public justification.

But the criticisms leveled against principlism apply also in large part to these public health ethics frameworks, namely (1) they “function like names, checklists, or headings for values worth remembering, but lack deep moral substance and capacity to guide action. That is, principles point to moral themes that merit consideration by grouping those themes under broad headings, but do little more.” Furthermore, (2) principles can be used to justify either side of an ethical argument and therefore leave moral agents free to deal with problems in their own way. For example, the concept of social justice that Gostin and Powers promote[105] does not help public health stakeholders choose which of two similarly disadvantaged populations to allocate scarce resources to, leaving it up to other factors such as stakeholders own bias. And, (3) that principles often

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[11] Moral considerations include producing benefits; avoiding, preventing, and removing harms; producing the maximal balance of benefits over harms and other costs (often called utility); distributing benefits and burdens fairly (distributive justice) and ensuring public participation, including the participation of affected parties (procedural justice); respecting autonomous choices and actions, including liberty of action; protecting privacy and confidentiality; keeping promises and commitments; disclosing information as well as speaking honestly and truthfully (often grouped under transparency); and building and maintaining trust. Conditions to override moral considerations include the program or policy’s effectiveness, proportionality of benefits and burdens, necessity, least restrictive infringement, and public justification. (Childress et al. 2002)

conflict with one another, and there is not a good way to adjudicate which principle deserves more weight than others in all cases.[103, p. 372]

Furthermore, and perhaps most importantly, one might argue that these frameworks are, as Baum and colleagues put it, “not sufficiently pragmatic to be useful in practice.”[106] No matter how much developers of public health ethics frameworks try, there is no framework that can account for the way people make everyday ethical decisions. When confronted with morally challenging situations, a person (even an ethicist) does not run and confront an ethics textbook, principles, or frameworks. They “apply themselves” by, along with their understanding of theory found in ethics textbooks, reacting in a way that reflects their lived experiences with similar problems, judgments, intuitions, temperament, and “gut feelings”.

Introduction to Community as Healing

In his book, “Community as Healing,” D. Micah Hester applies the ideas of classical pragmatists such as William James, John Dewey, and George Herbert Mead, to bioethics and clinical medicine. His motivation for his efforts is the way the standard principle-based account of bioethics and medical ethics fail to accommodate some of the most morally relevant details. Pragmatism as a general body of knowledge, as well as Hester’s theory of Community as Healing have ethical implications for public health, broadly, and HIV surveillance in sub-Saharan Africa.

Community as Healing begins where many accounts of pragmatism begin, with an exploration of what happens in practice. Arising out of practice are habits. Hester defines “habits” as tendencies to act, tendencies that have been acquired. Habits are actions waiting in reserve, mobilized by the circumstance in which one finds himself or herself. Habits are shaped by prior experience, and as such our culture and environment become “instructors.” Our norms, our beliefs, how we learn, how we talk, and even how we think are all largely learned. Therefore, our past and present community shapes our habits.

While habits can be inherited, habits can *also* be shaped by personal choices. If people were unable to create new habits and only used inherited habits, they would be devoid of responsibility. But we create habits because they allow for intellectual efficiency. For example, a musician practices a piece of music over and over again so that she need not think about each note, each physical twitch of the fingers, or the volume of each note played in order to play it well. If she had to think about each of these things, then playing music would not be very efficient, in that one would struggle to play a difficult piece each time they played it. But practicing creates the habits needed to play difficult pieces of music from beginning to end.

Habits can be thought of as inclinations that “prefer” and “choose” moments to manifest depending on the environment one finds himself or herself in. “They do not passively wait in reserve, “ says Hester, “but seek out conditions in which to act.” As a result, “[t]he active nature of habits can lead to the “unthinking” exercise of them.”[1, p. 9] As such, Hester distinguishes between two types of habits, which he calls “intelligent habits” and “habituations”.

Intelligent habits are developed *deliberately* and require intelligence (i.e. thought). Habituations, alternatively, are habits that are performed routinely and without thought; they are habits that we are not concerned about changing.

But habits are much more interesting than that. The same features of a habit that make it intelligent also make it a habituation. To use an analogy, without language, for example, we would not be able to communicate as well as we do. Yet, the things we say are restricted only to the things we know how to say in that language. Therefore, habits are, as Donald Morris puts it, a “double-edged sword. By forming habits we restrict the need for conscious consideration of what we are doing. As a result our thoughts are bounded by specific limits, and we may fail to consider all possibilities.”[107, p. 38] The musician *deliberately* (intelligently) creates musical habits by practicing. But those intelligent habits eventually reach their “intelligent horizons” and become habituations. Without creating new intelligent habits, the musician’s music will sound the same each time.

Hester is concerned with habituations in medicine. There are already quite a large number of opportunities to develop routine practices in medicine including, for example taking the patient’s history, performing blood-pressure checks and administering vaccinations. In addition, however, the field of medicine almost encourages the development of habituations: “Demands are placed on health care professionals that time spent with patients be quick and efficient in order to meet the “bottom line.” Of course, this does not bode well for intelligent habits that, admittedly, can be more time consuming than simple habituations.”[1, p. 11]

Habituations in medicine are dangerous because it not only turns the practitioner into an automaton, but in doing so also turns his or her patient into an automaton as well. It makes the assumption that each patient is the same and medicine can be applied to each case in the same manner. But John Dewey writes:

> "Just in the degree in which a physician is an artist in his work he uses his science, no matter how extensive and accurate, to furnish him with tools of inquiry into the individual case, and with methods of forecasting a method of dealing with it. Just in the degree in which, no matter how great his learning, he subordinates the individual case to some classification of diseases and some generic rule of treatment, he sinks to the level of the routine mechanic. His intelligence and his action become rigid, dogmatic, instead of free and flexible. (MW12, 176).

Each patient presents differently. If a physician were to diagnose each patient according to how their medical school textbooks instructed – that is, as robots computing, analyzing and responding from a rigid group of programmed rules – the patient would suffer. As Hester notes, although drawing on previously established categories of symptoms and conditions is useful, "these general notions of disease are never merely ends in themselves but are instrumental means of questioning and investigating that eventuate in a *specific* "right healing action." Medicine, therefore, can never merely be a strict science of classification but an art form that imaginatively applies the instruments of medical sciences…"[1, pp. 5-6] Medicine as a science relies on general principles that help the scientist deduce right action, but runs the risk of acting dogmatically, mechanistically, and rigidly. But art is individual, art is unique. And thus medicine as an art form treats the patient as an individual, not a general type.

Habits of Intelligence; Habits of Surveillance

To make medicine more of an "art form" than a "science" – that is, cultivate intelligent habits in medicine – Hester suggests that "habits of intelligence" must be created first. As it is defined by Hester, "[i]ntelligence is a complex of habits that work together to produce reflective thought and action."[1, p. 10] There are many habits of intelligence, including but not limited to suspending judgment, deliberation, experimentation and acceptance of fallibility. And those can be broken down further into fewer, more foundational habits until, as Dewey says, "The primary prerequisite of critical ability [and activity] is courage…[For] the easy course is always to accept what is handed out."[108, p. 134] Hester expands, "Critical reflection requires habits of courage in order to risk enacting intelligent deliberate judgments that may simply be wrong. All these habits of reflective thinking…embody an imaginative process that helps make otherwise restricted habits flexible and expansive."

Intelligence, as Hester defines it, is a way to take inventory of personal thoughts, ideas, emotions, and tendencies and *subsequently create new intelligent habits*. It can be described, in a way, as a form of personal surveillance. In the same way that intelligence allows us to gather, analyze, and implement changes in our personal habits, public health surveillance gathers and analyzes data so that better policies or practices can be created. Thus, HIV surveillance serves as a means of responding intelligently to the HIV epidemic.

But part of creating intelligent habits of public health is creating new habits of surveillance. Importantly, this is not to say that methods of HIV surveillance currently being employed are “not intelligent” as in, they do not require significant intellectual capacity. Rather in the pragmatic understanding of intelligence and habits, one might say that the methods of HIV surveillance currently being employed have become *habituations*; Habits that were previously conceived of intelligently, but have now, due to shifting circumstances, reached the limits of its intelligent horizons.

Habits of Morality, Moral Imagination, and Moral Artistry

Morality is a habit as well, and therefore morality can be exercised intelligently or habitually. Hester writes, “Moral deliberation, itself, cannot be rote application of principles and rules; it must be creatively flexible and adaptive.”[1, p. 12] Problem solving is often approached in a mechanistic, disciplined way. Ethicists oftentimes do this as well, by applying standard principles or frameworks to different situations. But in reality much of problem solving is an imaginative process, and therefore problem solvers – be it engineers, doctors, or moral agents – benefit from *refraining* from thinking about problems in the same rigid, routine way. In other words, solving an ethical problem (or as Hester says, “moral deliberation”) means that *a moral agent must use his or her moral imagination*.

Moral imagination is particularly important to understanding Dewey’s concept of dramatic rehearsal: “Deliberation is a dramatic rehearsal (in imagination) of various compelling possible lines of action.”[109, p. 132] Put another way, solving an ethical problem involves rehearsing (imagining) a story (or a *drama*). In so doing, a moral agent rehearses the response of others to their actions, and weaves their *narrative* with others’ narratives to form what Hester calls a “coherent story (or narrative).” By “coherent”, Hester means a story that, “adequately “expresses” the conflicts that characterize the particular problem to be solved.” Or put another way, a story where each moral agent recognizes the connection of their desires with those of others in order to fashion a common moral viewpoint.

Consequently, the solution to an ethical problem is what most people will accept, instead of deducing a solution from some abstract truth. Therefore, the most ethical path to follow, “will only arise after careful consideration of all persons affected by the current situation and the consequences of our proposed actions. In this light, deliberation by the moral philosopher must attempt to *create* a narrative that includes as many concrete interests as possible.”[1, p. 13]

For Steven Fesmire, “creating a narrative” means putting oneself into the place of the other:

> “[A] “complete” dramatic rehearsal strives to weave the interests and purposes of ourselves and others into an integrated and enduring tapestry.

> Hence, not only must we forecast consequences for ourselves, but also, as Mead observes, we must (and do) dramatically play the role of others whose lives interlace with our own. We must imaginatively project ourselves into the emerging dramas of *their* lives to discover how their life-stories or "narrative" may be meaningfully continued alongside our own. Immoral conduct is thus not merely a deficiency in one's capacity to follow moral laws or rules. Much more than this, immorality stems from a scarcity of moral imagination and a failure in moral artistry."[110, p. 571]

According to Fesmire, practitioners in either medicine or public health should not be expected to apply moral principles or rules because forsaking those is not what leads to unethical public health practice. What leads to unethical public health practice is *lacking moral imagination* and *an inability to rehearse the narratives of others* (what Fesmire calls "moral artistry"). The significance of this is the weight moral imagination and artistry places on each individual. This also hints at the social nature of morality (to be discussed further below). If there were no other narratives to imagine, there would be no need for moral deliberation. However, the moment another person becomes a part of the drama, their narrative must be woven into "an integrated and enduring tapestry."

This imagination requires a lot of work. And for public health, the challenge of moral artistry and imagination is magnified because of the sheer number of narratives that must be rehearsed. As it applies to HIV surveillance, moral artistry asks those that design and implement surveillance to rehearse the narratives of both the individuals in the community as well as the public health practitioners that depend on the data collected. It is incredibly difficult for the moral artist to imagine situations whereby each other's desires are woven into a coherent narrative. But it is *not* impossible. Hester, again:

> "[R]ecalling our earlier discussion of intelligent habits and habits of intelligence that lead to pragmatic understanding, we can begin to see that *moral artistry is actually the imaginative use of habits of intelligence in everyday social situations*. The moral artist never merely attempts to apply abstract rules or principles; that person learns to view problems through habits of intelligence that *creatively and dramatically rehearse possible solutions to problematic situations at hand,* adjusting desires and the situation in order to develop a story that takes the other seriously [emphasis mine]."[1, p. 14]

To rephrase in the context of HIV surveillance in sub-Saharan Africa, moral artistry – that is, the method for moral deliberation – requires the "imaginative use" of surveillance (a habit of intelligence for public health) in everyday social situations. Furthermore, moral artistry does not *unthinkingly* apply rules, principles, or even practice such as the dogma that epidemiological research is – and should forever be – separate from clinical care and screening services. But instead, a moral artist "creatively and dramatically rehearse[s] possible solutions to problematic situations…" For example, where there is limited access to HTC, a creative solution may be returning results via home-based HTC, as I argued for in chapter three.

Furthermore a moral artist adjusts their “desires and the situation” – such as the *desire* of those in public health that want to separate surveillance from clinical care, or the *situations* where HIV surveillance is carried out, for example, by using PMTCT sentinel sites to collect data instead of doing so anonymously as a part of other routine clinical care. This is all done “in order to develop a story that takes the other seriously,” which hints at the part of Hester’s theory that I turn to next, in which he discusses the notion that each person is not simply an isolated individual but a member of a community. This has implications for Hester in the clinical environment, but it also has implications for public health, broadly, and public health surveillance. This is because, coincidentally, public health has this same goal, namely to shift the individual’s perception of themselves away from an insular individual, and toward one where they view themselves in the context of a connected group of people.[111]

Social Products

Hester’s theory was created, as mentioned, in response to his disdain for the bioethics theories that give autonomy, in particular, primary importance. Autonomy asks the physician (and public health practitioner) to view the patient as an insular individual, or as Dewey describes it, “something static.” This habit(uation) of thinking arose out of the enlightenment period from thinkers such as Locke and Kant. But as a more modern philosopher, Dewey was able to reflect on the wisdom of viewing individuals in this way: “Such thinking treats individualism as if it were something static, having a uniform content. It ignores the fact that the mental and moral structure of individuals, the pattern of their desires, and purposes, change with every great change in social constitution…The individual cannot remain intellectually a vacuum [as autonomy describes].”[108, p. 80] Hester expands by saying, “Reason itself is not separate from experience, but arises with habits of experience.” As such, as argued largely by George Herbert Mead and modern day social psychologists, no human comes into the world as a static self, but is born into a community and from that very moment is being shaped by the community it is now a part of.

In response, Dewey, James and Mead all contributed to the creation of a *new individualism*, which does not pit individuals over or against society but sees individuals as fully integrated beings who are part of a community that shapes and molds who they are. And at the same time, these individuals shape and influence their community. In other words, our narratives are inextricably wrapped up in, and develop alongside others. Hester writes, “[e]ach of us…contributes uniquely to the community in a way that would be altogether lost to the community if that particular individual were not present.”[1, p. 53] A teammate, for example, on a sports team plays a role that would be lost if she were to leave the team. The teammate cannot be viewed as separate from the group, nor can she be viewed as – to use a word – just a mindless member of the hive. She is both unique (an individual), but also a role-player with limits of what she should or should not do to contribute to both her personal success and the team’s success.

Like the sports team, community, according to Dewey, is found in a “society that makes *provision for participation in its good of all its members on* *equal terms* and which secures *flexible readjustments of its institutions* through interaction of the different forms of associated life."[112, p. 105] We are social products, and as such our narratives are woven with other's narratives from the very moment we are born. But our communities must ensure equal opportunity for participation by readjusting institutions (e.g. increasing the number of PMTCT programs available to pregnant women).

But as mentioned, this is not to institute an all-for-one, one-for-all, "hive" mentality, but instead, produce a balance between the two sides of the spectrum; a happy medium between the individual's unique pursuits and the need to intelligently and imaginatively weave their own narrative with others. Hester sums this up: "The key, then, in positive, progressive human interaction, it would seem, is to balance individual and social interests by finding ways to retain individual desires and values (in their vast multiplicity and diversity) while making them work within the social good."[1, p. 53]

Moral artistry requires the "artist" to take an active role in their and other's narratives. As such, the engaged patient becomes the model for physicians and patients alike. *This is therefore the ultimate goal – for each individual to engage, participate, or otherwise live an integrated life in his or her community.* Hester calls this "meaningful" or "healthy living": "Healthy living is the common *participation* in, with, and by community. It is the significant, meaningful engagement in one's pursuits within a social context…To put it oversimply, a meaningful life integrates both individual and social aspects of life, where socially situated individuals actively participate in the life stories of themselves and their communities."[1, p. 17] This is particularly poignant, because often public health ethics describes the occasion when individual’s must be “coerced”, or their autonomy, privacy and liberty must be “limited” in order for the community to protect and promote the welfare of all its members, and to ensure social justice. But pragmatism and “Community as Healing” provide a model that at the same time says we ought to be more community-oriented (necessary for public health) and unique individuals.

The principle of autonomy, as it is conceived of in the Belmont Report, does not situate the individual in a social context as much.[10] As such, Community as Healing resists the principle of autonomy, and also American individualism, which, in the words of Bellah and colleagues, “values independence and self-reliance above all else,” and is “the first language in which Americans tend to think about their lives.”[113, p. xiv] In contrast, no one can contribute to the character of the community the same way as another, and as such using this theory better accounts for both the individual’s values and the social context that they live in.

Returning Results and Engaging the Community

In the context of the HIV epidemic in sub-Saharan Africa, an individual, in order to live healthily, must be engaged not only in her life story but the story of her community. Given the barriers to HIV testing and counseling, neither is possible. Regardless of whether one is HIV positive or negative, many people are not even *afforded the option* to become an engaged participant, because they cannot overcome barriers to learn of their status or are not educated enough about HIV. By returning results through home-based HTC, the individual is given the *opportunity* to become an engaged community member either by seeking out VCT or changing her behavior, or both. By giving her the opportunity to be an active participant in her care, she is able to create her own narrative and weave it into others. By "weave it into others" I mean, by being made aware of her status and receiving education (counseling) she is more likely to seek out care and is able to change her risky behavior that would affect others. Regardless of how covert or overt her behavior and/or attitude shifts are, by implicating others in her own actions, she engages her community and decreases the likelihood of spreading HIV. As such, she becomes integrated within and connected to the community more so than she previously was.

Linking HIV surveillance with clinical care has already begun to take shape in America. For example, one innovative (or, *imaginative*) proposal is creating an information exchange with health facilities to provide clinic alerts for persons who have not been tested for HIV or have dropped out of care. Collaborative efforts have been made by U.S. states and districts such as Louisiana, Washington DC and New York, for example, to use surveillance registries and track patients over time.[114] But this understanding of integration and engagement in community is applicable to many current public health initiatives and diseases, not just HIV.[12]

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[12] The efforts to eradicate *Poliomyelitis* (Polio) are one such example, where many children and adults were removed from their communities and placed in iron lungs, or unable to engage in their communities as they had before due to paralysis.

As mentioned above, a community is a society that makes *provision for participation in its good of all its members on equal terms* and which secures *flexible readjustments of its institutions*. But as is also mentioned above, by this account the circumstances in sub-Saharan Africa do not reflect a healthy community. Public health has the opportunity to make provision for the improved participation of more of its members by returning results and using home-based HTC, as well as the opportunity to adjust its institution of not returning results by adjusting its HIV surveillance practices. In so doing they significantly create the opportunity for individuals to become engaged participants not only in their own lives, but also in the broader community.

Furthermore, it helps to balance individual and social interests. For example, with improved education, an individual may begin to use condoms more or decrease their number of sexual partners. As a result, the individual can still maintain their interest, or desires, for sex but does so keeping societies interests in mind. This seems to be fair balance of individual and community interests, or in other words, this seems to be "healthy living".

Community as Healing

Hester investigates the implications of "healthy living" on medicine. When someone requires medical attention, they have experienced an event that no longer allows them to interact with their community as they use to. Any medical problem, from having the common cold, to cancer or dementia has altered an individual's place in their community to different degrees. The more a medical condition tears at the social fabric of one's life, the more intense that condition is felt. And alternatively, the more serious the medical condition, the more divorced from their community they become. Hester gives an example of a patient who is suffering: "I am not healthy. I cannot perform without medical attention. People treat me differently. My ability to carry out obligations to family, friends, job, and so on, are compromised…"[1, p. 70] The goal of medicine, then, is to patch up the individual so that he or she may integrate into his or her community once again. "[I]t should be evident that healing should be concerned with restoring the individual to a state of vital functioning, and vital functioning entails communal participation."[1, p. 71] In contrast, operating under the popular ethical principle of autonomy in medical situations does not allow the practitioner to view the patient as a part of a larger community with which he or she is trying to reconnect to, but instead as completely separate from that community. As such, autonomy misses the point entirely – we are not healing *this* individual so that *she* is healthy; we are healing this individual so that she can *reconnect with her community*.

Hester calls for medical practitioners to consciously become community themselves to heal each patient. He argues that the ultimate end that each patient seeks is "healthy living" and as such healthy living should be incorporated into the means used – the medical encounter – to reach that end. Put another way, what we use as means to our ends take on the character of those ends. For example, if the musician's end-goal is to perform well at a concert, she practices the music until she can play it at concert-quality over and over again; the means (practice) to her ends (the concert), take on the character of the ends. Since our ends are *relative* to our means, we can think of means and ends as part of a continuum. As such, the means we employ must *emulate* our ends to some degree. And, Hester argues, the same should go for medicine. If communal participation is the end-goal, then it must also be implicated in the means to that end: "Patient participation within a community of healing is, therefore, essential to the "healing" encounter. These kinds of encounters treat patients as members of the health care community, a community that, ideally, mirrors the form and function of the larger community in which it resides. This "community" emphasis is best accomplished through the promotion of patient agency…within the medical encounter itself."[1, p. 65]

While medicine is a *means* of achieving the *ends* of communal participation, Hester also believes the medical community should serve as an end in-and-of itself: "Means and ends intermingle and coexist in such a way that *when means are found to be satisfactory as ends themselves, this helps to create further meaningful, satisfactory ends as the outcome of these means*. [emphasis mine]"[1, p. 74] In the context of HIV surveillance, by returning results surveillance becomes more of an end in-and-of itself because it allows each individual a better opportunity to integrate in his or her community; each individual is treated as an end in-and-of themselves. In doing so, participants are given a valuable resource, such as education and knowledge of their own HIV status, which they can then leverage for other beneficial behavior and/or attitude changes. As Hester is quoted above, "when means are found to be satisfactory as ends themselves," such as using surveillance to return results, "this helps to create further meaningful, satisfactory ends as the outcome of these means," such as potential behavior and attitude shifts.

Healing the Community

According to Hester's account, "health care is about "preserving human affections" – that is, providing patients with the means to retain or restore their relationships to others within the community." As such, medicine is not about mending the patient's body much at all, rather making sure one's community remains intact, or – importantly for public health – is mended itself. But what happens if the community is not intact; what if the community is itself sick? Again, as Hester describes it, a healthy community is one that allows all its members to participate on "equal terms" and that readjusts its institutions according to the social conditions of that community. But barriers such as the psychosocial costs of being identified as HIV-positive, inadequate access to HTC, and the habitual belief that HIV surveillance must be separated from any form of clinical screening and/or care make it difficult to achieve a healthy community.

Community, like an individual, is an organism comprised of various sub-systems, or organs. Whereas a doctor (or any medical practitioner) aims to heal the individual, public health is the doctor's equivalent on a community level. As such, it is public health's aim to heal communities. In order to create moral medical encounters – that is, before community can be used as healing – public health must heal the community.

Since the landscape of the HIV epidemic is always shifting, public health must continually create intelligent habits to adapt and habituation is always a threat. Thus, cultivating intelligent habits of public health is an important part of the process of healing a community. As previously mentioned, however, before public health can create intelligent habits, it must first create intelligent habits of surveillance. To do this ethically, that is "morally deliberate" which habits of surveillance to create, one must act as a moral artist, and imagine a scenario (or a *drama*) whereby each person's narrative can be woven together with all other community member's narratives into a coherent tapestry. In this way a community can ensure the "provision for participation in its good of all its members on equal terms".

The second part of the definition of a healthy community describes its ability to, "[secure] flexible readjustments of its institutions through interaction of the different forms of associated life." On the continuum between means and ends, HIV surveillance unquestionably falls closer to the former. But means emulate ends, and as such public health must consider how HIV surveillance emulates the ends of stopping new cases of HIV worldwide and eradicating HIV. When UAT was developed in the 1980's, public health's ends were not eradication of HIV because there were no therapeutic options, and the psychosocial costs of being diagnosed as HIV-positive were too large. But today the ends have shifted to the elimination of the disease, and public health must ask how the means it employs to those ends, such as surveillance, fit within the continuum of means and ends. Pappas and Hyder articulate similar considerations based on the principle of beneficence when they write, "the health care needs of participants and their communities fuels considerations to use survey work as a vehicle to provide care."[115] By returning results via home-based HTC, surveillance becomes more of an ends in-and-of itself, and people are able to leverage their knowledge of their status and seek out counseling and treatment.

Conclusion

It would be a mistake to conclude that those who continue to support UAT in population-based surveys are simply caught in a mindless inability to create intelligent habits that allow them to ethically adapt to the shifting conditions of the HIV epidemic. Indeed, those who have chronicled this ethical debate since it began in the 1980's have observed that most decision makers involved have struggled with the question of how to balance the need for the most accurate public health surveillance possible with the claims of those who are tested. (Ron Bayer, personal communication, 2011) It is not that decision makers blindly adhere to rigid dogma, but often use a careful and pragmatic calculation. As such, my aim is not to criticize HIV surveillance decision makers or question their character. Rather, on a broad level my aim is to encourage decision makers to consider morally relevant variables (e.g. the utility of HTC) to any future ethical analysis. One such opportunity currently exists as discussions continue to take place within international public health organizations such as the CDC regarding returning results from population-based surveys in sub-Saharan Africa. (Mark White, personal communication, 2011)

By all accounts, efforts have been made to perform HIV surveillance ethically in the past. Ethics consults have been incorporated into the *process* of HIV surveillance almost since the very beginning of the epidemic, and in doing so has perhaps unknowingly employed the pragmatic method (using the scientific method to understand morality). However, the methods of HIV surveillance currently being employed have become *habituations*; Habits that were previously conceived of intelligently, but have now, due to shifting circumstances, reached the limits of their intelligent horizons. I have argued that the way to create new habits of surveillance is by paying more attention to the behavioral component of biomedical interventions we use in public health, and through paying more attention to the ethical dimensions and implications of public health practice. That is to say, creating new habits of surveillance by paying attention to those things that have, like the water fish swim in, been there for so long that we often have trouble seeing or talking about them. By paying attention to these dimensions, public health empowers the community to participate in its healing process and live healthily. As a community begins to live healthily it can then be used to heal each HIV-infected person situated within that community. In so doing, public health attends not only to its primary purpose of protecting populations, but its ultimate goal of healing each individual person within that population. And in so doing, I argue, public health takes one morally artistic step to bringing about both tangible and intangible public health outcomes required to create a world unencumbered by HIV and AIDS.

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Appendix: Figures and Tables

Figure 1

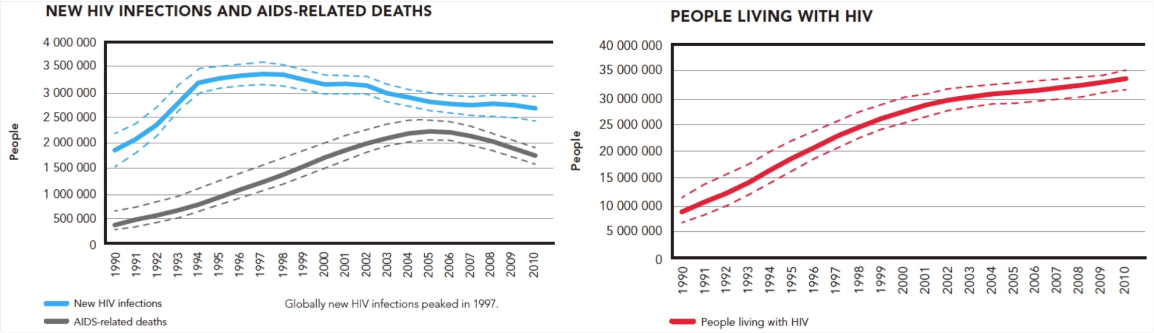


Fig 1: As long as new HIV infections (blue line) are higher than AIDS-related deaths (grey line), the burden of HIV/AIDS on the world will continue to increase (red line). Source: UNAIDS *World AIDS Day Report 2011.*

Figure 2

HIV Surveillance Practices in sub-Saharan Africa

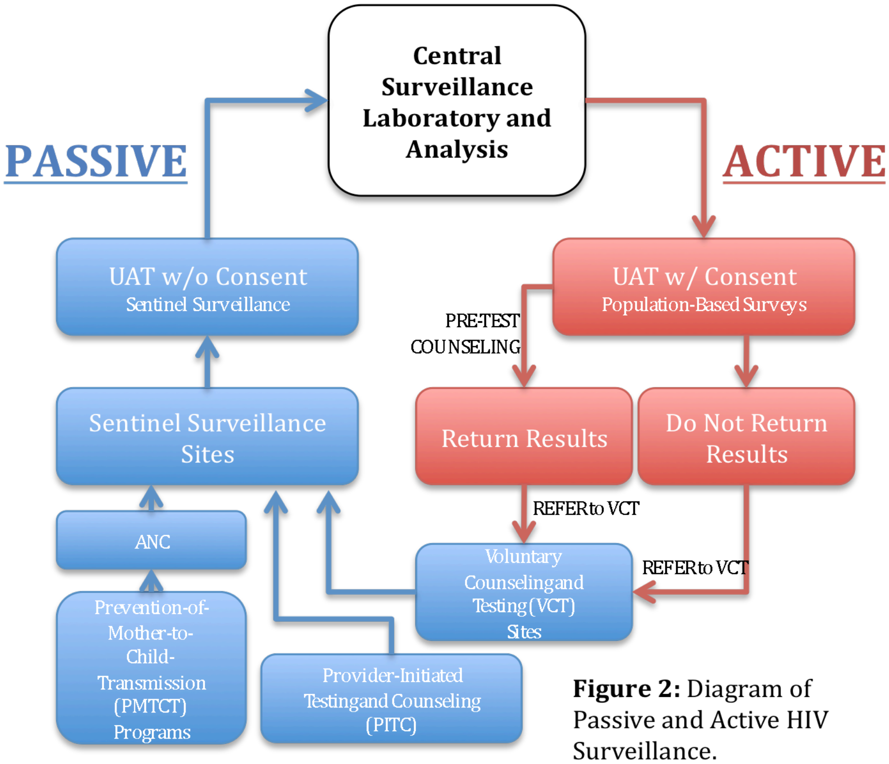


Figure 2: Diagram of Passive and Active HIV Surveillance.

Table 1

Table 1: How UAT Has Changed Over Time

	Past	Present	
	Passive (Sentinel)	**Passive (Sentinel)**	**Active (Popultion-Based)**
Consent	No	Yes (can be verbal)	Yes (must be written)
Counseling	No	No	Yes
Confidential	Yes	Almost 100%	Mostly
Voucher (Referral to VCT)	No	No	Yes
Return Results	No	No	Rarely

Table 1: Characteristics of different forms of UAT in the past and at present. Source: Jurja-Ivana Čakalo, M.D. PowerPoint Presentation.

Table 2

	Surveillance	Screening
Focus	Population	Clincial
Aim	Collect population-level data and evaluate public health programs.	Find individual cases of disease to prevent or treat at an early stage.

Table 2: Difference between the focus and aim of surveillance and screening.

Figure 3

Models of HIV Testing and Counseling

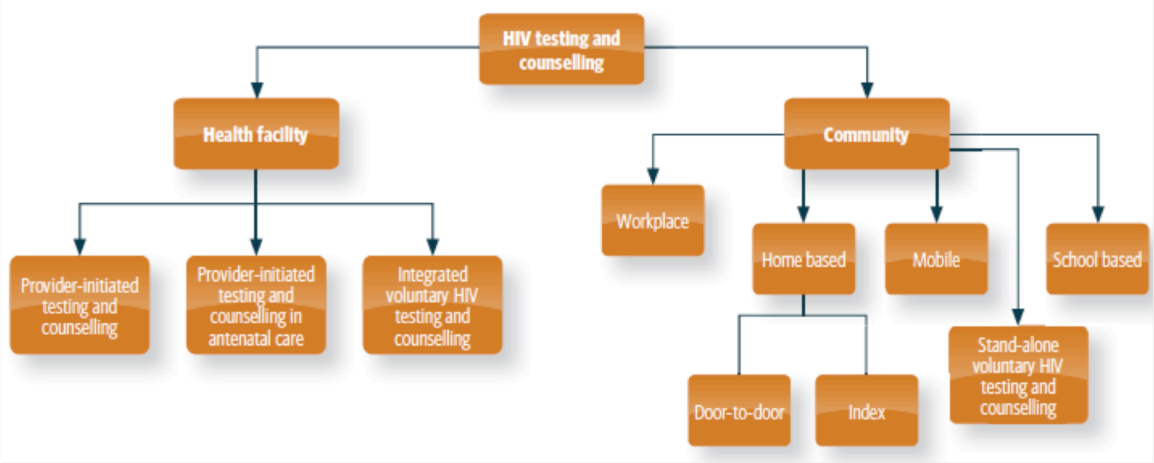


Fig. 3: Source: Taken directly from UNAIDS Progress Report 2011.

Figure 4

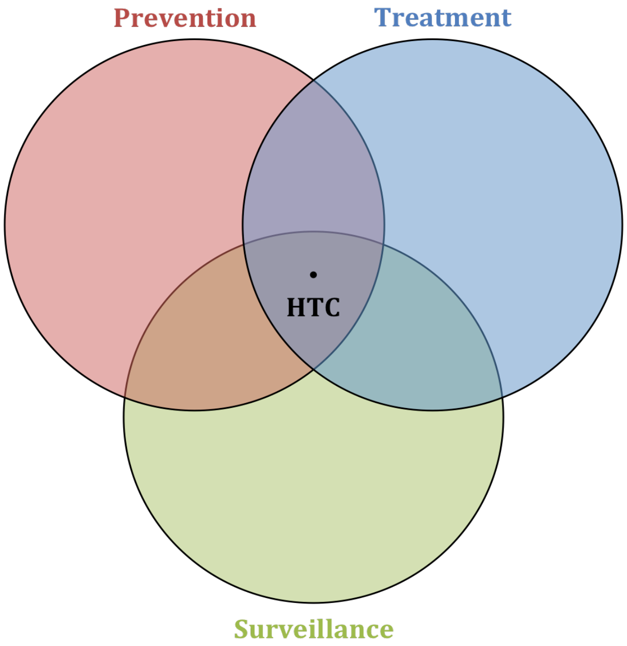


Fig. 4: HIV Counseling and Testing (HTC) services as a bridge between HIV prevention, treatment, and surveillance.

Figure 5

Self-Reported HIV Status Among HIV-Infected Persons Aged 15-64 Years, KAIS 2007

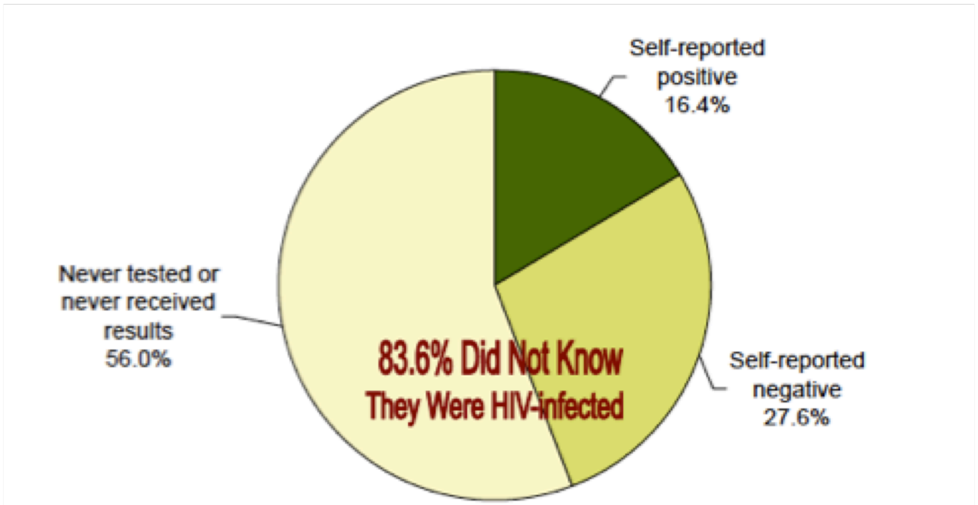
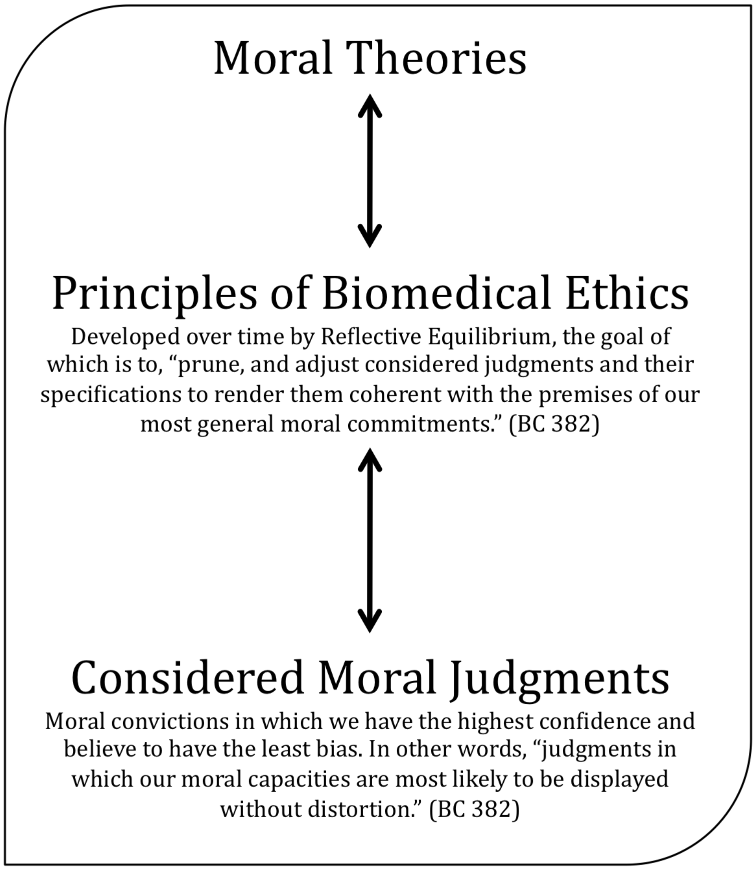


Fig. 5: The majority of HIV-infected persons surveyed in the KAIS did not know they were HIV-infected. Source: Kenya AIDS Indicator Survey (KAIS). 2007.

Figure 6



Moral Theories

Principles of Biomedical Ethics

Developed over time by Reflective Equilibrium, the goal of which is to, “prune, and adjust considered judgments and their specifications to render them coherent with the premises of our most general moral commitments.” (BC 382)

Considered Moral Judgments

Moral convictions in which we have the highest confidence and believe to have the least bias. In other words, “judgments in which our moral capacities are most likely to be displayed without distortion.” (BC 382)

Figure 6: Beauchamp and Childress method for arriving at four biomedical ethics principles.