The Ethical Balance Between Individual and Population Health Interests To Effectively Manage Pandemics and Epidemics

John Mary Mooka Kamweri

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THE ETHICAL BALANCE BETWEEN INDIVIDUAL AND POPULATION HEALTH INTERESTS TO EFFECTIVELY MANAGE PANDEMICS AND EPIDEMICS

A Dissertation
Submitted to the Center for Healthcare Ethics
McAnulty College and Graduate School of Liberal Arts

Duquesne University

In partial fulfillment of the requirement for
the degree of Doctor of Philosophy

By
John Mary Mooka Kamweri

May 2013
THE ETHICAL BALANCE BETWEEN INDIVIDUAL AND POPULATION HEALTH INTERESTS TO EFFECTIVELY MANAGE PANDEMICS AND EPIDEMICS

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ABSTRACT

THE ETHICAL BALANCE BETWEEN INDIVIDUAL AND POPULATION HEALTH INTERESTS TO EFFECTIVELY MANAGE PANDEMICS AND EPIDEMICS

By

John Mary Mooka Kamweri

May 2013

Dissertation Supervised by Professor Gerard Magill, Ph.D.

There is no overlapping criterion providing a basis for attaining balance between individual and population oriented ethical concerns generated in the pandemic and the epidemic interventions. The shortfall leads to competing individual and population interests that hamper the effective management of pandemics and epidemics. The libertarian model focuses on advancing individual rights. The epidemiological model focuses upon population health. The social justice model focuses on a broader perspective than individual rights and population health to include universal human rights.

This dissertation suggests a Mixed Interests Ethics Model (MIEM) to ethically negotiate a balance between the individual and population interests in pandemics and epidemics. MIEM involves a combination of models (libertarian, epidemiological, and...
social justice) that shed light on substantive ethical principles of each model (e.g.
autonomy, solidarity, and common good); which in turn require procedural standards (i.e.
necessity, reasonableness, proportionality, and harm avoidance) to negotiate between the
principles when they conflict.

The *UNESCO Universal Declaration on Bioethics and Human Rights* provides a
hermeneutical context for applying MIEM in so far as it places MIEM within the context
of promoting rights (individual and human) by considering the general ethical tension
between individual and universal rights as explained by the UNESCO Declaration.
DEDICATION

This dissertation is dedicated to Reverend Monsignor Joseph Mary Obunga.
ACKNOWLEDGEMENT

I am immensely privileged to benefit from the mentorship of Professor Gerard Magill, Ph.D., my dissertation director, and Professor Henk A. M. J. ten Have, M.D., Ph.D. and Professor David F. Kelly, Ph.D., who kindly accepted to be readers of my dissertation. I am equally grateful to Professor Rhonda Gay Hartman, J.D., who initially encouraged me to stay focused, when engaging multidisciplinary literature materials, in bioethics, seemed too intimidating.

This work would not have come to fruition without the generosity and kindness of Reverend Edward M Bryce, and the parishioners of St. Bede Church in Pittsburgh, Pennsylvania. Likewise, I wish to express my gratitude to the Spiritan Community, at Duquesne University, and the Apostles of Jesus Missionaries, who facilitated my education.

I am indebted to Fr. Paul Gaggawala, Fr. Augustine Idra, Fr. Peter Mainza, Fr. Richard O’Nyamwaro, Fr. Stephen Masinde, and Fr. Fred Wangwe for their support toward the completion of this endeavor. I am thankful for the prayers of my parents, siblings, relatives and all my friends. To God we owe praise.
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<td>Abstain, Be Faithful, or use a Condom</td>
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<td>AMA</td>
<td>American Medical Association</td>
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<td>ASBH</td>
<td>American Society for Bioethics and Humanities</td>
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<td>CAF</td>
<td>Children’s AIDS Fund</td>
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<td>CAWA</td>
<td>Campus Alliance to Wipe Out AIDS</td>
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<td>CDC</td>
<td>Center for Disease Control</td>
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<td>CEJA</td>
<td>Council on Ethics and Judicial Affairs of the American Medical Association</td>
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<td>CHUSA</td>
<td>Church Human Services AIDS Prevention and Care (Uganda)</td>
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<td>CIOMS</td>
<td>Council for International Organizations of Medical Sciences</td>
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<td>CPPR</td>
<td>Counterterrorism Planning, Preparedness and Response Act</td>
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<td>CS</td>
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<td>HA</td>
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<td>HECs</td>
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<td>IBC</td>
<td>International Bioethics Committee of UNECSO</td>
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<td>IRB</td>
<td>Institutional Review Board</td>
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<td>ICCPR</td>
<td>International Covenant on Civil and Political Rights</td>
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<td>ICESCR</td>
<td>International Covenant on Economic, Social and Cultural Rights</td>
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<td>JCAHO</td>
<td>Joint Commission on Accreditation of Healthcare Organizations</td>
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<tr>
<td>Acronym</td>
<td>Full Form</td>
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<td>IMAU</td>
<td>Islamic Medical Association of Uganda (IMAU)</td>
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<td>IPRP</td>
<td>Influenza Pandemic Response Plan</td>
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<td>MIEM</td>
<td>Mixed Interest Ethics Model</td>
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<td>MSEHPA</td>
<td>Model State Emergency Health Power Act</td>
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<td>NA</td>
<td>Neuraminidase</td>
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<td>PA’s IPRP</td>
<td>Pennsylvania Department of Health’s Influenza Pandemic Response Plan</td>
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<td>PEPFAR</td>
<td>President’s Emergency Plan for AIDS Relief</td>
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<td>PMAs</td>
<td>Policy-making and/or Advisory Committees</td>
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<td>PMTCT</td>
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<td>RECs</td>
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<td>SECAM</td>
<td>Symposium of Episcopal Conference of Africa and Madagascar</td>
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<td>SMC</td>
<td>Safe Male Circumcision</td>
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<td>TASO</td>
<td>The AIDS Support Organization</td>
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<td>UDBHR</td>
<td>UNESCO’s Universal Declaration on Bioethics and Human Rights</td>
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<td>UDHR</td>
<td>The Universal Declaration of Human Rights</td>
</tr>
<tr>
<td>UNCST</td>
<td>Uganda National Council for Science and Technology (UNCST)</td>
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<td>UNESCO</td>
<td>United Nations Educational, Scientific and Cultural Organization</td>
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<td>USAID</td>
<td>U.S. Agency for International Development</td>
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<td>USPHS</td>
<td>The United States Public Health Services</td>
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<td>VA</td>
<td>Department of Veteran Affairs</td>
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<td>WHO</td>
<td>World Health Organization</td>
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<td>WHO/GPA</td>
<td>World Health Organization/Global Program on AIDS</td>
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1. Chapter One

Amelioration of Individual Rights in the Influenza Pandemic Intervention

Introduction

The most problematic public health ethical issue in responses to bioterrorism and pandemics has been identified by scholars, such as Lawrence O. Gostin and colleagues, as the tension between the individual and population interests (common good).\(^1\) Individual health preferences are traditionally well defended in the libertarian-oriented model. Conversely, the epidemiological model is framed on the need to promote and protect population health, and safety. The ethical guide to effectively manage pandemics needs to be based on a criterion that balances between individual and population interests.

A. The Emergence of Influenza Pandemic and Prevention Initiatives

(i) H5N1 Influenza Pandemic and the Population Good

Following the influenza A subtype H5N1 (bird flu) of 2004, the World Health Organization cautioned of a possible mutation of the virus, and, outbreak of a highly pathogenic influenza A pandemic H5N1 virus that could spread between humans. Public health authorities estimate that morbidity and mortality in the United States, within 12-16 weeks, could reach 50 million requiring outpatient care, 2 million requiring hospitalization, and, 500,000 deaths.\(^2\)

A pandemic refers to a disease outbreak affecting the populations of several countries, or continents. The influenza pandemic occurs when a new influenza virus emerges for which people have little or no immunity and for which there is no vaccine.\(^3\)
Since 2003, several governments, worldwide, have undertaken the initiative to put into place influenza pandemic preparedness plans. Even prior to the anticipation of H5N1, in United States, the Center for Disease Control (CDC) had issued the 2001 draft *Model State Emergency Health Powers Act* (MSEHPA) to guide disaster preparedness.\(^4\)

The MSEHPA was drafted to enhance government regulative powers in matters of public health preparedness, surveillance, management of property, protection of persons, and communication.\(^5\) There was a feeling among some policymakers that the existing laws could not adequately provide the necessary authority needed for effective intervention in those five key public health areas. Moreover, states lacked the necessary public health infrastructure for management of pandemics and bioterrorism threats. The experts advanced the Model Act as necessary to strengthen states with the comprehensive powers needed to effectively manage disastrous disease outbreak, while respecting individual rights and freedoms.\(^6\) They justified government exercise of compulsory powers on the basis of the protection and defense of the common good of safety and health.

The MSEHPA encountered significant criticism for endorsing broad government coercive powers to promote and protect population wellbeing, while subordinating individual preferences.\(^7\) Some of the most contentious issues revolve around articles V and VI requiring the use of government regulative powers to carry out mandatory vaccinations, quarantine, involuntary treatment, confiscation of private property, and criminalization of non-compliant individuals.\(^8\) For instance, Article VI, Section 602 (b) states:
The Public health authority may isolate or quarantine, pursuant to Section 604, any person whose refusal of medical examination or testing results in uncertainty regarding whether he or she has been exposed or is infected with a contagious or possible contagious disease or otherwise poses a danger to the public.\(^9\)

With a pending threat of human-to-human H5N1 in 2004, several states adopted a version of the MSEHPA. The State of Pennsylvania, for instance, introduced a draft titled *Influenza Pandemic Response Plan (IPRP)* in 2005. The IPRP contains an ordinance mandating the governor to declare an emergency for purposes of protecting the health and safety of the Pennsylvania population. The proposed intervention includes possible mandatory measures such as involuntary vaccine, quarantine, and isolation.\(^{10}\)

The MSEHPA and the IPRP commit to the epidemiological goal of managing disease in populations by utilizing government efficiency and coercive powers to prevail over individual interests so as to do surveillance, effectively plan, coordinate, manage property, and protect populations.\(^{11}\) This public health paternalism is justified on the basis of protecting the population good of safety and health. Safety and health, in this tradition, constitute community or group compelling interests deserving of protection by health authority over competing individual choices.\(^{12}\)

The MSEHPA ignited a debate among scholars and health providers concerning priorities between population and individual interests. Authors of the MSEHPA and scholars in the communitarian tradition have since generated considerable amount of literature in defense of the population-good oriented approach. Of foremost relevance is Lawrence O. Gostin and colleagues who explain the fundamental ethical problem of population health as the balancing of the tension between the individual interests and the
common good of health and safety of the population. Gostin articulates the problem that:

Despite its success in many states, the Model Act has become a lightning rod for criticism from both ends of the political spectrum. Civil libertarians object to the diminution of personal freedoms and conservatives object to the diminution of free enterprise and property rights. In short, the Model Act galvanized public debate around the appropriate balance between personal right and common goods.

Gostin argues that the issue of government compulsory powers over individuals should not focus on whether they are relevant but whether there is balance to safeguard individual rights. He sees the rejection of substantial government presence into people’s social lives as symptomatic of a paradigm shift in American values towards individualistic oriented personal freedoms since the early beginning of the 21\textsuperscript{st} Century.

Gostin and peers support a legal and ethical framework that utilizes government compulsory powers in circumstances where there is credible belief that the individual will cause undue risk to population health.

(ii) Protection of Individual Rights

Some experts while unopposed to the need for government regulative powers consider the MSEHPA-sanctioned powers as too broad and invasive of individual rights. As observed by Ken Wing, the language of some provisions such as that in Article III takes paternalism to new levels. The article requires mandatory reporting, by providers, of “all potential cause of public health emergencies – within 24 hours.” Wing cautions that “Every doctor and every pharmacist would become an enforcement arm of the public
health authority." He is concerned with the protection of confidentiality and privacy rights.

Individual rights advocates countered the population-oriented epidemiological model with the defense of individual autonomy and a right to self-determination. George Annas, probably the most pronounced critic of the MSEHPA, agrees that government has responsibility to plan, coordinate, and communicate with the public but should not compromise civil liberties. He points to state coercive measures to quarantine, to provide mandatory vaccinations and to impose involuntary treatment as unhelpful for purposes of effective intervention policy. In his view, measures that aim at identifying and treating those who have been exposed to the infectious disease are more effective than targeting the public for quarantine.

Griffin Trotter is an outspoken critic of the notion of common good and the subsequent intrusive broad regulative public health measures. He rejects the idea that the moral problem in mass casualty medicine is achieving the balance between individual interests and the common good. Trotter refers to what others call common good as subsets of individual interest and frames the moral problem of public health intervention as balancing security and liberty. He does not accept the identification of the common good with community interests (corporate interests) that are distinct from those of the individual. For Trotter, the tension is between opposing groups of individual interests. Following this argument, he understands the balancing of the tension in terms of facilitating consensus in deliberative democracy. He advances the modus vivendi theory of permission or consent (generated from the procedural principle) to balance power and facilitate compromise.
Trotter shifts the intervention methodology from a defense of corporate social goals to the democratic deliberative procedure that commit to the prima facie norms of avoiding coercion and prioritizing liberty and autonomy. However, majority permission grounded in deliberative democratic procedures provides no firm basis for ensuring just outcomes since in mass casualty medical scientific facts and experience are raw data. Knowledge, which is the primary tool of interpretation in democratic deliberative procedures, is in short supply here. The critics of Trotter point out that ethical decision are primarily sourced from established substantive values, scientific knowledge, and experience.23

(iii) Compatibility of Individual Rights with Population Good.

Drawing from this intervention discourse, of strengthening public health powers rather than focusing on deliberative procedures, neither the individual-oriented libertarian model nor the population-oriented epidemiological model singularly provides comprehensive ethical resources for the effective management of pandemics. Dan Beauchamp states that in one version of the democratic theory the individual interests override any restrictions government seeks to impose on the individual apart from avoidance of harm to others.24 Accordingly, the role of government is “the protection of every individual’s private rights.”25

Reversely, the epidemiological model aligns with a view of democracy that condones government regulative powers, as necessary for “protecting and promoting both private and group interests.”26 Dan Beauchamp elucidates that, in United States, this view of community interests originates from the constitutional tradition. The common citizenship, constituting of divergent views and interests, is presumed to share “sets of loyalties and
obligations to support the ends of the political community.”

Public health and safety are considered valuable ends meriting societal commitment.

The most common example elucidating the commitment to population good is the 1905 case of Rev. Jacobson of Massachusetts. Jacobson refused to comply with the vaccination law and subsequent penalties following a mandatory vaccination measure by the board of health of the city of Cambridge to contain smallpox. The public health authority imposed the measure as necessary for public health and safety. Jacobson claimed the compulsory vaccination law by the state was an invasion of his liberty since it was arbitrary, oppressive and an assault to his person. He further claimed that the law was “… hostile to the inherent right of every freeman to care for his body and health in such way as to him seems best.” The Supreme Court determined that there are circumstances where the individual may be legitimately restrained.

However, despite the unanimity regarding the need to contain individual preferences, apparently none in the epidemiological approach holds Hobbesian totalitarian views of absolute supremacy of the state over the individual. Hobbes regarded individuals as intrinsically selfish and egoistic. In this case, the state is justified to impose its absolute will on the individuals to prevent chaos.

Likewise libertarian approaches do not advocate for anarchy despite the emphasis on individual autonomy; at least not in the sense of Robert Paul Wolff’s radical individual autonomy that is incompatible with state authority. According to Wolff, individual moral autonomy as it relates to state authority is the refusal to be ruled. Subsequently he considers anarchy as the only doctrine consistent with autonomy. However, all
libertarian approaches share a sturdy commitment to democratic deliberative procedures as an expression of the individual’s autonomous will.

This dissertation negotiates the ethical balance of individual and population interests by considering illustrative substantive principles, as follows: autonomy generated by the libertarian model, and, solidarity generated by the population oriented epidemiological model. But providing depth to this deliberation requires a thorough analysis of the underlying moral and political philosophy fueling the tension between the libertarian and epidemiological approaches.

B. Ethical Challenges and Analysis of the Prevention Models.

(i) The Epidemiological model: Rationing Dilemmas and Coercion

The influenza pandemic intervention highlights the tension between libertarian and epidemiological models due to: (1) acute shortages and rationing dilemma that involve deprivation and prioritization; (2) use of coercive measures, such as mandatory vaccination, that are protective of population health but invasive of individual rights.

The Influenza pandemic outbreak could create new complex challenges such as sudden increase in mortality and morbidity, overwhelming patient surge at health facilities, increased workload for individual staff, and shortages of medical supplies. The need to intervene for containment and treatment could lead to the states mandating the exercise of intrusive powers like isolation, quarantine and civil confinement, which could disrupt civil liberties. Other measures such as prioritization, triage, concerns with staff safety, and suspension of treatment of some non-Influenza pandemic related illnesses could also created a challenge to the ethical duty-to-care.33
In clinical practice, the primary ethical responsibility of the health provider is to implement the informed autonomous decision of a competent patient. Tom Beauchamp and colleagues define personal autonomy as, at a minimum, “self-rule that is free from both controlling interference by others and from limitation, such as inadequate understanding that prevent meaningful choice.” Courts have often attested to the right to self-determination in medical decisions of a person of adult years. This right associated with the legal doctrine of informed consent is based on the principle of bodily integrity.

In 1981, the Supreme Court of United States observed that:

>No right is held more sacred, or is more carefully guarded by the common law, than the right of every individual to the possession and control of his own person, free from all restrain or interference of others, unless by clear and unquestionable authority of law.

The right to refuse medical treatment is held as a constitutionally protected liberty guaranteed under due process clause of the 14th amendment of the U.S. constitution. Due process requires that no person shall be deprived of life, liberty, or property without due process of law. In clinical practice, the specification of the informed consent process requires the patient’s access to information, the patient’s understanding, and the patient’s voluntary choices. Intrusive involuntary measures during a pandemic influenza will present providers in the clinical settings with a new contrasting ethical paradigm for deliberations and deliverance of health care.

The epidemiological model justifies use of government regulative powers to prevent harm, maximize utility, and produce benefits for the good of the health of the population. Because of the focus on populations the epidemiological model utilizes utilitarian,
egalitarian, and communitarian ethical theories, and generates ethical principles such as solidarity. For instance, based on this framework, population health authorities have developed the Critical Care Triage protocol as an ethical basis for utility and equal access to scarce community resources during the influenza pandemic.\textsuperscript{36}

The Critical Care Triage aims at maximizing benefits for a larger number of patients in an overwhelmed critical care system. The assumption is that determining norms of distribution within the system of prioritization and triage offers groups of the same tiers equal access to health resources. The Critical Care Triage protocol involves four main criteria on the basis of which: (1) some are included who will benefit; (2) those with poor prognosis are excluded; (3) a ceiling is set on the amount of resources based on the minimum qualification for survival; and, (4) a prioritization pool is established.\textsuperscript{37}

The Critical Care Triage is a blend of triage protocols that allocate time and resources. Iserson and Pesik identify four triage models that allocate according to: time, resources, first-come basis, and, social value. When the priority is treating the most serious, it is time that is allocated. Resources are allocated when they are critically limited and only patients with best prognosis need to be considered.\textsuperscript{38}

The Critical Care Triage also adopted the color code futures of the already existing triage protocols as well as the Sequential Organ Failure Assessment (SOFA) score system. The SOFA score system was created by the European Society of Intensive Care Medicine in 1994 (and further revised in 1996) as predictor of prognosis in critical organ dysfunction.\textsuperscript{39} In recent times, the SOFA score system has been expanded as a predictor of mortality and morbidity in critically ill patients.\textsuperscript{40}
The most controversial aspect of the Critical Care Triage, as regards the individual versus population tension, is that it appears to ignore individual preferences and allocates critical time and resources in accordance with a social rotary (triage protocol). Secondly, the Critical Care Triage subordinates individual choices to collective societal wellbeing. However some scholars have advanced and defended the substantive and procedural values within the Critical Care Triage as fair trade-off tools.

(ii) Substantive and Procedural Values.

Within the epidemiological model, the Critical Care Triage has become widely accepted as a fair distributive justice policy for rationing limited resources in a pandemic outbreak. The ethical justification for the Critical Care Triage protocol was derived from substantive and procedural values set by the working group of the Toronto Joint Center for Bioethics.

In the document *Stand on Guard for Thee*, the authors identified ten substantive values (individual autonomy, protection of the public from harm, proportionality, privacy, duty to provide care, reciprocity, equity, trust, solidarity and stewardship) and five procedural values (reasonableness, openness and transparency, inclusiveness, responsiveness and accountability). This approach permits measures such as quarantine that restrict basic freedoms of mobility, assembly, and privacy. These strategies are considered necessary in the absence of flu vaccines and medication to control pandemic influenza and protect populations.

Alison K Thompson sheds light on how a combination of these commonly accepted ethical principles and procedural elements translate into practical application in decision making during the influenza pandemic. Learning from insights acquired in the Canadian
experience dealing with the 2003 near-pandemic SARS Thompson and colleagues developed ethical guidance based on substantive values such as stewardship, and, procedural values such as accountability. The guidance was intended to be illustrative of how “the (principles) ethical framework can be used to identify key ethical aspects of decision-making.” For instance, the values of solidarity and protecting the public from harm would require a procedural process that ensures that society provides care for all the ill during a pandemic.

The population collective interest in health and safety is well defended in the communitarian tradition. Michael Walzer and Dan Beauchamp point to the population common good of safety and health as the overarching principle of public health ethics. For these experts, the basis for common good ethos is the political community as expounded in the social contract theory. They emphasize the values of cooperation, egalitarian membership, and, social beneficence.

Communitarians such as Michael Walzer defend the importance of membership in a political community and the shared commitment to common good. Walzer supports a constitutional tradition, in the United States, where by “the public or the people were presumed to have interests, held in common, in self-protection or preservation from threats of all kinds to their welfare.” The regulative powers flow from this view of democracy that construes the role of government as protecting and promoting both private and group interests. This commitment involves communal provision of needs for survival based on proportionality and equality. These views are compatible with the epidemiological model which generates principles such as solidarity.
The Critical Care Triage framework has a theoretical basis also in John Rawls’s egalitarian ethical theory of “justice as fairness.” Justice, according to Rawls, proceeds from fairness. In Rawls theory of “Justice as fairness,” a just society is constitutive of the distributive principles of equal liberties, fair equality of opportunities, and difference principle, that govern the distribution of the primary goods of liberties, opportunities, income, and wealth. These primary social goods constitute the common good which Rawls defines as conditions and objectives that are similar to everyone’s advantage.

As articulated by Normans Daniels, justice in allocation of health resources is based on “fair equality of opportunities” Norman argues that the equal opportunity principle also requires public health initiatives aimed at promoting normal functions for all. When the Ethics Subcommittee to the Director, Center for Disease Control and Prevention deliberated on decisions to distribute vaccines and antiviral medication during a severe pandemic, they prioritized “the principle of preserving the functioning of society.” In this case, for instance, the scarce resources may not be made available to individuals with high risk complications since the goal is to restore health for groups.

With its commitment to ethical principles such as solidarity the Critical Care Triage should be seen as grounded not only in egalitarian and communitarian, but also in the utilitarian approach. Generally utilitarianism seeks the greatest good for the greatest number. Rule utilitarianism requires that rules that promote the greatest good for the greatest number ought to be adopted. For act utilitarianism, the emphasis is put on actions that promote the greatest good for the greatest number.

One utilitarian view of public health justifies policies and programs that maximize public health gains. Subsequently, the state is a means for providing for the aggregate
welfare. This notion of maximizing net benefits is founded on the principle of utility or the greatest happiness principle. In classic utilitarianism of John Stuart Mill, “actions are right in proportion as they tend to promote happiness; wrong as they tend to produce the reverse of happiness.”\(^{56}\) In modern utilitarianism the utility principle means that one ought to produce the maximal balance of good consequences over bad consequences.\(^{57}\)

For utilitarian, government regulative powers are means for attaining the public good. The Ventilator Document Workgroup of the Ethics Subcommittee of the Advisory Committee to the Director of CDC, proposed the principle of maximizing net benefits in decisions regarding priorities in ventilator distribution. Precisely, because the goal is to maximize net benefits, the subcommittee recommended that the specification of the principle should consider maximizing the number of lives saved, maximizing years of life saved, and maximizing adjusted years of lives saved.\(^{58}\)

However, as observed by Powers and Faden, systems that equate justice with priority setting based on quality and length of time need to be embraced cautiously. These systems, for instance, aim at maximizing the allocation of primary goods based on age, quality-adjusted life years (QALYs), or cost effective analysis. Yet the focus on aggregate welfare ignores the underlying morally unacceptable or obligatory conditions that distribute benefits and burdens.\(^{59}\) Conditions such as poverty or economic inequality have direct consequences for the health of certain sections of the population.

An outstanding example of the application of a utilitarian decent minimum health care provision is the 1994 Oregon Health Plan. Faced with scarcity of resources, Oregon set a goal of prioritizing resources (instead of people) to provide a decent minimum of health care services to all citizens with a family income below the federal poverty
levels. The Oregon Health Service Commission (OHSC) adopted a utilitarian approach that maximizes resources based on quality of well-being after treatment and cost effectiveness analysis.

A Priority list of treatment was ranked in accordance to the cost-utility analysis, also known as Quality-adjusted life-years (QALYs) that give primacy to the principle of the greatest health benefits for the money expended. Consequently tooth-capping, for instance, was ranked as a top funding priority over incapacitating hernias and tonsillectomies. Subsequently, criticism forced the health authority in Oregon to abandon the approach based on cost-effective analysis and to adopt prioritization based on clinical effectiveness and social values.

(iii) Libertarian Model: Autonomy and Public Deliberation

Conversely, libertarian oriented arguments reject moral justifications based on the norm of population good since the conditions for producing benefit, preventing harm, and, maximizing utility, do not necessarily focus on a commitment to liberty and autonomy. What others characterize as common good, libertarians construe as subsets of individual interests. The moral claims of the libertarian model are individual oriented and focus on individual rights of self-determination, government protection of individual’s basic rights, and, the norm of non-interference, as well as commitment to free market principles. The model generates ethical principles such as autonomy.

The libertarian model has foundation in the libertarian philosophers such as Nozick, Engelhardt, and Lomasky. In his ‘theory of entitlement’, Robert Nozick defends absolute ownership of property and liberal individualism in a free market society. Justice
in holdings is only in accord with free market procedures of acquisition of property, transfer of property and providing rectification.66

Because pandemics affect population health, individual preferences cannot adequately provide basis for prioritizing social goals and effective intervention of pandemics. Reversely the epidemiological approach that utilizes government efficiency and coercive measures to protect the common good of health subordinates individual rights. Accordingly, broad government coercive powers undermine the public’s cooperation and trust.67

To ameliorate individual rights in mass casualty intervention, libertarian oriented scholars have suggested deliberative democratic procedures to commit to the prima facie norms of avoiding coercion and prioritizing liberty and autonomy.68 In agreement with Engelhardt, Trotter considers the principle of permission or consent (Modus Vivendi) generated from deliberative procedural principle as the only legitimate principle of social justice. Accordingly, health care providers need to prioritize those values that “have been approved in public deliberation.”69

If we admit, however, the maxima that advance public permission is the only acceptable moral standard in public health emergence, the implication is that the circumstances and contexts in which a future pandemic will occur are well known to us. Yet, public health strategies evolve as health practitioners encounter emerging facts and new circumstances in a pandemics outbreak.

(iv) Trust in Government Intervention

More critically however, broad government regulative powers remain suspect for some good reasons. Trust in government intervention to determine and promote the
population ‘common good’ of safety and health suffered a major setback in the first half of the 20th Century. The American social programs to “breed better citizenry through science”- eugenics, led to involuntary sterilization of the vulnerable poor people. Scientists, mental health professionals, and, expert physicians determined that the poor were to blame for distributing genes for ‘feeblemindedness’. Health professionals attested that these genes were responsible for vice, crime and misery perpetuated by the poor.

Armed with its theory of social degeneration, the eugenic movement in Western Europe and North America sought to increase the frequency of ‘social good” genes in the population and decrease that of “bad genes.” By 1920 two dozen States in United States had enacted sterilization laws to promote negative eugenics. These laws generated public welfare actions based on prejudice, bias and segregation against classes and races. In 1924, for instance, Carrie Buck an eighteen years old woman was involuntarily sterilized at Lynchburg Hospital in accordance to the Virginia eugenic sterilization statute for no other reason but being epileptic and ‘feebleminded’. Dr. Ray Nelsons established that the last of the four thousand sterilizations at Lynchburg Hospital took place as recent as 1972.

Principlism as an ethical guide to research and clinical bioethics emerged in the second half of the 20th Century as a backlash against involuntary medical abuses directed at individuals. The story of the Tuskegee syphilis study by public health authority became public in 1972. In a study that begun in 1932, the Public Health Service authorities in Macon County, Alabama, subjected about six hundred black men to an involuntary and inhumane syphilis experimentation. The research subjects were never told that they
were afflicted with syphilis. Inconceivably, they were deliberately left untreated even though penicillin became available to health authorities.

In a related incident, the 2010 revelation that the United States government led the Guatemala syphilis experimentation makes the trust element in government-sanctioned involuntary public health measures even more suspect. From 1946 to 1948 Dr. John C. Cutler and colleagues infected nearly 700 vulnerable Guatemalans with syphilis and other venereal diseases in an involuntary experimentation. The infection process involved inoculation with live syphilis bacteria or by paying syphilis-infected prostitutes to sleep with prisoners. The unethical experimentation was funded through the National Institute of Health.74

The National Commission’s Belmont Report of 1979 determined that the Tuskegee syphilis experimentation was unethical. The Commission recommended three general principles for the conduct of medical research involving human subjects, namely, respect for persons, beneficence, and justice.75 In the practical application, the three general principles translate into a requirement for informed consent, risk-benefit assessment, and just selection of the subjects for research.

From these three general ethical principles underlying the conduct of medical research involving human subjects, Tom L. Beauchamp and James F. Childress outlined four basic principles of bioethics. The principles are autonomy, beneficence, non-malefice and justice.76 These four bioethics principles form the basis for ethics reflection in clinical medicine since the last quarter of the 20th Century. However these principles as useful as they are, have proved inadequate to the purpose of addressing population health intervention.
A more articulate precursor to the ongoing ethical debate regarding balancing the tension between the individual and populations has come from legal scholars interested in the interconnectedness of ethics and law in public health policy. In a treatise, *Public Health Law and Ethics: A Reader*, edited by Lawrence O. Gostin, several legal scholars draw on legal and ethical sources to expound on the decisive factors in population health practice. Additionally, a universal law framework for global health intervention has been advanced by organizations such as UNAIDS to provide forum for discussing the delineation of human rights in public health policy and intervention.

C. An Evaluation of the Legal Framework.

(i) Constitutional Provisions and Common Law

The dominant contemporary western political conception of the nature of a person and his place in the order of being revolves around the narrow notion of government as the single locus of power and the individual as the sole bearer of rights. As explained by Frohnen and Grasso, the realms of intermediary communities and institutions are increasingly losing their claim and exercise of the socially integrative rights of their own. Understood as objects for possession rather than social habits, rights have come to be viewed more in terms of individual claims against government and the individual against individual. As a result, the court system being an instrument of the state has emerged as the most effective place for vindicating one’s rights.

Not surprising, when the Center for Disease Control in United States wanted to strengthen public health infrastructure following the September 11th terrorist attack it looked to the legal expertise of the Center for Law and Public’s Health at Georgetown and John Hopkins Universities to draft the Model State Emergency Health Power Act
(MSEHPA). Thereafter, several states enacted the version of the Model Act in anticipation of a possible outbreak of influenza pandemic.

The MSEHPA utilizes a legal framework to reinforce government regulatory powers that protect population health (such as planning, surveillance, management of resources, and protection of persons). As suggested by Dan E. Beauchamp the basis for government regulative powers is the constitutional tradition. In this constitutional framework population wellbeing is safeguarded within the police power doctrine of the 10th amendment and justified on the principle of population self-defense.

Chief Justice John Marshall in Gibbon v. Ogden (1824) stipulated the boundaries of state police power as forming a portion of:

…that immense mass of legislation which embraces everything within the territory of the state, not surrendered to the general government: all which can advantageously be exercised by States themselves. Inspection laws, quarantine laws, health laws of every description, as well as laws for regulating the internal commerce of States, and those which respect turnpike roads, ferries, are component parts of this mass.

The question addressed by the Court pertained to the boundaries between Congressional powers over inter-state commerce and those powers retained by states as sovereign governments before the ratification of the Constitution.

The state police power was defined even more broadly by Chief Justice Shaw in Commonwealth v. Alger (1851) as:

The power we allude to is rather the police power, the power vested in the legislature by the constitution, to make, ordain and establish all manner of
wholesome and reasonable laws, statutes and ordinances, either with penalties or
without, not repugnant to the constitution, as they shall judge to be for the good
and welfare of the commonwealth, and of the subject of the same.\textsuperscript{82}

Cyrus Alger had erected and maintained a wharf over and beyond the boundaries
permitted in the Massachusetts’ statutes. Subsequently, States’ broad authority to
safeguard the safety, health, and morals of the community is presumed to be adequately
protected in the police power.\textsuperscript{83}

A combination of the legal and ethical discourse regarding balancing individual
liberty rights and the good of the population in the epidemiological framework tends to
start with the landmark Supreme Court case \textit{Jacobson v. Massachusetts (1905)}. Mr.
Jacobson refused to obey an ordinance by the Commonwealth of Massachusetts
providing for mandatory vaccination for smallpox. He alleged the unconstitutionality of
the ordinance for violating the “due process, equal protection, and the privileges and
immunity clause of the Fourteenth Amendment.”\textsuperscript{84}

The Court interpreted that “the liberty secured by the Constitution of the United
States to every person within its jurisdiction does not import an absolute right in each
person to be, at all times and in all circumstances wholly freed from restraint.”\textsuperscript{85} Based
“upon the principle of self-defense, of paramount necessity,” an individual may be
restrained for the common good.\textsuperscript{86} The Court stated that “a community has the right to
protect itself against an epidemic of disease which threatens the safety of its members.”\textsuperscript{87}

Police power allows states to broadly regulate matters affecting the health, safety, and
general welfare of the public.”\textsuperscript{88} However the Court further explicated that the
government’s intrusive actions over the individual are limited by the constitutionally
protected privilege of procedural justice - due process. The opportunity to be heard before deprivation of life, liberty, or property by adjudication is a fundamental requisite of the due processes clause of the Fourteenth Amendment.  

According to Lawrence Gostin, there are broadly two different kinds of restraint on police power. The first is substantive in nature (substantive due process and equal protection). It requires the government to provide an increasingly strong justification (good reason) for intrusion on individual liberty interest. Illness per se does not suffice as adequate reason for use of police powers to deprive liberty rights. As ruled in City of Cleburne v. Cleburne Living Center (1985), the restraint should be subject to three levels of scrutiny: strict scrutiny, intermediate scrutiny, or minimum rationality.

The importance of the individual interest at stake determines the measure of the level of scrutiny. When for instance a statute clarifies by race, alienage, national origin and gender, those laws need to be subjected to strict scrutiny. The laws are likely to be deemed as reflective of prejudice and antipathy against certain classes of people over others. At stake are people’s substantive constitutional rights and the rights to be treated equally by law.

In some cases however, the Equal Protection Clause requires only a rational basis scrutiny to pursue a sufficient state interest. For instance, laws pertaining to the treatment of those who have not experienced a history of purposeful unequal treatment such as the aged in United States are likely to be subjected to a minimum rationality scrutiny.

In Massachusetts Bd. of Retirement v. Murgia (1976), the Court applied a rational scrutiny to the analysis of the Massachusetts statute mandating the retirement of uniformed state police officer upon attaining the 50th birthday. The statute was interpreted
as not interfering with the exercise of a fundamental right since government employment
per se is not a fundamental right. The statute does not disadvantage a suspect class since
a class of police officers over age fifty is not deemed suspect. Robert Murgia had claimed
that his forced retirement at age 50 denied him equal protection in violation of the
Fourteen Amendment of the Constitution. $^{94}$

The second kind of restraint is procedural in nature (procedural due process). The
requirement is that government not only provide good reason but also “fair hearing
before depriving individuals of important liberty or property interests.” $^{95}$ Procedural due
process requires a consideration of: “the private interests that will be affected by the
official action; the risk of an erroneous deprivation of such interests through the
procedures used; and the probable value, if any, of additional or substitute procedural
safeguards; and consideration of the government interests …” $^{96}$

In Greene v. Edwards (1980), the Supreme Court of Appeal of West Virginia ruled
that the public health authority did not afford procedural due process to William Arthur
Greene before confining him involuntarily for TB control measures in Pinecrest Hospital,
pursuant to the West Virginia Tuberculosis Control Act. The court enumerated Greene’s
rights under the procedural due process safeguard as follows: “an adequate written notice
detailing the grounds and underlying facts on which commitment is sought; the right to
counsel; the right to present to cross-examine, to confront and present a witnesses; the
standard of proof to warrant commitment to be clear, cogent and convincing evidence;
and, the right to verbatim transcript of the proceeding for purposes of appeal.” $^{97}$

This legal framework provides a context for the ethical discourse in this dissertation
regarding the usefulness of substantive principles, such as autonomy and the common
good, and, procedural standards to negotiate balance between safeguarding personal liberties and population wellbeing. According to Gostin, the United States Supreme Court in the *Jacobson v. Massachusetts (1905)* case established the four constitutional limitations (standards) imposed on the regulative powers of public health authorities over individuals’ constitutionally protected preferences.

The constitutional limitations are public health necessity, reasonable means, proportionality, and harm avoidance. The application of these standards by courts to negotiate between conflicting interests in legal matters has enormous implications for the moral discourse to seek criteria balancing conflicting individual and population health interests.

In the ethical deliberation, necessity, reasonableness, proportionality, and harm avoidance are generally agreed upon standards to negotiate conflict between the principles in concrete cases. Public health necessity refers to the exercise of coercive powers only where necessary to prevent unavoidable harm. Reasonable refers to measures that ameliorate a health threat and not a blatant invasion of rights. Proportionality refers to benefits outweighing burdens. Harm avoidance refers to respect for the principle of bodily integrity and personal security.

The case of *Jew Ho v. Williamson (1900)* is an example of the use of unreasonable means. The Circuit Court of the Northern District of California ruled that the quarantine to contain a bubonic plague which was enforced only against persons of Chinese race and nationality, and not against persons of other races, was not reasonable regulation to accomplish the purpose sought. The Court ordered the discontinuation of the quarantine on the basis that it was “unreasonable, unjust, and oppressive, and therefore contrary to
the laws limiting the police powers of the state and municipality in the matter.” The law was found to be discriminatory and administered “with an evil eye and unequal hand.” Though bubonic plague or resulting death had not occurred in all blocks, quarantine was imposed upon the whole district making the entire population within the district vulnerable to the epidemic.

State coercive public health measures infringe upon individual liberties, but, the infringement may be necessary or unnecessary. In 1966, the New York State enacted a compulsory vaccination law on the grounds that it was necessary to protect those individuals most susceptible to communicable diseases such as polio. Since the cost of polio treatment was beyond the financial capability of families with limited incomes, the imposition of mandatory vaccination was necessary for the individual who would be afflicted and the taxpayer shouldering the financial burden.

However, coercive policies may be effective but unnecessary for purposes of attaining the sought public health goal. For instance, providing incentives for people to voluntarily accept to be vaccinated makes coercive measures unnecessary. Seeking the least infringement alternative is a more plausible moral consideration.

The application of the standard of proportionality refers to a legitimate exercise of police powers in a manner by which the burdens of the public health infringement on the individual do not outweigh the benefits. The judiciary has repeatedly interpreted the imposition of public health measures whose burdens (harm) outweigh the benefits as disproportionate and illegitimate exercise of police powers. For instance, though the judiciary has consistently upheld the constitutional legality of statutes that require the
vaccination of children before admission to public schools, exemptions are granted in cases of medical contraindication to immunization.

In cases where benefits outweigh the harm, courts often rule in favor of government compelling interests. In *Skinner v. Railway Labor Executives Association* (1987), the Supreme Court ruled that the toxicological testing contemplated by the Federal Railroad Administration (FRA) on its employees to ensure the safety of the travelers and employees themselves was not an undue infringement on the justifiable expectations of the employees’ privacy. The government’s compelling interests to protect the population against the growing number of train accidents, evidently resulting from alcohol and drug abuse by rail-road employees was regarded as outweighing the privacy concerns of the employees.

The case of *Yick Wo v. Hopkins* (1886) is the commonly given example of use of public health powers to punish (cause harm) rather than promoting wellbeing. San Francisco public health authorities passed an ordinance requiring a permit from the board of supervisors to operate a laundry in a wooden building. This was justifiable on safety grounds. However, Chinese laundry owners were denied permits while only one out of about eighty non-Chinese applicants was denied a permit. At the time the ordinance was passed most wooden laundries were owned by Chinese persons. The court found the action of the City of San Francisco authority as discriminatory and intended to segregate against an ethnic group.

(ii) Universal Law framework

Not all legal and public health experts agree with tenets of the aforementioned legal framework based on the constitutional tradition of the public good of health to produce
health benefits, prevent harm, and maximize utility over competing individual preferences. In his critique of the MSEHPA, George Annas emphatically dismisses the effectiveness of trade-offs between civil rights and public health measure. In his view, mandatory vaccination, treatment, or criminalization of dissenting behavior “undermined public trust in public health authority.”

Some experts argue that pandemic interventions involve ethical problems that require a global mandate as provided within the universal legal framework of human rights. Moreover for those who emphasize civil and political rights, the epidemiological approach that focuses on health and safety is indifferent to the diminution of individual and human rights in emergency health interventions. Health is conceived as not merely the absence of illness and disease but as encompassing other societal factors that are root causes of all diseases. For instance, factors such as hunger, poverty, wars, discrimination, and, violation of civil rights, interfere with the health of individuals and populations. This social justice trajectory has resulted in a new way of defining population health intervention.

George Annas understood the celebration of the 50th Anniversary of the Universal Declaration of Human Rights as an occasion to explore and link health promotion and treatment of diseases with human rights strategies. He construes the goal of human rights and the goal of public health as one and the same, namely, “to provide the conditions under which people can flourish.” Therefore, the agenda for human rights should be broadened to include making “basic health care available to everyone and to prevent diseases and injury and to promote health worldwide.” Annas further
proposed use of the language and concepts of human rights to propel individuals and nongovernmental organizations to advocacy for promotion of human rights in health care.

The legitimacy and justification for application of human rights in public health policy lies in their adoption by nations. The treaty provisions stipulate a universal right to health and a number of nations have included a right to health care in their constitutions.\footnote{In the preamble of the Constitution of the World Health Organization (WHO), this right to health is defined as a “state of complete physical, mental, and social well-being and not merely the absence of a disease or infirmity.”\footnote{In this context, the responsibility for protection and promotion of public health extends beyond governments to individuals and to non-governmental organizations. Consequently, human rights advocacy has become the foremost preferred means of enforcing compliance with human rights goals. Yet the absence of a clear conceptual clarity of the meaning and scope of the right to health makes the practical implementation and the judicial interpretation turbid. The universal rights framework is gaining prominence with the realization that purely individualistic rights as promoted in the libertarian model are less accommodating of competing social interests. The alternative epidemiological model justifies population health intervention in terms of primary social goods, such as focusing on access and equal opportunities, and less attentive to a vision of human nature and experience as understood in the social justice paradigm.\footnote{The moral weight of human rights is defended on the basis that they are prior to institutions and they impose duties collative to rights.}}

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Frohnen and Bruce have observed that scholars need to pay attention to the analysis of rights since they are “poorly understood,” yet, “widely discussed.” The danger with the (human) right approach, as Stephen Holland observes, is merely restating the core dilemma of public health – which is – the conflict between the individual and community. For instance, in population health when one asserts and pursues the right to autonomy he is confronted with a competing right of the common good.

To enhance respect for rights while abridging the tension between individual and population interest in the management of pandemics, the United Nations Education, Scientific and Cultural Organization (UNESCO) advanced the use of a bioethics principles’ framework. For instance article 27 of the declaration specifically requires the balancing of the application of principles in certain circumstances (such as a pandemic) posing a serious threat to public health, and, or the protection of the rights and freedoms of others. Article 26 acknowledges the interrelation and complementary nature of principles. Innovatively, the Declaration recommends commitment to the spirit of professionalism, honesty, integrity and transparency in the application of principles.

However the guidance to states on how to limit the application of conflicting principles is short of specifics to effect practical change. The standard is states’ laws, including laws consistent with international human rights, enacted in the interest of public safety and health wellbeing of the populations. Yet, as demonstrated in the case of pandemic interventions in United States, state laws are always contestable based on whether they are oriented towards safeguarding the interests of the individual or those of populations. But what is of uttermost relevance in the UNESCO guidance is the
principles-based approach that offers ground for interpretation and negotiation between conflicting principles.

Bioethics principles provide a way to extricate balance from various seemingly incompatible foundational moral theories underlying the pandemic intervention ethical discourse. The aforementioned utilitarianism, egalitarianism, communitarian, and, libertarianism ethical theories have basis in the philosophical moral systems of deontology and consequentialism. These moral philosophy approaches respond to the question of right and wrong from sharply contrasting view points. Adopting the principles approach accords health policy-makers with a heuristic methodology, as presented by Beauchamp and Childress, that is “a dialectic process of interpretation, specification, and balancing,” using mid-level principles to resolve complex dilemmas.\textsuperscript{120} Principles are specified for a context to take into account “feasibility, efficiency, cultural pluralism, political procedures, uncertainty about risks, noncompliance by patients, (or), moral dilemmas.”\textsuperscript{121}

Deontology refers to an approach that considers moral value as depending on the nature of the action itself. In this case, it is obligatory to perform or to avoid some actions due to their intrinsic nature that makes them right or wrong. Duties and rules are essential to the advance of this approach. Reversely, consequentialism looks to consequences or effects of actions to determine moral value.\textsuperscript{122} This distinction is relevant to the question of the moral justification of decisions and actions in a pandemic intervention. For instance, the utilitarian or consequentialist argument for mandatory quarantine to restrict a few people and bring about the greater good of health for the greater number may be
unpersuasive to a libertarian-deontologist more concerned with personal intrinsic rights of personal dignity and self determination.

In bioethics, the principles approach is seen as overlapping between moral and ethical theories. Unlike abstract moral philosophy theories, principlism is focused on applied ethics by making moral principles suitably specific and practical to resolving problems. Tom Beauchamp and Walters define an ethical principle as “a fundamental standard of conduct from which many other moral standards and judgments draw support for their defense and standing.” Beauchamp and Childress do not consider principlism to be foundationalist in the sense libertarianism and utilitarianism are understood as comprehensive moral theories.

In public health discourse, scholars who have adopted principlism have moved beyond the four biomedical principles to include even those outside the health field. Ross Upsher who argued that clinical ethics is not an appropriate model for ethical reasoning in public health proposed a different set of principles. Because of its focus on populations, Upshur argues that public health requires the principles of harm avoidance, least restrictive means, reciprocity, and transparence. The UNESCO’s Bioethics Committee took it to a new level in 2003 by drawing fifteen fundamental principles to set a global minimum moral standard for bioethical conduct. The adoption of these principles by member states gives the declaration moral authority and reason for commitment.

The principles approach provides a way to initiate trade-offs between conflicting principle so as to harmonize individual and population choices. As proposed by James F. Childress and colleagues, meaning and scope comprise the two dimensions of moral considerations. By determining and interpreting the meaning and scope of conflicting
substantive principles, we can establish which aspects increase or decrease conflict among them and which considerations yield to others.\textsuperscript{127}

Explicating on the tension between the individual and population interest, as expounded in this chapter, this dissertation suggests Mixed Interests Ethics Model to negotiate the ethical balance of individual and population interests by considering illustrative substantive principles of autonomy generated by the libertarian model, and, solidarity generated by the population oriented epidemiological model. The amelioration of individual rights in the pandemic intervention requires trade-offs between the conflicting substantive principles.

Engaging the libertarian and the epidemiological models to negotiate balance between individual and population involves the related principles and standards. Principles address substantive issues, and standards address procedural issues. The principles require interpretation of the scope and meaning to harmonize the moral commitment to the individual and population. The standards ensure that the moral commitment is retained as the scope of the principle is being rendered partially compatible.

For instance the meaning and range of the scope of the substantive principle of autonomy involves consent, voluntariness, and privacy.\textsuperscript{128} The meaning and scope of substantive principle of solidarity involve equity, collaboration, communication, and coordination.\textsuperscript{129} Negotiating between conflicting principles require a commitment to the commonly accepted procedural standards of public necessity, reasonableness, proportionality and harm avoidance.
D. Summary

This chapter discusses the tension between individual and population interests that hinder the effective management of epidemics. The epidemiological model traditionally gives primacy to the health of populations and involves the use of coercive powers that limit individual rights. The libertarian model focuses on individual preferences to ameliorate individual rights in the influenza pandemic interventions.

The divergent moral theories that inform the epidemiological and the libertarian approaches do not clearly effectuate practical ethical solutions to bridge the divide between individual interests and population interests. Moral theories, however, as sustained in the epidemiological and libertarian models, translate into substantive principles and procedural standards on the basis of which overlapping criteria of Mixed Interests Ethics Model (MIEM) can be based to negotiate balance between individual and population interests in the pandemic.
2. Chapter Two

Amelioration of Human Rights in HIV/AIDS Epidemics Intervention

Introduction

The mastery of the epidemiological intervention of HIV/AIDS since the 1980s has been gradual and so has been the articulation of the ethical dilemmas. The transformation began with civil liberties activists introducing the notions of privacy, confidentiality, and anti-coercion, into the epidemiological vision of infectious disease prevention. As prophylactics, antiretroviral therapies, and research options, became available, the debate focused on equity, access, and the issues of discrimination. In recent times there has been a shift from preoccupation with the notion of population health as a primary good to a focus on the overall wellbeing of persons as subjects of human rights meriting respect and protection. The social justice vision accrues from the interrelation nature of HIV/AIDS that transcends individualist preferences and state capabilities.

In the heterogeneous global community of HIV/AIDS prevention, the integrative socio-cultural and institutional rights and values, that are only partially incorporated in the epidemiological model but largely ignored in the libertarian model, permeate all aspects of decision-making and policy development. Yet the prospect for the effective management of HIV/AIDS is diminished by the often incongruent interpretation of human rights, disagreements over standards, and poor management of conflicting rights. These conditions do not enable the diminution of the tension between individual and population interests in HIV/AIDS intervention. The shortfall explains the cause for the
A rising prevalence rate of heterosexually transmitted HIV in Uganda after years of remarkable success in reducing the HIV prevalence rate.

A. The Story of Uganda’s ABC Approach and the PEPFAR Initiative

(i) An overview of the history of HIV/AIDS epidemics in Uganda

Uganda is praised for successfully reducing the HIV prevalence rate from 18% in 1992 to 6.2% in 2002 by committing to an epidemiological model that utilized behavior change and science. The Abstain, Be faithful and use a Condom, known as the ABC strategy focused on core family values of monogamous marriages, fidelity, abstinence for the unmarried, and delay of sex debut for teenagers. Condom use was encouraged in circumstances where one is unable to AB. But this story is incomplete absent a background narrative of the context and circumstances that made the nation embrace the ABC approach.

It was a double tragedy when HIV/AIDS first emerged in Uganda in the early 1980s. As an epidemic disease, HIV/AIDS created a drastic surge in morbidity and mortality. Scientific tools were inadequate for purposes of intervention, prevention, and treatment. The social problems created by HIV/AIDS were equally devastating to individuals and communities largely dependent on family unity and social coherence as safety-nets for cultural and economic stability. HIV/AIDS was mostly infecting people with intimate mutual relationships who were dependent on each other such as couples, fiancées, workmates, schoolmates, and neighbors. Suspicions of witchcraft and stigma prevailed in the absence of satisfactory scientific explanations.
Shockingly, the HIV/AIDS prevalence peaked to an estimated 15 percent in 1991.\(^5\) By 1989, there was already an enormous devastating AIDS impact upon families and households in central and southern Uganda. Health authorities estimated that 12.6 percent of all the children under 15 in Rakai District were orphans.\(^6\) In 2002, over 60 percent of the entire population of Rakai District was below 19 years of age. Inconceivably, the district had lost most of its adult population to AIDS related death. This was barely two decade since the first AIDS cases in Uganda were diagnosed in 1982 as “a mysterious disease” that had infected seventeen fishermen in Rakai District in southern Uganda.\(^7\) By 2004, Uganda with an approximate population of 24.7 million had the national AIDS related death toll estimated at about 900,000.\(^8\)

Since communities lacked adequate scientific knowledge and tools to undertake meaningful intervention they engaged the socio-cultural sex ethos discourse as a strategy to combat HIV/AIDS. As Tony Barnett and Piers Blaikie observed, it was a strategy to deal with risky sexual behaviors in a risky environment characterized by civil disruption and economic disparities.\(^9\) The connection of risky environment to a risky behavior is uniquely relevant for purposes of understanding the choice for the behavioral change approach in Uganda HIV/AIDS intervention. For unlike in the West where high risk environment referred to homosexuality, blood transmission, and intravenous drug-use as the epidemiological typology modes of HIV/AIDS transmission, the infection context in Uganda involved heterosexual relationships and mother-to-child transmission.\(^10\)

In this case, risky societal values and cultural practices such as, polygamy, ritual circumcision, and widow inheritance were reassessed and examined in the light of the surging epidemic. Other practices hitherto considered inappropriate but tolerated such as
extramarital sex, casual multiple sex, transaction sex, and, intergenerational sex were subjected to the scrutiny of the public ethos system.\textsuperscript{11} Parents who lost teenager children through AIDS ardently counseled living children about risky sexual behavior of men and women in the neighborhood.

In Ugandan cultural setup, the individual’s wellbeing is a collective responsibility of the family and the community. The established tradition of core moral values provided the justification for re-examining the meaning and purpose of sexuality, marriage, faithfulness, family and parenting to promote the individual’s health and the common good. In this sense the common good constituted of the notions of good health, and economic and socio-cultural stability. The political unrest and the weak economy that affected livelihoods had resulted in limited family support and increased individual risks in morals and health. Most experts concur that the political and economic environment of the 1970s and 1980s created risky conditions that enhanced the rapid spread of HIV/AIDS in Uganda.\textsuperscript{12}

The political instability which begun with a brutal dictator Idi Amin in the 1970s, was characterized by corrupt governments, a broken economy, collapsed foreign trade, moral lapse, and, overt violations of human rights. In 1972, Idi Amin expelled the Asians whose investments and entrepreneurship formed the back-born of Uganda’s economy. Likewise he deposed cultural leaders, thereby weakening the powers and abilities of communities to provide supervised economic, cultural and moral guidance to individuals and families.\textsuperscript{13}

The civil conflicts and wars between 1979 to 1987 plunged the country into deplorable poverty. Uganda’s HIV literature attributes the increase in polygamous marriages,
transactional sex, multi partner sex, and transgender sex, to the poverty factor. Some wealthy married men took advantage of the poverty of teenage girls to engage them in intergenerational sex for monetary favors. Wealthier women also did likewise with teenage boys. Some women resorted to prostitution in towns along highways to boost their incomes. Highway truck drivers involved in commercial sex activities rapidly spread HIV/AIDS across towns in the 1980s.

Besides, the wars displaced many families whose incomes depended on subsistence-farming on family land. The disruption affected livelihoods. A majority of the families lived on less than a dollar a day. Inflation rose to over 100 percent. HIV/AIDS could not have come at a worse time when even low income job-opportunities were scarce. Families were forced to cut down on food provisions and also withdraw children from schools to save cash for medical expenses. By 1987, it was evident to Ugandan that HIV/AIDS required a holistic social-cultural approach in addition to scientific measures.

The very first public effort to combat the spread of HIV was an informal message to individuals and communities to “zero-graze (or zero-grazing).” The term was metaphorically used to encourage limiting sexual activities to one person (lover) or be abstinent until one identifies a non-infected person (abstain). In a society where customs and taboos limit the use of explicit sexual language in public, the notion of zero grazing captured the imagination of the community, and, allowed broader latitude for public expression and conversation of sexual matters.

In Uganda folk cultures (given diverse tribes) where euphemisms and metaphors are in common usage in daily casual conversations and music, it is not surprising that foreign researchers attribute the genesis of zero-grazing term to diverse sources. For Robert, the
source is Yoweri Museveni whose Hima pastoral people have a practice of tethering a
cow on a peg to restrict roaming allover in good grazing field, thereby resulting in
circular grazed area (zero of the zero-grazing).\textsuperscript{18} For those familiar with the Heifer
Project, introduced in Uganda in 1982, zero grazing originates in the practice of
improving the health and milk yield of a donated special breed cow by feeding it indoors
rather than letting it graze unrestrained outdoor. As Epstein found out, zero grazing
meant avoiding indiscriminate and uncontained sexual relations.\textsuperscript{19}

The zero-grazing message of engaging carefully in sexual relationships was
disseminated in informal and formal public gathering including churches.\textsuperscript{20} However, not
all campaign efforts presented the HIV/AIDS awareness message in positive manner.
John Mary Waligo, a Catholic priest scholar, pointed out that some moralists, including
some religious leaders and self-righteous people considered HIV/AIDS to be a
punishment from God for the ‘pervasive’ sexual behavior of the victims. For these
moralists, AIDS was a disease for prostitutes, fornicators and those who engaged in
extramarital sex. AIDS had provided an opportunity for them “to preach against sexual
unfaithfulness, marriage infidelity, promiscuity, and sexual liberalism.”\textsuperscript{21}

The practice by indigenous traditional healers of attributing HIV/AIDS to witchcraft
aggravated the discrimination and stigmatization of the affected individuals and families.
The indigenous religious-spiritual tradition in Uganda assumed that ill-health is caused
by either natural or unnatural causes. Since communities were unable to identify the
natural cause of HIV/AIDS, traditional healers simply attributed AIDS to witchcraft.
Some of the traditional healers used the occasion to enrich themselves at the expense of
the vulnerable and stigmatized AIDS patients who were desperate for a cure. Because of
witchcraft suspicions, conflicts emerged in families, work places, and villages.\textsuperscript{22} This resulted in further stigmatization and poor provision of community support, counseling, and palliative care.

The negativity began to change to positive messages when prominent Ugandans such as artists, clerics, medics, educators, and political leaders began to speak out and lead the HIV/AIDS awareness campaigns through education and a call for change of lifestyle. In 1989, the most inspirational Ugandan musician of the time Philly Bongole Lutaaya became the first known Ugandan artist with AIDS who embarked on a nationwide HIV/AIDS awareness campaign calling on the youth particularly those in schools to pay attention to the danger of HIV/AIDS and change their sex lifestyles.\textsuperscript{23} Many more individuals and local social organizations followed suit using music, mass media, homilies in churches, and local community meetings calling on individuals to take personal responsibility in combating the spread of a disease they called \textit{siliimu}.\textsuperscript{24} AIDS was named \textit{siliimu} (slim) because of making the patients abnormally slim or skinny.\textsuperscript{25}

Two years earlier in 1987, the AIDS Support Organization (TASO) had been founded by Dr. Noelina Kaleeba and fifteen other colleagues, to help people with AIDS “live positively and die with dignity.” Dr. Kaleeba’s husband had died of AIDS. TASO was established to empower HIV/AIDS patients to cultivate self-esteem, hope, respect for life, protection of their communities, and, care for oneself.\textsuperscript{26} The Organization also created social awareness for compassionate care, mutual support, and elimination of stigmatization and discrimination of people with AIDS. In 1986, the Ugandan First Lady, Janet Museveni and colleagues founded the Uganda Women’s Effort to Save Orphans
(UWESO). The organization was to offer childcare support, child counseling and income-generating activities for orphans.\textsuperscript{27}

By the end of 2003, there were at least 750 registered community based organizations (NGOs/CBOs) in Uganda caring for HIV/AIDS patients and affected communities.\textsuperscript{28} The earliest most significant mobilization and education effort came from faith-based organizations. In 1989, the Catholic Bishops of Uganda used the language of Catholic social teaching to confront the interrelated realities of HIV/AIDS, poverty, and ignorance. The Bishops initiated HIV/AIDS care support programs in churches (parishes), schools, and hospitals to aid the affected individuals and their families. One of the earliest successful endeavors was the establishment of HIV/AIDS homecare special programs. In the context of mutual cooperation and solidarity the bishops called for the strengthening of moral and family values.\textsuperscript{29}

The Anglican Church in Uganda also developed and extensively implemented HIV/AIDS education and support programs. The 1990 AIDS education pilot project by the Islamic Medical Association of Uganda (IMAU) was selected by UNAIDS as a “Best Practice Case Study.”\textsuperscript{30} The IMAU program was a massive effort to equip religious leaders and lay communities with HIV/AIDS knowledge and capacity for behavior change. Yet the contribution of faith-based values and moral vision associated with the decline of HIV prevalence rate in Uganda has been minimally recognized in public health commentaries. In the international press, commentators who gauge the contribution of faith institutions solely based on the anti condom and abstinence policies cast faith-based involvement as obstructive to the cause of HIV prevention.\textsuperscript{31}
(ii) The ABC Approach

To gain perspective of the success of combating the spread of HIV/AIDS in Uganda, the story of President Yoweri Museveni has to be told. When Museveni came to power in 1986, he adopted the ABC approach and made the fight against HIV/AIDS a priority public policy. The government proactively coordinated a wide array of non-governmental organizations (NGOs), community based organizations (CBOs) and activists to promote policies and programs designed to influence behavior change involving abstinence, being faithful (monogamy), and condom use (ABC).\textsuperscript{32} In 1986 the president asked the Ministry of Health to set up the HIV/AIDS Control Program – the first of its kind in Sub-Saharan Africa. In 1992 he established the Uganda AIDS Commission which oversaw the creation of the National Strategic Framework to ensure focused and harmonized response to HIV.\textsuperscript{33}

The ABC strategy was implemented through social mobilization and empowerment of communities to engage a comprehensive behavior change approach and support government initiated epidemic intervention programs. To strengthen behavior change approaches, the government used broad intervention strategies such as education of the masses through widespread media campaign, schools, faith based organizations, government ministries, government agencies, employers, employees, and community based organizations. Radio programs and advertisement, including billboards, were used to disseminate information about HIV/AIDS and the ABC strategy.\textsuperscript{34}

The goal of educating the public was to provide knowledge of the manner of infection, prevention, and eliminate stigmatization and discrimination against HIV seropositive people. The government made a commitment to address the risky behavior
and the risky social-political environment both of which had created conducive conditions for the rapid spread of HIV/AIDS. The government stabilized the hitherto volatile political situation and improved the rights of vulnerable populations as it launched a massive campaign to combat HIV/AIDS.\(^{35}\)

The economy in the 1990 grew at an average of 6.9 percent per annum as compared to the economic stagnation of early 1980s. At the same time Uganda’s per capital income growth averaged about 3.2 percent.\(^{36}\) Many family members were able to reunite and reconstruct their homes and family. More importantly freedom of speech was enhanced in 1990 when the government stopped its control of the mass media. The action resulted in an increase in the number of radio and television stations that provided broader forum for investigating and discussing moral and cultural traditional practices impacting the spread of HIV.

Access to health facilities improved with the government’s investment in health care. For instance in 1995, about 8 percent of the population lived more than 10kms away from a health facility of any kind. But by 2001, 49 percent of the population had access to a health care facility within a distance of 5kms. There was also improvement in sanitation and healthier diet and lives. Access to safe water increased from twenty four percent in 1992 to 60 percent in 2002.\(^{37}\) Certainly the social-political and economic environment had turned around from being highly risky to being favorable for behavior change.

The second aspect of the government’s ABC strategy was to support scientific approaches of prevention, detection and treatment. Through the public media and school programs the government actively promoted the use of condoms. For instance condom use increased among sexually active men in 1995 from 9 percent to 15 percent in 2000.\(^{38}\)
The government also heavily invested resources in health care through universities, research centers and regional hospitals to improve HIV/AIDS interventions in areas of testing, treatment and vaccination research. With the help of International organizations and foreign aid, the effort led to remarkable improvement in safe blood supplies, provision of antiretroviral therapy, prevention of mother-to-child transmission of HIV, and treatment of tuberculosis and other related opportunistic diseases.\(^{39}\)

Uganda successfully reduced the prevalence rates of HIV from an average of 18 percent between the early 1990s to 6.2 percent by 2002.\(^{40}\) The decline in HIV infection is attributed to an increase in sex abstinence, monogamy and condom use. The claim is supported by evidence from data from Uganda’s Demographic and Health Survey (DHS) conducted in 1988, 1995 and 2000.\(^{41}\) Further evidence is available in the national-level findings by two Global Programs on AIDS (GPA) survey of 1989 and 1995.\(^{42}\) These sources investigated changes that occurred in abstinence, monogamy and condom use during the late 1980s when HIV levels were declining and the early 1990s when the reduced levels of infection appear to have been sustained.\(^{43}\)

The data from these sources was analyzed by researchers from the Alan Guttmacher Institute in 2003 who came to the same conclusion that “positive behavior change in all three areas of ABC, abstinence, being faithful (monogamy) and condom use have contributed to the decline of HIV in Uganda to sustain a lower level.”\(^{44}\) The report by Sunshield Singh and colleagues elaborates on the reasons for the decline. In the case of abstinence, “fewer Ugandans reported having sex at young ages in 1995 to 2000 than in the late 1980s.”\(^{45}\) Among women aged 15-17 the proportion of those who had ever had sex decreased from 50 percent in 1988 to 46 percent in 1995 and 34 percent in 2000. The
same trend of decline was also observed among those aged 18-19 though on a much smaller scale. Declines in the proportions of men aged 15-17 who had ever had sex were observed between the 1989 and 2000. However, overall among sexually experienced unmarried men, the decline was just over half in 2000 as compared to 1995 when the proportion was nearly three-quarters.  

The values of monogamy, and, be faithful meant that less sexual partners led to less exposure to HIV. Data from Uganda in 1989 and 1995 as reported by the Joint Program on HIV/AIDS (UNAID) and the World Health Organization attests to this assumption. The number of men with one or more casual partners declined from 35 percent to 15 percent and for women from 16 percent to 6 percent. There was a decline in multiple partnerships in both sexually active unmarried men and women. Among women the decline was from 31 percent in 1989, to 15 percent in 1995 and from 59 percent to 26 percent among men.

Susheela’s report demonstrates that between 1989 and 1995 there was a decline in the proportions of women and men, both married and unmarried, who had multiple sexual partners. The decline in HIV infection rates between 1987 and 2000 has been linked to less exposure to HIV, partly caused by less exposure to sexual intercourse with multiple partners. On condom use the report conclude that “current or recent use of condoms rose among all sexually active women and men, especially among those in young age-group.” There was an increase from 3 percent in 1995 to 6 percent in 2000 overall in proportion, among sexually active women who reported condom use for any reason, including pregnancy prevention. The condom use increase among sexually active women of age 15-17 was from 6 percent to 25 percent. Among sexually active men the use of
condoms increased from 9 percent in 1995 to 15 percent in 2000. The increase among men aged 15-17 was from 16 percent to 55 percent.\(^50\)

While condom use played some role, much of the HIV decline is attributable to behavior change since condoms were not easily available until the mid-1990. Moreover a government ban on condom advertisement was lifted in 1994 when already evidence of HIV reduction was noticeable.\(^51\) Moreover by the year 2000, only 8 percent of the population in Uganda used condoms on a regular basis.\(^52\) However there is a narrative allegedly sustained in UNAID until as recent as 2006 that overemphasized the success of condom use over the impact of behavior change (pattern reduction and fidelity) in the decline of HIV rates in Uganda.\(^53\)

According to Helen Epstein the reasons for neglect of partner-reduction campaigns such as zero-grazing had more to do with western donor-countries preferences than facts in the field. Epstein states that the year 1996 when UNAID was established vast international health bureaucracies that had been established in 1970s, were receiving funds from wealthier western donor-countries to strengthen programs that market and distribute contraceptive in developing countries. So the strategy that was identified by public health authorities, when HIV begun to spread, was programs and commodities such as condoms, HIV testing kits, and STD services that could easily be paid for by the donor countries and easily delivered by these organizations.\(^54\)

This dynamics, according to Epstein, explain why Maxine Ankrah’s 1989 important research which established that partner reduction and fidelity were the major contributing factors to Uganda’s HIV, was overlooked by UNAID experts. Michel Carael, by then head of the UNAID’s evaluation-and-monitoring unit, analyzed Ankrah’s report and
another WHO commissioned “Kinsey-survey’ report on Uganda sexual behavior and concluded that condom use was responsible for the reduction of HIV preference rate in Uganda. But researchers Rand Stoneburner and colleagues later viewed the same report and concurred with Ankrah that the reason for HIV decline had more to do with substantial partner reduction and fidelity.

Edward Green accused the international global program of bias against behavior change approaches (abstinence, faithfulness, and monogamy) and paying lip service to the ABC strategy in favor of spending resources on condom promotion, and other treatable sexually transmitted infections. Green attributes the reluctance to engage in effective AIDS prevention strategy to the era of sexual revolution. When AIDS appeared, availability of contraceptives and reproductive liberties had jettisoned the western society to greater sexual freedom. The tradition norms and values that informed sexual behavior were being eroded and replaced by the new values that “full sexual expression was health for both straight and gay.”

In spite of the aforementioned moral quandaries, it is a well-documented fact that Uganda through the ABC approach achieved a significant drop in HIV prevalence rate from early 1900s to 2002. The behavioral change approach of abstinence, be faithful (monogamy), and use of condoms helped scale down the HIV prevalence rates. The reasons for behavior change is attributed to the commitment of the local communities, the families, prominent individuals and the government to courageously address the risky behaviors in a risky environment and to the use of social ethos tools to combat HIV/AIDS. Understood in this perspective, the ABC approach is compatible with the
definition of public health by the Institute of Medicine (IOM) that: “Public health is what we as a society, do collectively to assure the conditions for people to be health.”

(iii) The Relevance of the ABC to PEPFAR

In 2003 when President Bush launched the President’s Emergency Plan for AIDS Relief (PEPFAR) initiative to assist developing countries combat HIV/AIDS he selected the Uganda ABC strategy as the model to be emulated by the PEPFAR funded programs in the sub-Saharan Africa. According to the Office of the U.S. Global Aids Coordinator, the initially five-year program allocated $15 billion to help fifteen mostly sub-Saharan African nations, including Uganda, to combat HIV/AIDS, tuberculosis, and malaria. The initiative was renewed in 2008 and the funds tripled to $48 billion for another extended five years.

By 2007, Uganda had approximately received $635 million of the PEPFAR funds to combat HIV/AIDS, tuberculosis, and malaria. The aid made it possible for the country to successfully reduce mother-to-child (PMTCT) HIV transmission by providing services to 681,200 pregnant women, provide anti-retroviral treatment to 106,000 individuals, palliative/basic health care and support, and, increased prevention programs in support of behavioral change and use of scientific preventive tools. The PEPFAR policy also included a requirement that 33% of the funds for HIV prevention be used on abstinence-only programs. Another provision excluded prostitutes from benefiting from the funds.

Surprisingly, one area that did not record further improvement despite the availability of funds is the prevention of heterosexual transmission of HIV/AIDS. The results of the 2008 evaluation indicated adult HIV prevalence rate had risen to 6.4 percent. Definitely this confirmed the fears that Uganda HIV experts had begun to express that HIV
prevalence rates had stabilized at an unacceptable high rate of between 6.1 percent and 6.5 percent and possibly increasing. 65 Between 2009 and 2011, the prevalence rate was between 6.5 and 7 per cent.66

There is hardly consensus in the international community regarding reasons for the regress in the prevention of heterosexual transmission of HIV in Uganda after a decade of remarkable success. Some Ugandan health professionals attributed the problem to complacency due to the introduction of anti-retroviral medication. This meant that most people become indifferent to the sex behavior-change message as they exclusively committed to scientific interventions. But several scholars have established a connection between the apathy towards the ABC strategy with the debate in the International Community about the relevance or irrelevance of condoms. This trend seemingly explains the cause for the rising HIV prevalence rate in Uganda.67

The often disagreeable condom debate in global ethics is framed as the tension between those who are pro abstinence but anti-condom, and, those who are pro-condom but anti-abstinence.68 In reference to United States influence, the pro-abstinence and anti-condom are categorized as the US-based social conservatives who use the ABC mantra to justify the promotion of their “long-standing agenda regarding people’s sexual behavior and the kind of sex education they should receive.”69 Critics such as Jonathan Cohen and Tony Tate see the defense of abstinence and faithfulness as incompatible with the goal of advancing sex freedoms of the unmarried, gay and transgender people.70

Reversely, some experts worry of critics who use the ABC debate as a platform for apportioning inordinate credit to condoms while denigrating the importance of behavioral change. In 2003, Edward Green argued that the international AIDS program
disproportionately favored and allocated most resources to condom promotion over behavioral change. Subsequently, it took UNAID more than a decade to come to terms with Uganda’s informed claim that behavior partner reduction was the main reason for HIV reduction. The official position of UNAID up until 2004 was to highlight condom use as having played the leading role in Uganda’s HIV prevalence rate reduction.

The condom controversy was linked to the PEPFAR funds even before the congressional approval. President Bush’s administration and most Republican Congress representatives put more emphasis on promotion of abstinence in the PEPFAR program. The Democratic counterparts preferred a condom prioritization policy. The competing views in congress were reflective of the debate among the American public on whether condom use or persuasion to abstain from sex until marriage was the most effective method to prevent HIV among the American teenagers. Critics claimed that studies showed that abstinence-until marriage programs indicated “no long-term success in delaying sexual initiation or reducing behavior changes among participants.”

The condom versus abstinence-only debate in United States was framed, by journalist Steve Sternberg as “a clash between science and ideology.” He explained that ever since AIDS emerged in the 1980s, the AIDS-prevention policy in United States always provoked a political stormy debate. It was not a coincidence therefore that soon after Uganda received the PEPFAR funds in 2004, a debate begun to ensure in the international community as to whether Uganda’s ABC approach was the best method to combat HIV/AIDS. Competing ethical claims dissected the ABC. While some advocated for “C” excluding “A” and “B”, for others it was nothing but AB.
Just as the MSEHPA became “a lightning rod for criticism” in the pandemics planning, so did the ABC become the pivotal ethical issue generating disagreement between pro-abstinence and pro-condoms activists. Gradually, the relevance of the ABC epidemiological strategy came to be construed by some as a discrimination problem rather than a legitimate community-safety issue as was held by others. The abstinence (or abstinence-only) strategy and policies that hindered accessibility to condoms were viewed as obstacles to the effective control of HIV/AIDS. Eventually, with the increased awareness of the importance of human rights in public health interventions (yet, with obscure interpretation of human rights) the PEPFAR funds provided an opportunity for civil societies, faith-based institutions, and politicians to advance uncompromising maxims regarding the ABC approach.81

The pro-abstinence advocates comprised of those who admitted to some partial effectiveness of condoms to those who were strictly anti-condoms. Some faith-based institutions considered condom-use sinful and immoral. A prominent Ugandan preacher and HIV/AIDS activist, Pastor Martin Ssempa is one of the leading advocates for abstinence-only policy in Uganda. Using his Makerere University Community Church as a platform, Ssempa repeatedly blasted those in the international community promoting condom-use in Uganda.82

As Director of the Global Center for Uganda’s ABC Strategy, Ssempa took his anti-condom fight to a global platform. In a letter addressed to Steven Lewis, the then UN secretary general’s special envoy for HIV/AIDS in Africa, Ssempa demanded that Lewis be fired for his advocacy for condom-use in Africa.83 Ssempa claimed:
He (Lewis) is using the entire body of the UN for his personal agenda of “condomize” the developing nations. Why he has the audacity to fight the only nation which has demonstrated success in reducing HIV/AIDS is utterly beyond me… (Lewis) is fabricating lies to further attack Uganda’s ABC strategy.\textsuperscript{84}

Lewis had allegedly blamed the US PEPFAR program for causing the (lack of) condom crisis in Uganda.\textsuperscript{85}

Ssempa was emboldened by support from other abstinence-only advocates such as Uganda’s First Lady Janet Museveni. In 2006, Mrs. Museveni initiated a No Apology Abstinence Training Curriculum in seven districts of Uganda. Reportedly, in the first three months of the initiative, 13,500 students signed for a four months training program to commit to abstinence.\textsuperscript{86} Earlier on in 2003, Mrs. Museveni had presented a memo to the US Congress in support of an abstinence policy for HIV prevention in Uganda.\textsuperscript{87}

Condom use as was debated in the global community advanced two incompatible views. One group blamed policies that prioritized the use of condoms and disregarded the effectiveness of behavioral change.\textsuperscript{88} The pro-abstinence and faithfulness (fidelity) alleged that condoms were ineffective since HIV virus seeps through the porous condom. Additionally the promotion of condoms aided the spread of immorality in society.\textsuperscript{89} There are those however who admit to some role for condoms in so far as their use comes second to behavior change and are the best intervention given circumstances such as commercial sex workers and some settings involving students.\textsuperscript{90}

For other ethics commentators and health policy makers, the new rise in HIV prevalence rate was attributable to the (alleged) government’s policy of abandoning condom use and reverting to abstinence policies. These critics repeatedly assailed the
PEPFAR program, under President Bush, for what they perceived as a promotion of the abstinence-only policy at the expense of condom use. The most direct criticism came from the Human Rights Watch report issued in 2005. The authors, Cohen and Tate asserted that “Uganda was redirecting its HIV prevention strategy from scientifically proven and effective strategies (such as condoms-use) towards ideologically driven programs that focuses primarily on promoting sexual abstinence until marriage.”

These experts asserted that “there is scanty evidence that abstinence contributed significantly to the reported decline in HIV prevalence in Uganda in the 1990s.” They argued that partner reduction in casual sex as was practiced in the zero-grazing campaign strategies of the 1990s was largely responsible for HIV reduction than abstinence. Following this conclusion, Cohen and Tate pillared skepticism on the whole idea of the effectiveness of the Uganda ABC strategy, categorizing it as a “uniquely American invention.” They claimed that many HIV/AIDS experts in Uganda attested to their ignorance of the alphabetic sound bite of ABC until branded so by the United States government.

Cohen and Tate came to the conclusion that “Uganda’s anti-AIDS effort in the 1990s cannot be reduced to a particular government intervention such as abstinence-only or ABC.” The authors characterize ABC’s promoting of institutions such as marriage and discouraging condoms and sex (for its own sake) as obstacles to “the realization of internationally recognized human rights, including the right to information, the right to the highest attainable standard of health, and ultimately the rights to life.”

The connection of the ABC and PEPFAR to human rights gained further attention when a section of women human rights advocates pointed out that the condom discourse
masked underlying human rights issues of discrimination and stigmatization based on
gender inequality and discrimination. These critics argued that women in developing
countries lack power, autonomy, and wellbeing, and, are unable to negotiate sex options
or condom use due to gender subordination. Linda Fuller argues that:

ABC can only be a viable prevention option for women and girls if implemented
as one component of a package of interventions aimed at addressing deep-rooted
gender imbalances. These would include, among others, advocacy for the
empowerment of women and promotion of women and girls’ rights.

The shift from the epidemiological oriented ABC approach increasingly became
inevitable as advocates questioned the justification for the use of government powers and
donor resources to promote societal norms that burden women, and sustained
discrimination based on gender and sex orientation. This perspective was clearly in
line with the new paradigm in the international community that characterized HIV/AIDS
as a human rights issue. This change is succinctly articulated by Daniel Whelan:

Many HIV prevention initiatives continue to be formulated within a traditional
public health framework – a framework that lacks the tools necessary to address
the determinants of societal vulnerability to HIV/AIDS. In order to more
adequately address these challenges of vulnerability, a human rights approach has
been developed. This approach is now understood to be the central insights,
opening new pathways for effective prevention and impact alleviation policies
and programs.
Consequently, human rights are understood as the new language of wellbeing in the context of which the underlying societal conditions of disease, disability and death should be analyzed.\textsuperscript{102}

According to Jonathan Mann and colleagues, health and human rights approaches complement each other for the advance of human wellbeing. These scholars point to the HIV/AIDS epidemics as illustrative of how individual and population vulnerability to diseases and disability is connected to the respect of human rights.\textsuperscript{103} Experts attest to the fact that public-health initiatives are more likely to succeed when they consider human rights than when they neglect human rights. But it is unclear how this compatibility translates into effective practical HIV prevention policy, particularly when rights conflict.

In 1996 UNAIDS incorporated human rights into its overall strategic plan of combating HIV/AIDS. The human rights approach was deemed necessary to counter the trend that fueled the spread of HIV/AIDS through societal and structural factors of poverty, discrimination, and women subordination.\textsuperscript{104} Susan Timberlake stated that UNAIDS drew the link between vulnerability and human rights from examining the relationship between HIV/AIDS and (nations’) laws, policies, marital relations, family, property relations, migration, sex work, homosexuality, and drug use.\textsuperscript{105}

To move the initiative forward UNAIDS proposed further action and articulation of general and ethical principles to guide policy formulation and professional conduct in HIV-related initiatives. Those actions relate to ethical issues of “wellbeing and beneficence, equity and distributive justice, autonomy and respect for persons, confidentiality and informed consent, and the duty to treat.”\textsuperscript{106} However UNAIDS did not
offer a succinct articulation of the criteria for balancing conflicting rights as required in article 29 of the UDHR.

As Uganda continues to lose its grip on the epidemiological oriented ABC approach amidst the rising HIV prevalence rate, there seems to be no comprehensive ethical guide integrating the epidemiological model with the social justice model in HIV/AIDS prevention. The divide regarding conflicting rights was evident in the counteraccusation between Dr. Zainab Akol, the coordinator of the national Aids Control Program, and, Mr. Godfrey Tumwesigye of the Human Rights Network Uganda (HURINET). When interpreting the cause of the high prevalence rate of about 7 percent in November 2011, Dr. Akol attributed it (partially) to “the uncoordinated response to the epidemic by pro-gay and lesbian civil liberties.” She explained that:

They are spoiling our response to HIV/AIDS. They are derailing us by dragging us to human rights issues of homosexuals. We in the ministry do not want to know your sexual orientation. We treat everyone so long as that person is sick.

Akol further claimed that Uganda had missed a $270 million AIDS grant from the Global Fund because of the civil society’s lobbying. But Tumwesigye countered that all HURINET needed was for the Ministry of Health to “streamline lesbian, gay, bisexual, and transgender (LGBT) in HIV/AIDS activities.” The Global Fund’s report attributed the refusal to provide the grant mainly on Uganda’s failure to disburse a significant amount of money from the Round 7 grant. The second reason further stipulated in article 4.10 of the Independent Appeal Panel states that “the panel found that the TRP’s (Technical Review Panel) concerns regarding enhancing social and gender equity and human rights and their implications on the soundness of approach as determined by the
TRP were founded.”

Though this document does not elaborate on the TPR’s human rights reference, the statement provides the hint that corroborates Dr. Akol’s claim.

The exchange between Akol and Tumwesigye was symptomatic of the ethical quandary resulting from the application of rights-based approaches in an incoherent and non-robust manner. At issue here is the tension between the lifesaving-centered approach that is reticent about gay rights, and, a monolithic human rights vision that regards disease control as subordinate to the cause of advancing gay rights. Tumwesigye’s priorities resonated with the complaint made by Human Rights Watch (HRW) to the United States Congregational caucus regarding Uganda’s alleged support for homophobia. Of concern were the human rights of lesbian, gay, bisexual, and transgender people.

Human Rights Watch demanded from the Office of the Global AIDS Coordinator the names of all Ugandan organizations that had received funding under the PEPFAR grants. The purpose was to identify organizations that received the PEPFAR funds and yet promote discrimination based on sexual orientation or gender identity, or promotion of abstinence-only policy. This methodology of naming and shaming, often used by Human Rights Watch, identifies a priority right and the right-violators so as to remedy and protect the vulnerable subjects. Cohen and Tate employed this approach in 2005 when naming Mrs. Janet Museveni, Pastor Martin Ssempe, Youth Forum, and, Family Life Network, as Uganda’s PEPFAR funded individuals and organization supporting the abstinence-only agenda while disregarding the human rights of individuals.

But this confrontational approach met an equally uncompromising counter response from some Ugandan legislators who decided to counter gay rights activism. A bill drafted
by an anti-homosexuality parliamentarian in Uganda, allegedly supported by American Evangelical groups, sought to strengthen an old ant-homosexuality law imposed by the British colonial government. Bahati’s bill included provisions for several forms of punishment for aggravated homosexual activities. The bill recommended a death penalty for HIV positive same-sex act with minors. One clause proposed imprisonment not only for convicted homosexuals but also for those who fail to report such activities. Bahati advanced this bill also “to strengthen the nation’s capacity to deal with emerging international threats to the traditional heterosexual families.”

The move to severely punish gay activities infuriated and galvanized local and international gay rights advocates who sought the intervention of western governments to impose punitive action including cutting donor HIV/AIDS funds to Uganda. The government of Sweden warned it was to cut aid to Uganda. United States threatened to expel Uganda from the trade pact – the African Growth and Opportunity Act (AGOA) if the bill was to be enacted into law. The toughest stance came from Britain. At the 2011 Commonwealth Heads of Government Meeting (Chogm) in Australia, the Prime Minister David Cameron threatened to withhold some aid from governments that do not reform anti-gay legislation.

In December 2011 the United States Secretary of State, Hillary Clinton, announced that her government had adopted a policy of attaching foreign aid to fighting discrimination against gay people abroad. Secretary Clinton stated that “Gay rights are human rights and human rights are gay rights.” Accordingly, in the presidential memorandum President Obama directed all Federal Agencies to promote the rights of
lesbian, gay, bio-sexual, and transgender persons overseas. The president emphasized that “no country should deny people their rights because of who they love.”

The basis for respect of the human rights of gay and other sex minorities is implied in article seven of the UDHR which maintains the right of every person to equal protection against any discrimination and incitement against such discrimination. This right to non-discrimination is founded on the *prima facie* principle of the inherent dignity of each and every person. Article one of the UDHR states that “all human beings are born free and equal in dignity and rights.” This enunciation spells out the basis for the legitimacy of interventions to protect the human rights of sexual minorities.

However, the – aid for gay rights promotion – policy appears to be based on a narrow and monolithic vision of human rights as articulated in “gay rights are human rights and human rights are gay rights.” Such value statement does not appear to be firmly anchored in the substantive ethical principle of the inviolability of human dignity, and subsequently, could generate more inconsistence than coherence. Besides, while discrimination based on sex orientation violates human rights, the imposition of policies in form of absolute maxims does not cast democratic credentials of developed nations in good light. The democratic credentials of the global civil society, as observed by Matt Baillie Smith, is in the ability to facilitate dialogue and debate, which is good for idea of global justice and equity.

The intervention policy such as aid-for-gay rights promotion founded on an incoherent conceptual framework is counterproductive since the ramification is the deprivation of lifesaving aid to the poor and the HIV/AIDS victims. For instance when the Global Fund withheld the round 10 grant to Uganda, Dr. Akol revealed the aid was
urgently needed to put 100,000 more (HIV seropositives) people on lifesaving ARV.\textsuperscript{126} Moreover, the growing trend of developed nations to rely on coercion to foster the cooperation of poor nations in HIV/AIDS intervention is contrary to principle of mutual collaboration for the common good. It is a well argued conclusion in bioethics and population health that coercion diminishes rather than enhance trust in health interventions.

Frederic Reamer reminds us of Socrates’ recognition of the “importance of moral inquiry” and of a “systematic examination of the moral features of life.”\textsuperscript{127} As the role of public health increasingly stretch beyond the defense of epidemic disease (epidemiological model) to the protection of human rights (social justice model), the need grows for guarding against polarizing moral stances. Ethicists ought to adopt a strategy that strikes balance by engaging in critical interpretation of human rights and guarded application of the standards of moral justification.

B. The Epidemiological Model and the Social Justice Model

(i) The Epidemiological Model in HIV/AIDS Intervention

Epidemiology is concerned with understanding and altering factors that determine population patterns of health and disease. Since the early days of the HIV/AIDS epidemics experts emphasized the importance of intervention strategies of monitoring, prevention, and treatment based on typology of HIV transmission patterns among various populations and regions of the world.\textsuperscript{128} These classifications of patterns of transmission based on groups at-risk have tended to change overtime due to the changing socio-
political and cultural contexts. But basically, epidemiologists focus their attention on the phenomenon of the interaction of virus and the human population.\textsuperscript{129}

Following this epidemiological model Peter Piot identified several epidemiological factors accounting for HIV prevalence variable in different parts of the world. The list included virological (HIV-1 subtype variations, levels of viremia), genital factors (STDs, absence of male circumcision, dry sex), sexual behavior (rate of partner change, mixing sexual partners, types of sexual intercourse, early sex debut, levels of condom-use), demographic variables (proportionality of sexual active age, male-to-female ratio, proportionality of urban to rural populations, migration patterns), economic and political factors (poverty, war and social conflicts, performance of health care systems, response to the epidemics).\textsuperscript{130}

However, the challenge for epidemiologists remains the issue of understanding the interplay between biological factors and the socio-cultural experiences that shapes public health.\textsuperscript{131} The National Research Council (NRC) of the United States National Academy of Science was aware of this challenge in 1996 when they developed the HIV intervention framework incorporating individual, societal, infrastructural, and structure underpinnings. The epidemiological factors pertaining to individuals involved biological and behavioral aspects.\textsuperscript{132} Societal factors entailed risk behavior such as high prostitution rates, multiple partners by men, and, gender discrimination and subordination. Infrastructural factors were poor communication, poor access to STD treatment, and, inaccessibility to condoms. Structural factors involved underdevelopment, poverty, civil unrest, and, low respect of human rights.\textsuperscript{133}
More relevant to the question of PEPFAR and ABC debate is Frederic Reamer’s observation that the first response to HIV/AIDS in United States was “to consider the role of public health as a defense against the threat of epidemic disease.”\textsuperscript{134} The initial approach was to deal with HIV prevention in terms of changing the sexual and drug-use behavior of risk groups. The risk groups targeted for public health actions were homosexual, bisexual men, and the intravenous drug users.\textsuperscript{135} The measures included screening, testing, reporting, restricting intravenous drug use, and, closure of gay bathhouses.

But this categorization turned out to be morally problematic as homosexual men were targeted and blamed for the spread of HIV. One particular intervention that highlighted the tension between civil liberties and the public health goal of communal protection was the closure of gay bathhouses. When the Director of public health in San Francisco, Mervyn Silverman, ordered the closure of the fourteen gay bathhouses, he reasoned that these facilities provided the environment that encouraged and facilitated multiple unsafe sexual activities contributing to the rapid spread of the new epidemic.\textsuperscript{136} Objecting to the counteraccusation that these broad measures were an affront on legally protected private behaviors of gay individuals, Silverman argued that the bathhouses were not fostering gay liberation but public hazards.\textsuperscript{137}

As Reamer observed, the dominant ideological voice from the gay community was not of cooperation but radical individualism that was libertarian-oriented. They were determined to defend “the right of adults to conduct their sexual lives free of state interference, even in the face of decisions that could lead to illness and death.”\textsuperscript{138} This position was articulated by Neil Schram, president of a gay health professional
organization – the American Association of Physicians for Human Rights, who advised that each individual is responsible for himself, and, the public health professionals had no role enforcing behavioral norms.

For Thomas Stoddard, enforcing behavior change was a civil liberties issue. At stake were the principles of sexual privacy and equal protection of the law. However some gay medical professionals recommended compromise measures and limited restrictions to cab the health threat posed by the bathhouses. This approach sought for a balance between the traditional role of public health to protect populations against an epidemic disease and the newly articulated civil liberties.

(ii) The Evolving Phases of HIV Moral Discourse

Ronald Bayer identifies three phases of the evolution of ethical discourse in HIV/AIDS intervention in the United States. In the early 1980s when there was limited therapeutic options, prevention strategies involved coercive state measure. During this phase emphasis was put on behavioral change. But there was also a growing commitment to civil liberties to guard against government intrusion in people’s private lives. The compromise came with the 1986 voluntarism consensus when competing parties settled on education, voluntary HIV testing, and confidentiality as a strategy to replacing state coercion. Surprisingly, however, discrimination still remained a critical issue.

The second phase which Ronald Bayer calls “the resurgence of public health traditionalism” started to occur from the mid-1989 when health professionals introduced antiviral therapies and clinical prophylaxes with potential to lower viral load and consequently reduce infectiousness and AIDS incidents. Support grew for mandatory screening of infants at high risk of HIV infection, and, the routine screening of HIV
pregnant mothers to prevent transmission of HIV to offspring.\textsuperscript{144} As resistance eroded the Center for Disease Control (CDC) advised in 1999, and later recommended in 2000, that all U.S.A states conduct confidential name-based reporting of HIV infection cases to provide for better follow up.\textsuperscript{145}

In 1989, when the legislators in the state of New Jersey voted in favor of named reporting of HIV seropositive cases several other states begun to require contact reporting in at least some circumstances.\textsuperscript{146} Twenty states enacted statutes treating the intentional transmission of HIV as a felony or a misdemeanor.\textsuperscript{147} As of 1999, thirty-one states had enacted legislations criminalizing nondisclosure of HIV status in certain situations.\textsuperscript{148} The Presidential Commission on HIV Epidemics (1988) endorsed the criminalization of the knowing transmission of HIV.

This era of therapeutic promises is characterized by two notable occurrences: the resurgence of public health value over commitment to civil liberties\textsuperscript{149}, and, the rise of HIV/AIDS advocacy alliances.\textsuperscript{150} For instance the antiretroviral medication zidovudine (AZT) that had been approved by the Food and Drug Administration (FDA) in 1987 became available for use by AIDS patients. With the development of subsequent HIV/AIDS cocktail, public health measures such as HIV antibody testing that had been suspect due to privacy and confidentiality issues were now being considered for all persons at risk. Moreover, technological advances had made testing easier for the public. The medical development of the years preceding 1989 brought the promise of effectiveness of early HIV intervention.\textsuperscript{151} Resultantly AIDS activism grew with bold demand that government actively fund AIDS research and programs. Community-based
AIDS service organizations became larger and well organized to provide education and counseling to persons with AIDS.\textsuperscript{152}

Gay activists and civil liberties alliances against name-reporting of the seropositive contacts began to unravel in favor of a disease control approach.\textsuperscript{153} For effective follow-up, the standard procedure in venereal disease control was contact tracing. This measure was also seen as an ethical duty to warn and protect those who would be exposed to the disease infection. The attempt in the early 1880s to co-opt HIV named-reporting standard into the HIV control measures had encountered rigid resistance from gay activists and civil libertarians.\textsuperscript{154} The approach was interpreted as an intrusion in the protected privacy and confidentiality interests of individuals.

The third phase beginning mid-1990s developed from the demand for equity in accessing HIV therapies. The AZT, for instance, was very expensive for low-income people.\textsuperscript{155} The best chance for the poor to access therapeutic intervention was participation in research. Yet women, persons of color, and drug users were under-enrolled in research. As regards women the inequity was partially based on a perceived need to protect the fetus or fertility.\textsuperscript{156} Until 1993, the federal government rarely funded HIV studies in women. Consequently, the unique vulnerability and manifestation of HIV infection in women was poorly understood by medical professions resulting in failure to diagnose and treat HIV victims.\textsuperscript{157} Women coalitions protested the underrepresentation of women in research thereby excluding them from accessing HIV research and experimental drugs. They framed the issues as a violation of the justice principle of equity and fairness.\textsuperscript{158}
Women’s advocacy rejected protectionalism (research as hazardous to women) and categorized it as an injustice that denied women the benefits of scientific knowledge necessary to advance women’s health and wellbeing. They complained of missing out on diagnosis, monitoring and free study medication. This new development resulted in the understanding of research as a benefit to be accessed and not as hazards deserving of protection. This meant a shift from the traditional research policy that focused on scientific rigor and protection of subjects from undue risks to the understanding of justice in research broadly as prioritizing collective benefits (social beneficence) for populations.

In 1994 the National Institute of Health issued guidelines on the inclusion of women and minorities in clinical research. These guidelines and subsequent federal involvement indicated a shift from overemphasis on traditional clinical research ethical principle and benchmarks of risk protection of subjects to the promotion of access to clinical research. This new way of comprehending participation in research as a benefit to be accessed and not as harmful endeavor deserving of protection increased women’s prospects for access to therapeutic measures, but also raised a whole lot of new sets of conflicts regarding the evaluation of risks to the individual and societal benefits in medical research.

The 1990s generated a wave of advocacy alliances targeting inaction or exploitation of vulnerable populations in HIV intervention. The demands pertained to inequities and lack of access to HIV research and resources as a matter of justice. For instance, in 1994, the International Working Group on Microbicide (IWGW) was established with the initiative of the World Health Organization’s global program on AIDS. The purpose was
to ensure close coordination of a number of separate research programs targeting 
microbicides development for women use. By 2002, the alliance consortium for the 
development of microbicides comprised of developers from thirty-four biopharmaceutical 
companies, scientists from twenty-six nonprofit research institutions, and representatives 
from twenty health research and advocacy groups.

One important key arm of the Global Campaign for Microbicides is the Global 
Advocacy for Microbicides. This international advocacy movement has foundation in the 
July 2000 Rockefeller Foundation international meeting for scientists, research 
organizations, advocacy groups, pharmaceuticals representatives, and donors who 
gathered to find ways to accelerate the development and availability of safe, effective and 
accessible microbicides. The Advocacy working group that held its first meeting in 2001 
in Warrenton, Virginia involved sixty advocates from twenty-eight countries.

The group mapped out a five-years working plan to raise awareness for microbicides, 
accelerate product development, access to, and use of topical microbicides. The 
rationale for education and advocacy was “to create political will and momentum 
necessary to propel the scientific enterprise forward – whether through highlighting the 
urgency of the task at hand, educating those in position to make a difference, or 
fomenting political pressure for change.” The advocacy component of the microbicides 
development should not be seen as unrelated to the development in global health, in the 
late 1990s, that sought to add advocacy skills and tools to public health voices seeking 
the improvement of “respect for human rights in particular communities or nations.”

By 2000, HIV/AIDS advocacy had become a formidable means for minority groups 
to influence policy and access to HIV/AIDS resources. Definitely, civil liberties, gay
rights, and women’s rights advocacy had become active players alongside epidemiologist in the initiative to combat the spread of HIV. Cathie Lyons points out that the HIV/AIDS activists became “a social and political force affecting every decision-making process, structure and institution which had a role to play in the HIV/AIDS crisis.” They thought to champion critical issues of “funding, prevention education, access to experimental drugs, community-based care, insurance, discrimination, and other human rights issues.”

If one agrees with Bayer’s three phases of the HIV/AIDS moral discourse, then, the fourth phase is the period following the year 2000 which could be characterized as the phase of the social justice model. Social epidemiologist acknowledged the inadequacy of the epidemiological model to address the social ills rooted in the social structures that impact negatively on the health of population. HIV advocacy brought to the attention of health providers the necessity of addressing issues of social inequality associated with class, gender, sexual identity, and economic disparities. To broaden the notion of population wellbeing, scholars such Madison Powers and Ruth Fadden argued that Social justice is the moral foundation of public health.

(iii) The Social Justice model

The social justice model regards the social justice theory as the foundational moral justification for the social institution of public health. This approach considers health as one of the other essential dimensions of human wellbeing such as personal security, self-determination, and respect for the dignity of individual persons. Within this framework differences occur regarding the task of social justice in population health intervention.
For some it is to ‘secure a sufficiency of the dimensions of health for everyone.’ For others the task is to secure basic capabilities that are fundamental to human flourishing.  

Focusing on the conceptual notion of human flourishing, Jennifer Pram Ruger had argued since 1997 for a social justice approach as a new foundational paradigm for health. She expressed her dissatisfaction with the existing ethical theories that treat health or a right to health as an inappropriate focal variable for accessing social justice or rights. These theories embrace health care in terms of a right to certain health-care services (utilities, community values, liberties, opportunities, resources, and primary goods) as the appropriate variable. She was critical to approaches that frame a claim to health equity in terms of “health care demand for equality of access or entitlement to health services,” and not in terms of health as functional wellbeing. As a result two diverse approaches have emerged, one considers inequality in terms of “differential access to care (services),” and the other as “differences in health (conditions or functioning).”

Following this distinction, Ruger argued that “health” ethics, policy and law, moved towards the trajectory of “health care” (services) with two dichotomous paradigmatic position of consequentialism and proceduralism. While consequentialists want to “access health policies and laws by their consequences”, proceduralists emphasize the important of fair procedures to achieve effective results. Ruger made the case that:  

It is time for an imaginative new theoretical model, one that addresses these issues and bridges the divide between procedures and consequences, between the collective and the individual, between the personal freedom and the welfare, equality and efficiency, science and economics.
For Ruger, a new vision based on human flourishing provides us with a health “capability approach” as the most effective new foundational paradigm for health. Ruger’s support for Amartya Sen’s capability approach stems from a commitment that invokes social justice theory from Aristotelian point of view of human flourishing as the end of all social activities.\(^{182}\) As applied to health inequality, capability relates to well-being in terms of a set of functions, and, personal freedom to achieve wellbeing.\(^{183}\) This means, “…what human are able to do and be, and, what is possible for them, and, it suggests that our social obligation involves enabling all to live flourishing lives.”\(^{184}\)

The importance of Ruger’s exploration of the social justice framework lies in her focus on the person (capabilities and wellbeing) in health intervention rather than on health goods or “things.” Ruger’s eudaimonia vision of health and wellbeing is different from consequentialist or a procedurist perspective. However, as Levy and Sidel observed, the task of social justice is not so clear cut in global-health usage. Social justice encompass a wide array of concepts such as: preventing human rights abuse (such as of vulnerable populations), equitable distribution of societal goods and burdens (such as equal access), justice as it conforms to moral principles (such as “all people are equal”), equal participation (vision of society that is equitable), and, legal mechanisms promoting safety and security of persons in different moral systems of divergent cultures.\(^{185}\)

Levy and Sidel concluded that all these social justice concepts hold in common the premise that all people have “inalienable rights.” This implies a definition of social justice that comprises of the notions of equity and fairness in society.\(^{186}\) Levy and Sidel approached this question of social justice by addressing the issue of social injustice that “adversely affects the health of individuals and communities by creating conditions that
provide unequal opportunities for individuals and groups to meet their basic needs.”

From this perspective, social injustices “violate fundamental human rights”. In one way social injustice is “the denial or violation of economic, socio-cultural, political, civil, or human rights of specific populations or groups in the society based on the perception of their inferiority by those with more power or influence.” Another way of considering the definition of social injustice is based on the definition of public health by the Institute of medicine, as “what we, as a society, collectively do to assure the conditions in which people can be health (policies and action).

The human rights paradigm which regards human rights as the bedrock of social justice treats population health intervention primarily as a human rights issue. Accordingly, human rights are the language of wellbeing in the context of which the underlying societal conditions of disease, disability and death should be analyzed. When Jonathan Mann became head of the World Health Organization’s AIDS program, he made the language of human rights the preferred choice to guide the ethical discourse in the global HIV programs. Mann was skeptical of public health’s (epidemiological approach) competence to address ethical issues in the field of HIV/AIDS intervention. Likewise, he considered bioethics not comprehensive enough to encompass the goals and responsibilities of improving population wellbeing.

This vision of human rights as linked to health policy has roots in “the right to the highest attainable standard of health” which is referred to as the right to health in international law. The World Health Organization (WHO) defines health as the “state of complete physical, mental, and social wellbeing and not merely the absence of disease or
The AIDS epidemic since 1980s inspired a global commitment to health policies that advance human rights and overall human wellbeing.

In HIV/AIDS, the social justice model emerged from the identification of human rights violations rooted in socio-cultural-political factors such as homophobia, racism, poverty, sex-orientation bias, and gender inequity. As discussed in the aforementioned discrimination against gay communities and bias against women in the early days of HIV in United States, a necessity arose to improve the needs of those marginalized and socially disadvantaged as a condition for improving health and overall wellbeing. It is from this perspective, therefore, that the Uganda ABC approach was targeted for criticism for its perceived infringement on the human rights of minority groups.

Some human rights advocates regard the ABC and PEPFAR strategies, in so far as they regulate individual behavior and sex choices, as prejudicial and discriminatory against women and gay preferences. Subsequently, from these concerns derive civil and political advocacy for sexual freedom and gender equity in HIV interventions. Human rights advocates consistently demanded that the government of Uganda and the PEPFAR patterns address a broader range of HIV/AIDS human rights related issues such as non-discrimination and non-stigmatization based on gender and sex orientation choices.

The significance of introducing the social justice model in Uganda’s HIV/AIDS intervention is that it introduced key futures of human wellbeing that extend beyond good health to the respect of the dignity and rights of persons. By addressing other dimensions of wellbeing, the social justice model ideally improves the prospects for good health as
promoted in the epidemiological model. Additionally, the social justice model prevents
the diminution of individual rights as protected in the libertarian model.

However if there are lessons learned from the advocacy-driven cellulose sulfate
(Ushercell) clinical trial of 2007 in Uganda, the deployment of the social justice model
in infectious disease intervention (epidemiological model) requires rigorous negotiation
of ethical balance between group-oriented rights claim to access benefits with the
individual safety concerns. A justifiable ethical pathway should engage a critical
interpretation of the right-based main ethical concepts such as equity, participation, and
access, and, a careful examination of the application of the human rights standards.

C. Human Rights Advocacy in HIV/AIDS Intervention and the Cellulose Sulfate
Clinical Trial.

(i) The Cellulose Sulfate Microbicides (Ushercell) Clinical Trial

Probably the most recent case in medical research that evidence the tension and the
need to balance between protecting the safety of the individual and (specific population)
benefit in the social justice model is the failed 2007 cellulose sulfate (or Ushercell)
microbicides clinical trial. Microbicides connote a range of scientific products being
researched on and developed as inhibitors to enhance women’s ability to protect
themselves and their partners from HIV and sexually transmitted infections.

In 2007 a cellulose sulfate (CS) gel clinical trial to prevent HIV was halted in Uganda
and other sites because more participants in the active product arm seroconverted than
those in the placebo. The $24m Phase III randomized, double-blinded, and placebo
controlled trial to assess the efficacy of a candidate micobicides 6% cellulose sulfate gel
(Ushercell) was conducted in Uganda, South Africa, Benin, Burkina Faso, and India. The Global Campaign for Microbicides involved the Contraceptive Research and Development Program (CONRAD) of the Eastern Virginia Medical School to conduct the clinical trial on 1425 HIV negative women. CONRAD halted the CS trial in January 2007 when the researchers established that the trial product increased women vulnerability to HIV infection.200

The Global Campaign for Microbicides seeks the acceleration of microbicides product development, access, and use. This campaign has its foundation in the 1997 symposium of women’s Health Advocates on Microbicides (WHAM) and the Population Council. The members of WHAM disbanded by 1998 and formed the Global Campaign for Microbicides.201 The advocacy was prompted by scientific evidence that shows that women have greater biological susceptibility to HIV than men. Yet, early HIV research initiatives committed scientific expertise and resources to protecting men’s health.202 While scientific tools such as condoms are largely available for men’s use, women’s options are limited to negotiating with male partners who are at times reluctant to use condoms. Coupled with the condom problem is women’s greater social vulnerability to HIV exposure due to reduced personal autonomy and violence against women.203

The microbicides initiative is presented as requiring social advocacy to propel scientific endeavors beyond the epidemiological harm-protection paradigm to a commitment to social justice approaches relating to broader issues of women wellbeing.204 Experts who put emphasis on protecting individual research participants from harm tend to insist on scientific rigor as the measure for ethical research
protocols.\textsuperscript{205} Those who prioritized access and broader social benefits for women commit primarily to attaining social justice goals.\textsuperscript{206}

Dr. Lut Van Damme of CONRAD and principal investigator of the phase III cellulose sulfate clinical trial attest to the fact that CS underwent eleven safety and tolerance trials prior to human use in phase III. According to Van Damme, in the prior Phase II clinical trial of cellulose sulfate that involved 500 women in Africa, India, Belgium and United States, there were no safety concerns that arose.\textsuperscript{207} Karen Honey writes that unlike nonoxynol-9 that increased the rate of infection with HIV, cellulose sulfate (in phase II) presented no indication of such problems.\textsuperscript{208}

Between 1994 and 1996, a controlled trial of Nonoxynol-9 film was conducted on 1000 seronegative female commercial sex workers to establish whether Nonoxynol-9, an approved spermicide, is also a microbicide.\textsuperscript{209} The clinical trial was halted in 2000 after it was established that even a low dose N-9 gel, if used frequently causes sufficient virginal irritation to increase a woman’s risk of HIV infection. A 50 percent higher rate of HIV infection was recorded in the experimental arm than in the placebo.

Critics question the commitment to scientific rigor prior to the CS phase III clinical trial. Wang Tao and others maintain that the stimulatory effect of low concentrations of cellulose sulfate was not unfamiliar knowledge. Such data was available from “independent libraries, including CONRAD.”\textsuperscript{210} Tao and colleagues suggest that the importance of the data “seems to have been overlooked because the studies measured viral accumulation rather than infection rate or used X4-tropic rather than R5-tropic test virus.”\textsuperscript{211}
Pedro Mesquita and colleagues were later to establish that cellulose sulfate has tissue toxicity. Consequently, cellulose sulfate compromises the vaginal tissue layers that form the first defense against HIV and may have increased vulnerability to HIV. In a laboratory experiment at Albert Einstein College of Medicine, the researchers observed that cellulose sulfate destroyed a protein desmoglein in the group of cadherins proteins responsible for stitching cells together. The loss of the proteins results in “leaky” tissues.\(^\text{212}\)

The research scientists incubated uterine epithelial cells (or reconstructed vaginal tissue) with one dose of cellulose sulfate. The experiment was repeated with one dose of nonoxynol-9, PRO 2000, and tenofovir gel. They used transepithelial electric resistance (TER) technique and confocal microscopy to monitor and evaluate tissue integrity and cellular junction. Changes occurred in the structural protein as detected at the RNA and protein levels. The scientists observed, through a confocal microscope, that cellulose sulfate and N-9 selectively destroyed the protein desmoglein. By measuring the HIV p24 protein the researchers determined that there was viral translocation allowing diffusion of virus across the epithelium.\(^\text{213}\)

Mesquita and his team concluded that cellulose sulfate may have increased susceptibility to HIV due to its toxicity to vaginal tissues resulting into the loss of the protein secretory leukocyte inhibitor. According to these scientists, the critical gap in the microbicides project design was the “lack of biomarkers predictive of efficacy and safety.”\(^\text{214}\) It appears in the aggressive pursuit of social beneficence for women as a demographically disadvantaged population, the risks to the individual women participants were not adequately assessed. Much as participation and access are important for
pursuance of social justice goals to benefit specific populations, scientific rigor and validity are necessary for generating reliable data to safeguard individual safety and dignity.

The cellulose sulfate clinical trial project was not unrelated to the movement in mid-1980s in the United States when women’s coalitions raised the issue of women underrepresentation in research as a matter of justice. Women’s advocacy rejected protectionism (research as hazardous to women) and categorized it as an injustice that denied women the benefits of research participation. They demanded for greater participation in scientific research and access to experimental drugs. Exclusion of women was construed as denying them the benefits of scientific knowledge necessary to advance women’s health and wellbeing. Additionally, women missed out on the benefits of diagnosis, monitoring, and free study medication.215

In developing countries women are further disadvantaged due to socio-cultural vulnerability.216 In 1995, Lori Heise and colleagues argued that HIV prevention strategies of condom use, partner reduction, and, treatment of recurring STDs in so called risk groups was an inadequate approach to addressing women’s health needs in developing countries. These experts argued that women’s poverty and powerlessness in sexual choices should be countered with a commitment to addressing inequalities and the development of technologies women can have control over.217

Categorizing access to scientific research participation as a social justice issue or moral obligation was a leap into uncharted new ethical domain. But this development emerged out of a broader trajectory in multinational research, starting in the 1880s, that required a revision of the existing ethical principles to respond to the new legal,
socioeconomic, and administrative challenges in low-resource countries.\textsuperscript{218} The effort to generate guidance for international biomedical research involving human subjects materialized in 1993 when the World Health Organization (WHO) and the Council for International Organization of Medical Sciences (CIOMS) promulgated a joint ethical guideline.\textsuperscript{219} The 2002 version of the CIOM followed suit as external sponsored clinical trials increased in low-income developing countries and new issues and challenging ethical questions arose.

The 1993 International Guidelines for Biomedical Research Involving Human Subjects and the subsequent revisions sought to provide guidance on the application of ethical guidelines in the local circumstances particularly in low-income developing nations. Researchers from external sponsors had encounters issues such as standard of care and the use of comparators that fall short of the best current practice. The guidelines also sought safeguard against the exploitative clinical trials in populations that cannot afford the resulting new products, thereby, making the product available for use only by the rich.

The link between the external sponsored clinical trials and the social justice issues of poverty and exploitation of the underprivileged fitted into the broader narrative in the global community that classified public health as a social justice issue. It was not surprising therefore, that Global Advocacy for Microbicides became an important key arm of the scientific endeavors of the Global Campaign for Microbicides. But conflicting interests were in the offing in the absence of a succinct criterion on how the advocacy was to balance between the requirement for scientific rigor to protect individuals and the push for acceleration of experimental products as a right to benefit a specific population.
By 2002 most ethics experts had concurred that scientific measures need to be anchored in social justice vision to have a realistic chance of effectively managing pandemics such as HIV/AIDS. Scientists were now to rely on advocacy groups to channel scientific data and new products towards benefitting the poor and minorities. As was defined in the global microbicide partnership, the role of advocacy was to “create the political will and momentum necessary to propel scientific enterprise forward.”

Advocacy was understood as the shaping or influencing the ideas and decisions that inform policy and practices. Heise and colleagues stressed that, “the choice to focus on access and use rather than product development is both deliberate and significant.”

Subsequently, one of the questions the International Consultation of the Microbicides was initially faced with was the possibility of moderating ethical standards in the interest of science for the good of specific populations. The consensus was to prioritize the need to protect individual subjects of research from potential risks. The experts acknowledged however that “for those involved in clinical microbicide trials, the distribution of benefits (as expression of social beneficence and justice) is perhaps an even harder challenge.”

Questions pertaining to balancing of scientific method with advocacy method are complex. As cautioned by Lawrence Gostin and colleagues, advocacy method which is pragmatic and goal oriented tend to foster a populist rather than a rigorous approach, while science method arrives at conclusions by way of experimentation, proof, and verification. The complexity is demonstrated in the conflicting approaches manifested in the failed cellulose sulfate clinical trial. The 2005 Global Campaign for Microbicides information literature stated that “Participation do not increase their (research
participants) risk of becoming HIV infected as a result of being in the trial.” As it
turned out in 2007, participation in the cellulose sulfate microbicide candidate trial
indeed increased susceptibility to HIV.

The campaign to accelerate the microbicides scientific products may have diminished
the need in the pre-clinical safety evaluation of cellulose sulfate to vigorously exhaust
issues of predictive biomarkers of cellulose sulfate safety and efficacy. As was suggested
by Tao and colleagues in 2008, the works by Flexner et al (1991), and Meylan et al
(1994), that detailed the ability of sulfated polyanions to enhance HIV replication both in
vivo and in vitro, was not unfamiliar literature to researchers. The reason cellulose
sulfate candidate microbicide trial was expected to be scientifically rigorous was because
seronegative women were recruited in a non-therapeutic science project with potential
risks for seroconversions. Guideline 1 of the Declaration of Helsinki requires sound
scientific methods for research involving human subjects.

Microbicides development is part of the global advocacy initiative to address the
problem of women vulnerability to HIV because of biological susceptibility and sexual
powerlessness. The issues morally obligates the global community to act urgently, yet,
based on an effective criteria that enables the balancing of conflicting interests between
individuals and populations, and, between specific populations. Linda Fuller, for
instance, identifies many culturally oppressive and HIV susceptible practices such as
abusive marriages, child marriages, polygamy, widow inheritance, and shameful sex
rituals. However, while these practices are accepted in many tribes in Africa there is no
justification for Fuller’s broad-brush indictment of the male gender in Africa.
The depiction of marriage, for instance, in Africa as solely a form of enslavement and conveyor for HIV transmission to women,\textsuperscript{229} ignores the reality of socio-cultural interrelations of husband and wife, father and daughter, brother and sister, and, father-in-law and daughters-in-law. Yet there is a prevailing vulnerability paradigm that treats heterosexual men (particularly in Africa) as the irresponsible vector of HIV since (allegedly) men deliberately engage in sex behavior and not women.\textsuperscript{230} This paradigm carries along with it the real danger of complacency for women in combating HIV/AIDS in Uganda since the implication is that risky behavior is a category for men’s sexual activities. Only a balanced approach to HIV/AIDS prevention can render the effective control of the epidemic.

(ii) Philosophical differences

When Jonathan Mann sought to generate ethical guidelines for population health practice he looked to human rights for the provision of coherence and identity. To separate population health ethics from the biomedical foundation of medical ethics Mann proposed the separation of the language of disease, disability, and death from the language of wellbeing that underpins the right response to the underlying social injustices manifested in traditional mortality and morbidity condition.\textsuperscript{231} Mann and proponents of the social justice model point to the universal acceptance of human rights to justify the commitment of population health strategies to the shared common vision of inalienable rights.

The Universal Declaration of Human Rights adopted by the United Nations General Assembly on December 10, 1948, enunciated that “all human beings are born free and equal in dignity.”\textsuperscript{232} Accordingly, everyone is entitled to all the rights and freedoms set
forth in the Declaration without discrimination such as based on race, color, sex, language, religion, or political. Equality of human dignity is the pivotal human rights norm and principle upon which all other UDHR principles draw determinability for inalienability. Though a consensus seem to have emerged among ethicists that human rights play a central role in informing population health policy, there are philosophical differences over the nature, the source, and the specification of human rights.

According to Jack Donnell, reductionists understand the nature of rights in terms of a simple beneficiary theory. Rights language is interchangeable with duty language such that rights-holders mean nothing more than “objects or passive recipients of benefits.” Correctly understood, rights entail obligations that are generally beneficial. Yet the simple beneficiary theory “confuses what is right with what is a right.” Likewise, another form of reductionism is manifested in legal positivism. Accordingly, what constitute the claim of a right is “legal recognition and government protection.” On the basis of this meaning, Rex Martin confuses civil rights with human rights by making a claim that a society which lacks civil rights has no human rights. Donnell objects that government may be the source of the rights of the citizen but certainly not the rights of man.

The human rights discourse is also complicated by competing specifications of human rights principles. As observed by Markus Rothhaar, for instance, those who hold the notion of “dying in dignity,” in support of euthanasia, regard pain and suffering as contradictory to human dignity. Freely choosing ones death even with the help of others is “the ultimate triumph of freedom and dignity over adverse circumstances of human existence.” Conversely, the Christian tradition construes human dignity in terms of
“inviolability of every human life including one’s own.”\textsuperscript{237} Moreover other ethicists such as Ruth Macklin consider human dignity as a useless concept apart from meaning respect for personal autonomy in terms of requirement for informed consent, voluntariness, confidentiality, and non-discrimination.\textsuperscript{238}

(iii) Interpretation of Human Rights

The 1966 agreement led to the merger of the two human rights treaties – the International Convention on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR).\textsuperscript{239} Yet even then, liberal states such as the United States focused on civil and political rights while countries founded on the notion of solidarity and government obligation to meet basic economic and social needs prioritized economic, social, and cultural rights.\textsuperscript{240} These two sources are relevant to the ethical discussion that theorizes the complementary nature of human rights and public health to advance human wellbeing.\textsuperscript{241} Though in recent times it has become agreeable that these aspects of human rights are indivisible and interrelated, this has not always been the understanding.\textsuperscript{242}

According to Gostin, ever since the language of human rights began to be used by civil libertarians to confront stigma and discrimination against persons living with HIV/AIDS,\textsuperscript{243} “most of the discussion of human rights has assumed that the field is devoted to individual rights and liberties.”\textsuperscript{244} Based on this view of human rights, advocates frame human rights as negative, stressing the right of individuals “to be free from government interference”; and, the government’s responsibility to “refrain from abuse and overreaching.”\textsuperscript{245} Civil libertarians tend to interpret human rights in terms of
individual possessions (rather than social habits) obligating the government to refrain from restricting the individual.

The language of civil and political human rights, because of its universality and emphasis on equality is attractive and accommodative of advocacy for freedoms against discrimination and stigmatization in HIV/AIDS intervention.\textsuperscript{246} Gostin explicates that while this view is correct, most scholars stress the equally important human rights tradition of economic, social, and cultural rights. This perspective projects human rights as positive and places “obligation on government to act for the common good.”\textsuperscript{247} Understanding this dual human rights traditions shades light on the tension between the emphasis on socio-cultural rights and the commitment to non-discrimination and non-stigmatization in HIV/AIDS prevention in Uganda.

Elucidating on Sue Henry’s work on human rights, Kieran Donoghue observed that beginning in the 1970s the global south challenged the Western attitude of relegating the economic, cultural and social human rights to a secondary character. The initiative culminated in the use of human rights language to explicate the concept of development, though originally the key Western countries were not supportive of the 1986 UN Declaration of the Rights to Development.\textsuperscript{248} In 2001, when the United Nations Secretary General, Kofi Annan, proposed a new global fund to fight AIDS, tuberculosis, and malaria, the wealth nations pledged $1.7bn in its first year.\textsuperscript{249}

The importance of promoting the economic, social and cultural human rights in HIV/AIDS intervention rose out of the realization that it was a moral responsibility for developed countries to aid poor nations as they combat the epidemic. Gavin Yamey and William Rankin framed this issue as economic imbalance and a matter of justice.
argued that the gap between the aggregate national income of wealthier nations and those of poor countries is disproportionate. They framed the moral obligation as:

Wealthier countries must take the lead in acting justly. The colonization of regions now struggling with the rising HIV rates, like India and Africa, left behind a legacy of exploitation and oppression and an ongoing power imbalance between rich and poor countries.  

Yamey and Rankin further warned of a danger whereby donor nations may want to advance their needs and not the needs of the poorest countries themselves. This intuition explains the multiple standards for the application of human rights in HIV/AIDS intervention in Uganda.

(iv) Standards of Moral Justification

In practical application, advocates seek the incorporation of human rights in public health policy based on three distinct sets of standards. These are: legal mechanism, conceptual frameworks, or, substantive ethical principles. The justification for using a legal mechanism to foster human rights strategies in public health initiative is the transformation of human rights into international law through the adoption, by nations, of the Universal Declaration of Human Rights (UDHR). Although the UDHR was adopted as a statement of aspiration, the legal obligation of governments derives from the various formal treaties signed by individual countries and incorporated into domestic law.

Several international and national monitoring bodies ensure compliance by governments that ratified human rights. These governments are obligated to report regularly to the monitoring bodies and demonstrate the level of engagement in respecting and protecting those rights. Most relevant to this dissertations are four of the seven
monitoring bodies listed by Gruskin and Bravenman: the Committee of the elimination of Forms of Racial Discrimination (of the International Covenant on Elimination of All Forms of Discrimination); Committee on Economic, Social, and Cultural Rights (of the International Covenant on Economic, Social, and Cultural Rights Treaty); Human Rights Committee (of the International Covenant on Civil and Political Rights Treaty); and, Committee of the Elimination of All Forms of Discrimination Against Women (of the International Convention of the Elimination of All Forms of Discrimination Against Women).\textsuperscript{255}

International treaties and their corresponding monitoring bodies are of invaluable relevancy to international law for purposes of legitimizing legal obligations. Subsequently, government representatives tend to draft human rights norms and standards in political forums and accord them less flexibility than in ethical frameworks.\textsuperscript{256} On the advocacy level, human rights advocates identify the utilization of a legal mechanism standard to ensure governments compliance with human rights obligations in public health intervention. This process targets the “jurisdictional transformation of human rights concerns in infectious disease laws.”\textsuperscript{257}

Japanese courts, for instance, used a legal mechanism framework based on universal human rights law to mandate the compensation of former leprosy patients. The patients were subjected to forced isolation (even when sulfone became available), sterilization, forced labor, and arbitrary punishment based on a 1931 lifetime confinement law. The law was repealed in 1996 and the confinement of the leprosy patients in the national leprosaria was found to be a violation of human rights.\textsuperscript{258} Sase and Gruskin interpreted the leprosy experience as setting precedent for the subsequent disease control laws in
Japan that oblige the state to respect the human rights of patients. In HIV prevention the laws relate to the abolishment of mandatory isolation, testing, and name reporting as respect to for human rights. The subsequent amendments to the existing laws have incorporated human rights concerns for appeal rights, shortened hospital stay, independent review, and, abolishment of ban on unemployment.259

In South Africa activists used the language of human rights, and with judicial intervention, to compel the government to ease restrictions on the use of nevirapine to prevent the transition of HIV from mother-to-child. The Constitution Court of South Africa ruled in 2002 that the government’s nevirapine policy violated the healthcare rights of women and newborn in the South African Constitution.260 The success in South Africa energized advocates to pursue the same legal strategies targeting the incorporation of non-discrimination laws in constitutions or by initiating judicial interventions in some countries. This approach most likely explains the resolve of gay or anti-gay advocacy targeting the reform of the Uganda’s anti-homosexual law.

A legal mechanism as a tool for enforcing human rights may be helpful but unnecessary since the validity and strength of human rights lies in its moral source and not its legal justification. There is a narrow legal positivism that assumes that human rights imply government recognition and protection by incorporation into constitutional rights.261 According to Jack Donnelly, this vision of human rights is inconsistent with the universality of human rights. While legal rights are “defined by their recognition in law,” human rights are recognized by the universality of their moral force.262 It is more important to foster genuine international collaboration and cooperation than seeking legal enforcement of human rights.
The second standard, as suggested by Grunskin and Braveman, is the use of conceptual framework formulations based on human rights principles to initiate analysis and advocacy for human rights in health policy. As argued by Angus Dawson, frameworks provide the most plausible tools for abridging the gap between theory and practice in public health ethics. However the complication here is that there is no unanimity in ethical discourses concerning the primary role of frameworks in public health ethics (or bioethics) application. Another complication is that in this work, Grunskin and Braveman do not clearly articulate those human rights principles that should constitute the conceptual frameworks formulations.

As observed by Mita Giacomini and colleagues, some formulations of ethical frameworks in health policy documents often fail to anchor specific ethical concerns around robust, coherent and meaningful substantive values of basic principles. Mita Giacomini and colleagues studied several frameworks in Canadian health policy and concluded that ethical frameworks can be incoherent and lacking secure foundational theory and methodologies essential for robust ethics discourse. These experts established that frameworks “vary substantially in justification, coherency, form, and content.”

In one vision, as suggested by Giacomini and Colleagues, an ethical framework must be anchored in “coherence between terminal values (goals), procedural values (process), and substantive values (criteria/principles).” The real strength of an ethical framework is underpinned by legitimacy, transparency, and clarity as can be evaluated from its genesis, content and purpose. But Mita Giacomini and colleagues argue that since frameworks are constructed on a foundation of conventional ethics, they must be
developed with attention to the role of tacit meaning and values underlying their ethical theories and arguments.  

In another vision, as advanced by Angus Dawson, frameworks generally ought to be pragmatic and focused on aiding day-to-day practical actions even if it means taking certain theoretical considerations for granted. Dawson understands a framework as a conceptual formulation (framing device) that makes relevant values explicit to guide or frame decision-making. In his view, “a conception of public health ought to be the foundation for public health ethics.” Subsequently, the starting point of public health ethics is the notion of public health as a special type of social activity focused on a set of aims, methods, actions, and outcomes. For instance the aims could be improving population welfare or reducing inequalities. Actions may involve legal intervention, education, and information.

Understood from this consequentialist perspective, human rights advocates may initiate the ethical discourse by focusing on any of the key element (intermediary maxim) of the principle of equity such as availability, accessibility, and quality. Yet, the underlying substantive value of the equity principle may be obscured when the frameworks lack consistence between terminal, substantive, and procedural values. In the frameworks studies by Giocomini and colleagues, even when a concept such as equity was shared among different frameworks, the interpretation was divergent. In some “equity” meant “access based on need”, in other “access based on ability to pay”, and yet other, “participation and equity of health.”

The third standard is the use of human rights principles to guide the design and implementation of public health policies and programs in a manner that ameliorates...
overall socio-political-cultural wellbeing of all people. The relevancy of the principles-based approach to linking human rights to global health was brought to light by Henk ten Have and colleagues in the United Nations Educational, Scientific and Cultural Organization (UNESCO). In the work *The UNESCO Universal Declaration on Bioethics and Human Rights: Background, Principles and Application*, these experts elucidated the UNESCO generated fundamental ethical principles that are universally adopted by many countries. These basic principles underpin the human rights framework and seek to strike a balance between the individualistic and communitarian moral perspectives.

According to these experts the context for applying these principles are notions (procedural values) such as professionalism, honesty, integrity and transparency. Substantive principles and procedural values provide the crucial foundation for defining, focusing, and deliberating on the context of any (human rights) framework. For, the strength of an ethic lies in the formulation that is robust in the moral justification, coherence, and context. The relevancy of the basic principles of human rights framework to this dissertation is that it provides an interpretive methodology that gives relevance to principles in the balancing of individual and group interests that in turn improves population health (epidemiological) and ameliorates human rights (social justice).

The *Universal Declaration on Bioethics and Human Rights* (UNESCO) addressed the general ethical tension between individual and universal rights, and between competing universal rights. Ten Have and Jean commend the innovative element of the declaration that struck balance between individualists and communitarian moral perspectives. For instance the declaration seeks balance between the principles of autonomy (Article 5) and solidarity (Article 13) in a manner that clearly articulates the underlying human dignity...
and freedoms. Article 27 of the UNESCO document is consistent with Article 29 of the Universal Declaration of Human Rights in the requirement that certain rights be restricted for purposes of protecting the community.

Permissibility of restrictions is limited to the purpose of securing important societal interests of public safety, protection of public health, and, the protection of the rights and freedoms of others. Laws made by states providing for these purposes must be consistent with international human rights laws. These provisions, for instance, are relevantly connected to the Uganda HIV/AIDS prevention policies. The case of Cellulose Sulfate microbicides studies highlights the need to balance between the principle of social responsibility and health (Article 14) towards women, and, the principle of human vulnerability and personal integrity (Article 8) of women. The case of the ABC approach and PEPFAR points to the need to anchor the principle of non-discrimination and non-stigmatization, within a framework that respects cultural diversity and pluralism without infringing upon human dignity, human rights, and fundamental freedoms.

One substantive principle however that is implied but not specifically enunciated in the UNESCO declaration, yet, clearly underlies all articles that stipulate the duties and responsibilities of individual and groups to uphold human dignity and wellbeing is the principle of the common good. More specifically, in case of a pandemic or epidemic, the principle of the common good underlies the goal of striving for a right balance between individualistic values, universal human values, and cultural differences, as stipulated in the UNESCO declaration article 27 and the UDHR article 29. As defined in the Catholic tradition, the “common good” is “the sum total of social conditions which allow people, either as groups or as individuals to reach their fulfillment more fully and more easily.”
The principles-based approach has a long held association to the tradition in Catholic social teaching regarding the dignity of the person, solidarity, and the common good. The notions of the dignity of the person and the common good are intimately interrelated. In this tradition, HIV/AIDS is primarily a justice and a rights issue rooted in social relationships that either enhance the spread or alleviate the epidemic.\(^{284}\) Economic exploitation and social disparities that generate poverty, racism, and gender discrimination undermine the rights and responsibilities of individuals and communities and impedes the containment of the AIDS crisis. The principle of the common good offers a framework of analysis rooted in social justice that serves the good of all.\(^{285}\)

The common good is a balancing principle between the individual’s invaluable values to self and the inherent social responsibility to others. The recognition of the dignity of the person is the condition upon which is rooted the respect of universal, inviolable, and inalienable rights of persons. This vision of equality of persons is the cornerstone upon which is based the exercise of greater solidarity for the promotion of structures and relationship that serve the wellbeing of all.\(^{286}\) The principle of solidarity follows necessarily from the principle of common good. As explained by Pope John Paul, “solidarity is the firm and persevering determination to work for the common good…for the good of all and for each person because we are all truly responsible for each other.”\(^{287}\)

Though the UNESCO declaration avoids the wording “common good” but article 13 lists solidarity as one of the basic principles underpinning human rights ends.

The UNESCO bioethics principles-based framework is gaining grounds in the practical application of human rights guidance of public health policy in epidemics and pandemics. This approach brings clarity to policy and human rights actions in population
health intervention because it utilizes the proven methodology of bioethics principles in individual medicine which address substantive issues, which in turn require interpretation of the scope and meaning of substantive principles.

The use of substantive principles-based framework as demonstrated by the UNESCO bioethics principles is suitably relevant for the practical application of human rights to HIV/AIDS intervention in Uganda. However even though the UNECSO bioethics principles provide for ethical robustness and coherence, the shortfall is the lack of succinct criteria for balancing principles that conflict. This dissertation proposes Mixed Interests Ethics Model as criteria to balance between conflicting principles. MIEM innovatively anchors the ethical discourse of conflicting interests between individuals and populations in a critical analysis of the substantive principle, procedural values, and, appropriate ethical standards to provide for effective management of epidemics.

The MIEM strategy provides a heuristic context for articulating the goals, objectives, and the moral justification in a manner that promotes cooperation and trust, and ameliorates human rights more effectively than other approaches such as solely legal positivism focused on coerced compliance and punishment. When for instance the substantive principles of common good and individual autonomy conflict as in the case of the cellulose sulfate microbicides clinical trial, clarity is established by a consideration of the scope and meaning of each of these substantive principles in the given context.

For instance the meaning and scope of the substantive principle of common good involves social relationships, interdependence, mutual concern, and responsibility. The specification of the substantive principle of autonomy involves informed consent, voluntariness, and privacy. The analytical interpretation of such conflicting principles
within this framework provides clarity as to which areas of decisions or actions increase or decrease conflict and consequently leads to effective population health intervention.289

D. Summary

This chapter explicates the broader question of rights as human rights, as raised in the HIV epidemic intervention, and not as the narrow perspective of individualistic rights discussed in the first chapter. The broader perspective of human rights requires the ethical discourse that focuses beyond the epidemiological and the libertarian models to addressing rights issues as discrimination and prejudice based on gender and sex-orientation. Improving the respect for human rights strengthens the individual’s claim for autonomy and freedoms, as well as society’s quest for the population goods of health and safety. But this vision requires the balancing of conflicting rights.

As demonstrated in this chapter, the diverse philosophical visions and the multiple interpretations of human rights principles, and, the application of competing human rights standards complicate the diminution of the conflict between individual and the population interests as well as between specific populations. The UNESCO bioethics-principles strategy innovatively derives a set of values such as honesty, professionalism, integrity, and transparency to provide the spirit that should guide the balancing between conflicting principles. This hermeneutical context enables MIEM to derive clear criteria for balancing between individual and population interests by negotiating between the substantive principles, procedural values and application of standards to effectively manage the HIV/AIDS pandemic.
3. Chapter Three

Mixed Interests Ethics Model (MIEM)

Introduction

Probably the most prominent ethical question in proposed public health interventions, as argued by Alan Cribb, is “how we ought to balance population health promotion with the interest and freedoms of individuals.” Connectedly, the international community is in the midst of a defining moment in the shaping of global bioethics and population health ethics. With the reemergence of highly virulent microbes resulting in the HIV/AIDS epidemic and a threat of influenza pandemic, a need has arisen to guarantee population health and safety in pandemics and epidemics, while also safeguarding individual and basic universal rights. Yet, there seems to be no overlapping consensus as to which criterion best balances conflicting interests between the individual and the population health.

The narrow focus of the traditional public health framework on the epidemiological goals of health and safety do not adequately address individual and human rights concerns. Likewise, libertarian overemphasis on autonomy and individual rights tend to conflict with population health interests. The social justice perspective that prioritizes human rights concerns in HIV/AIDS intervention does not appear to offer a definitive answer since disagreements prevail over the nature and source of human rights, as well as the application of diverse human rights standards.

One of the emerging trends in global bioethics and public health ethics formulation is to develop a cross-cultural, principles-based bioethics that is interpretive and analytical in
method. Explicating the UNESCO declaration on bioethics principles and human rights, Henk ten Have and Michele S. Jean state that:

It provides a framework of general principles that is open to various interpretations and applications in the context of human rights and fundamental freedoms, leaving many specific issues and controversies open for further debate.²

The principles approach accounts for variations of ethics norms within any culture, as well as plurality of values among faith groups, gender, race, and different classes of people.³

The methodology of engaged normative interpretation and analysis has been made popular, in contemporary times, through the principles-based approach in a systematic application of the four biomedical principles of autonomy, beneficence, non-maleficence, and justice to resolve actual bioethics problems. According to Tom Beauchamp and James Childress, the principles-based approach was meant to function as “an analytical framework that expresses the general values underlying rules in the common morality.”⁴

The introduction of the principles-based approach in population health ethics is connected to the new understanding that “public health ethics is a new sub-discipline within the broader field of bioethics.”⁵ Many ethics scholars agree that bioethics principles are essential, and have withstood criticism to provide ethical benchmarks for ethicists and clinicians.⁶ There are ethicists who envision global bioethics and public health ethics as justified, within the cross-cultural paradigm, based on basic moral principles that are universally accepted, such as those in the universal human rights declaration.⁷
Proponents of the principles trajectory in global health concur that the principles approach can help to overcome the conflicting interests that arise in the application of competing human rights claims. For instance, some ethicists suggest that the conflicting principles, such as autonomy and solidarity as applied in the context of pandemics, and epidemics can be balanced by adopting a spirit of professionalism, honesty, integrity, and transparency. This set of criteria is proposed for guidance in policy decision-making processes; ethics committees; assessment and management of risks; and transnational practices.

But the aforementioned criteria do not specify a succinct procedural standard to benchmark practical decision-making and policy development. To abridge this shortfall, this dissertation suggests Mixed Interest Ethics Model (MIEM) to balance between individual and population interests, and to effectively manage pandemics and epidemics. MIEM adopts the formulation of the principles-based approach as in the UNESCO bioethics document, and involves generally accepted and proven clear procedural standards, such as necessity, reasonableness, proportionality, and harm avoidance, to negotiate between conflicting principles.

A. Analytical Identification of the Epidemiological, Libertarian, and Social Justice Models

(i) Brief Overview of the Three Models

The strictest expression of individual interests synonymous with self-rule, is embodied in libertarian ethics. Libertarian approaches maintain that the individual is the basic unit of social analysis. According to David Boaz, libertarianism is characterized by
commitment to individualism, individual rights, spontaneous order, limited government, free markets, the rule of law, and natural harmony of interests. The autonomous individual is the source of moral authority, and common actions derive justification from permission or consent. Accordingly, moral obligation ensues from contracts or mutual agreements between rational persons.

Subsequently, the consideration of distributive justice consists not in patterned distributions based on merit, need, equality, or societal contribution, but “justice in holdings” consists in the transferring of resources based on principles of justice in acquisition and in transfer. In a free society, free market offers the neutral option among persons’ desires since “it reflects and transmits widely scattered information via prices, and coordinates persons’ activities.” Proponents of the free market, such as John C. Goodman and Gerald Musgrave, argue that the American health care crisis is solvable by resorting to a market system where individual patients, and not government bureaucracy, take actions in the individual’s interest. What is required is the creation of incentives, freedom of information, and choices in the healthcare insurance and hospital marketplace.

Libertarians favor procedural principles, as in deliberative democracy, since the approach allows for multitudinous opinions of individuals and ensures the realization of individual autonomy on a collective scale. However, differences occur regarding the best method of deliberation. Of notable relevance to this dissertation is the Modus Vivendi theory that frames deliberation as “open-ended, problem-centered dialogue.” Subsequently there is no justification for broad government intrusion in individual freedoms, privacy, and confidentiality. Libertarians favor limited government whose role
is to ensure the rule of law to protect civil liberties. For in the libertarian view, when civil liberties prevail, trust in government endeavors and effectiveness is enhanced. Liberty is understood as the absence of coercion, or any other form of forceful interference, from other agents.

Griffin Trotter made the most elaborate argument for a libertarian model (which he characterized in terms of pluralistic approach) in disaster population health intervention. He singled out government coercion as the most controversial aspect of public health intervention for its intrusion into the interests of the autonomous individual, and for its inadequacy to enhance trust and cooperation. To put the argument in perspective, Trotter identified three general rationales used to justify coercive measure in public health intervention. The most controversial, according to Trotter, is the use of coercion to prevent self-harm. The second entails use of measures such as quarantine and isolation with intent of preventing harm to other people. The third form of coercion involves the appropriation of private property, or conscription of health workers, for purposes of enhancing the health benefits of others.

The only basis for government imposition of coercive powers, according to Trotter, is procedural principles of public (democratic) deliberation and permission. The acceptable strategy is one that balances power and facilitates compromise, as with the open-ended, problem-centered dialogue characteristic of the modus vivendi theory. In mass casualty medicine, an effective policy package does not come by way of “neat formulations of substantive justice and other ethical principles,” but by compromises and mutual concessions worked out by parties with different perspectives. So Trotter recommends
that urgent ethical decisions during disasters should mostly “manifest values that have been approved in public deliberation.”

According to Trotter, the effectiveness of disaster intervention, such as in the pandemics, ensues from public facilitation of compromise, and not from rational consensus that embeds pre-fixed values regarding right, and the good, onto the discourse structure. The appropriate agency to manage deliberation, decision ratification, leadership, and enforcement, is a forum involving roles by appropriate individuals, communities, and organizations. A commitment to the *modus vivendi* means being “lax on rules of discourse, guarded about congeniality, and absolutely bereft of hope or aspirations for a morally robust political canon.”

Unlike the libertarian model that tends to be individual-centered, the focus of the epidemiological model is to understand and alter societal patterns of disease. The epidemiological model utilizes a population strategy that “seeks to control the determinants of (morbidity and mortality) incidents in the population as a whole.” According to Jonathan Mann, the standard epidemiological techniques traditionally sought by public health are the identification of risk factors associated with diseases, disability, and premature death. Subsequently, information, education, and clinical-based services were regarded as critical to changing individual behavior and improving the overall goal of prevention.

But changing, or mandating limits, to the behavior of individuals necessitates the deployment of intrusive government regulative powers. Support for coercive government measures increasingly gained momentum with the rise of the threat of bioterrorism, and the naturally occurring pandemics and epidemics, such as influenza pandemic and
HIV/AIDS. Population health policy makers deem it necessary to utilize government regulative powers and efficiency to limit individual freedoms so as to safeguard the good of population health and safety. To prevent infectious diseases from spreading in the population, public health practices of surveillance, screening, case reporting, contact tracing, mandatory treatment, isolation, and quarantine were included in the disaster preparedness plans.\textsuperscript{25}

The long held public health tradition in United States is to use both voluntary and mandatory measures to control communicable diseases. There are several cases such as “Typhoid Mary” that bring to light the moral complexity of these measures. Mary Mallon was involuntarily committed to a life of isolation on North Brother Island, in New York, for a total of 26 years, until her death in 1938, to prevent typhoid transmission.\textsuperscript{26}

In another case, during the influenza pandemic of 1918, referred to as the Spanish Flu, public health authorities imposed mandatory control measures that included quarantine, isolation, prohibition against public gathering, and ordinances against spitting, coughing, or sneezing in public.\textsuperscript{27} As recently as 2001, the initial \textit{Model State Emergency Health Power Act} (MSEHPA) designed for adoption by States in preparation for public health emergencies included coercive measures, such as mandatory isolation and quarantine, that impose restrictions on the freedom of the individual.\textsuperscript{28}

In HIV/AIDS intervention, the traditional public health strategy of mandatory screening, reporting, criminalizing, and warning those at risk began in the early 1980s.\textsuperscript{29} The specific populations targeted for these mandatory measures were pregnant women, infants at high risk, gay, and HIV positive people. The divide emerged between those who favored the government’s coercive measure to produce good health (epidemiological
model), and the civil libertarians who prioritized the values of privacy, confidentiality, and limiting government interference with individual choices.\(^{30}\)

Aside from the issue of Individual rights and freedoms, pandemics and epidemics tend to create critical inadequacies and acute shortages of community health resources, raising the problems of access and inequity. The use of government regulative powers to selectively deprive certain individuals of societal goods by allocation and prioritization strategies requires ethical justification. Having considered population health and safety as social goods, ethicists and epidemiologists have traditionally turned to the ethical tools of distributive justice to address issues of deprivation and inequity. Within the epidemiological model ethicists utilize ethical theories such as utilitarianism, libertarianism, contractarian, and communitarian for the justification of general principles governing the distribution of opportunities, wealth, and rights.\(^{31}\)

One version of individual liberty, based on John Stuart Mill, is founded on a commitment to the utilitarian doctrine of happiness as the ultimate end of man’s moral actions.\(^{32}\) Applying this utility principle, Stuart Mill argued that being in possession of a right imposes an obligation on society to defend the individual’s right. Securing the individual’s interests is a paramount need. Stuart Mill maintained that “to everyone’s feelings, the most vital of all interests.”\(^{33}\) But another utilitarian version prioritizes the collective societal net benefits. John Rawls explained that this version of utilitarianism describes society as “rightly ordered, and therefore just, when its major institutions are arranged so as to achieve the greatest net balance of satisfaction summed up over all the individuals belonging to it.”\(^{34}\)
Yet there has also been renewed consideration of Kantian deontology regarding the treatment of autonomous persons as ends-in-themselves, and not as means, and the consideration of the autonomy of the will as the supreme principle of morality. Following a Kantian exposition of the autonomous individual, Robert Nozick developed a vision of a free society where “diverse persons control different resources, and new holdings arise out of the voluntary exchange and actions of persons.”

Contractarian Rawls proceeds from an abstract notion of the original position to conceive the notion of justice as fairness. From justice as fairness one infers the principle of fair equality of opportunities. This egalitarian concept of justice requires that “all primary social goods be distributed equally unless an unequal distribution would be to everyone’s advantage.” In developing Rawls theory of justice as fairness, Norman Daniels and colleagues interpret the principle of equal opportunities as involving the promotion of “normal functioning for all” in health interventions.

Ideally an ethical theory is meant to be comprehensive and consisting of a definitive normative framework for resolving moral problems. But contemporary moral vision is characteristically pluralistic, and no single ethical theory can convincingly claim monopoly of a definitive source of moral value to adequately respond to all diverse moral dilemmas. Unconvinced about the ability of any foundational ethical theory to generate overlapping rational criterion to resolve ethical dilemmas in a pluralistic culture, Tom Beauchamp and James Childress advanced the “non-foundational” common morality to infer mid-level principles. Though, other proponents of the principles approach consider common morality as alternative foundational moral thought.
In the fifth edition of *Principles of Biomedical Ethics*, Beauchamp and Childress, commit to common morality as the ultimate source of moral norms. By common morality these experts mean “a set of norms that all morally serious persons share.”⁴² These are characterized as the most basic norms in moral life that bind all persons in all places.⁴³ Beauchamp and Childress draw the example of human rights as a category that “represents this universal core of morality in (recent) public discourse.”⁴⁴ Henk ten Have, a human rights proponent, explores the connection of common morality with interpretive bioethics whereof, “ethics proceeds from empirical knowledge, viz. moral experience.” In this sense, “moral experience is humanity’s way of understanding itself in moral terms,” and ethics infers the “interpretation and explanation of this primordial understanding.”⁴⁵

Henk ten Have finds Beauchamp and Childress argument interesting in so far as these scholars make a distinction between particular morality, which “express norms unique to particular cultures, groups, and individuals,” and universal norms which constitute “a set of commonly shared principles and norms related to the objective of morality (i.e. promoting human flourishing).”⁴⁶ Ten Have elucidates that:

Common morality is not simply a morality among many others; its principles represent at an abstract level the human experience that following them will ameliorate the human condition. Therefore more important than a consensus is a justification of principles (relating to the achievement of the objectives of morality). Whether or not there is universal agreement on some principles (which is a matter of empirical study), the question how principles of common morality can be justified, however, is crucial (which is a matter of normative analysis).⁴⁷
Since moral judgments are not directly deducible from common morality, “a continuous work of analysis, clarification, interpretation, specification, and balancing is required in order to make a moral judgment on a specific case or problem.” Subsequently, ethical principles are considered as providing “a fundamental standard of conduct from which many other standards and judgments draw support for their defense and standing.” Principles are considered to be methodologically heuristic, yet substantively robust, due to their basis in common morality that is universal and a historical.

Beauchamp and Childress adopted Rawls’ notion of reflective equilibrium to underpin the legitimacy and usefulness of the mid-level principles for reasoning through considered judgments to moral commitments. Rawls’ commitment to a Socratic approach led him to “the study of principles which govern actions shaped by self-examination.” Consequently, Rawls argues that our sense of justice requires a re-examination of our initially considered judgments upon our awareness of their regulative principles. There may be a likelihood that our initially considered judgments were subject to certain irregularities and distortions despite being rendered under favorable circumstances.

Accordingly, developing a system of ethics starts with broad considered judgments (what is right or wrong) and drawing out a provision set of principles that reflect those judgments. Ethical theory construction, or investigation, occurs in “a reflective testing of moral principles, theoretical postulates, and other relevant moral beliefs to render them as coherent as possible.” For Rawls, the best account of a person’s sense of justice is one that matches his judgment in reflective equilibrium, not one that fits judgment prior to
that exercise. In this sense Beauchamp and Childress construe the goal of reflective equilibrium as “to match, prune, and adjust considered judgments in order to render them coherent with the premise of our most general moral consideration.”

The principles approach has gained prominence in the social justice model, in so far as human rights are considered the surrogate, or bedrock, of social justice. The human rights paradigm is made practical by generating substantive ethical principles. When the UNESCO Universal Declaration on Bioethics and Human Rights (UDBHR) was composed, the primary aim was to provide “a universal framework of principles and procedures to guide States in the formulation of their legislation, policy or other instruments in the field of bioethics.” The goal was to aid all people worldwide so they would “benefit from the advances of science and technology within the framework of respect for human rights, fundamental freedoms and cultural diversity.”

The UDBHR introduced a set of substantive principles such as: respect for human dignity and human rights (article 3.1), benefit and harm (beneficence and non-maleficence, article 4), autonomy and responsibility (article 5), informed consent (article 6), protection of persons unable to consent (article 7), respect for vulnerable persons (article 7), privacy and confidentiality (article 8), equality, justice and equity (article 10), and non-discrimination and non-stigmatization (article 11).

The other principles are solidarity and cooperation (article 13), social responsibility and promotion of health (article 14), sharing and benefits (article 15), protection of future generations (article 16), protection of the environment, and the biosphere and bioethical issues (article 17). While some principles, such as autonomy, prioritize individual interests, others such as solidarity give primacy to societal good. When society is
threatened, for instance by a pandemic, the UDBHR document recommends a balance via the restriction of individual interests.\textsuperscript{60}

Rather than giving preeminent status to general norms of organized sets of beliefs, proponents of the principles approach view justification of moral thinking in terms of reflective equilibrium and coherence. For Beauchamp and Childress, the plausibility of the reflective approach is that it brings all conflicting interests into play, and aligns diverse moral commitments into coherence so as to test the results against other moral commitments.\textsuperscript{61} But as demonstrated in the aforementioned ABC and PEPFAR initiative, as well as the microbicides CS clinical trial discourse, not all advocacy initiatives in HIV/AIDS are committed to critical interpretation, analysis, and balancing of conflicting interests. In the microbicides CS clinical trial, benefit to society appeared to override concern for rigorous scientific study to ensure individual safety. From a moral philosophy perspective, the choice was in favor of the utilitarian societal net benefit over Kantian treatment of persons as ends-in-themselves.

One distinguishable form of incongruent interpretation and application of human rights is narrow legal positivism. This type of reductionism gives primacy to the legal enforcement of human rights over their moral strength.\textsuperscript{62} The possession of human rights implies legal rights, and legal enforcement, regardless of competing moral considerations.\textsuperscript{63} But as Jack Donnelly rightly argues, “the special function of human rights almost requires that human rights be unenforceable.”\textsuperscript{64} Human rights are distinctively self-liquidating such that rights-claims and enforcement comes into play when the enjoyment of human rights is threatened or denied. This explains why framing
HIV/AIDS prevention strategies in Uganda in terms of legal rights enforcement has not provided an effective human rights remedy.

The narrow legal positivism trajectory is evidenced in the trend of criminalizing sex-orientation behaviors in some countries as part of the HIV/AIDS prevention strategy. Reversely, western donor countries coerce countries such as Uganda into enacting laws to enforce the advancement and protection of the sexual preferences of specific demographic populations, such as those of homosexuals. Absent from this conflict is a consideration of procedural values of persuasion, negotiation, and a rational moral dialogue across cultural barriers. Consequently, human rights principles, such as autonomy and respect for the dignity of persons, do not mean anything other than mere compliance with legal rights and their enforcement.

Though contemporary legal positivists recognize the moral force of human rights, it is actually the legal recognition and enforcement that matters to them when it comes to the question of justification. The source of the legal model of human rights is traditionally linked to the framework of human rights as civil and political rights. Civil rights as a human rights category arises in “the conflict between the citizen and governmental tyranny.” According to Alan Rosenbaum, “these substantive rights are formal assurance for the individual citizen against arbitrary government treatment.” Subsequently, equality before the law and procedural due process provide the means for enforcing these rights.

In this view of human rights, the governance of human rights is by a system of rules, or principles that can potentially be translated into law. According to James Fawcett, “Here the focus of human rights is the elimination of arbitrary restraints on the
individual.” The natural freedoms of the individual “may be limited only in the interest of the public order in the wide sense, and by action of the community, to which he can be said to have consented.” The individual “rises sovereign over the limited province of the State,” since he is the “ultimate unit of all law” as regards the possession of these inherent rights.

When the yearning for a whole new global social cooperation emerged in the mid-twentieth century, the vision of civil liberties was inadequately suitable for the task of a collective goal of human flourishing. A complimentary paradigm was necessary to serve the social, economic, and cultural purpose. The U.N. General Assembly reaffirmed the interdependence and interconnectedness of the two Covenants: the civil and political rights, and, the economic, social and cultural rights. However, a summary distinction between the two Covenants characterized the civil and political rights as “legal” rights, and, the economic, social, and cultural rights as “program” rights.

Globally most human rights theorists now concur that human rights are indivisible in the sense that civil and political rights mutually reinforce the economic, social, and cultural rights and all derive from a single principle of fundamental human dignity. Yet that recognition alone has not bridged the divide since civil liberty advocates continue to prioritize legal rights and their enforcement, over social, cultural and economic considerations in the pursuance of a global civil society. That thought trend appears to be consistent with international policies that attach life-saving aid to the promotion and enforcement of civil liberties in developing countries.

The legal positivism model of human rights primarily entails emphasis on legal rights and government action (recognition and protection). As observed by Lawrence Gostin,
some human rights advocates have restricted the human rights discourse to the possession of individual rights and civil liberties. In this context government must refrain from abuse and overreaching. Respect for human rights means the individual’s right to be free from government interference. George Annas acknowledges that despite the fact that the United States adopted the International Covenant on Economic, Social, and Cultural Rights (ICESCR) not much progress (in the United States) has been made towards an integrative vision with the International Covenant on Civil and Political Rights (ICCPR).

Connected with narrow legal positivism, is another form of reductionism whereby the possession of human rights is reduced to merely beneficial obligations. Accordingly, utility is right, and what is right is a right. Jack Donnelly considers this approach as issuing from Jeremy Bentham’s simple beneficiary theory of rights. For Bentham, “being the intended beneficiary of an obligation is a necessary and sufficient condition for the possession of a right.” Donnelly objects to this characterization of rights and argues that rights are “entrenched in a system of justifications and thereby substantially transformed, given them priority, in ordinary circumstances over, for example, utilitarian calculations, mere interests, or considerations of social policy.” As Donnelly’s argues, “the simple beneficiary theory confuses what is right with having a right, and thus obscures the true nature of rights.”

But as liberal advocates increasingly concede to liberty-limiting principles such as the harm principle, offence principle, and legal paternalism; they are becoming “mindful of the need for a philosophical rethinking and clarification of the human rights conception.” Moreover, according to Alan Rosenbaum, the differentiation of human
rights into four distinct classifications, namely civil rights, political rights, social and economic rights, and cultural rights has become standard feature in global human rights perspective.\textsuperscript{86} For this reason, ethical tools such as substantive (human rights) ethical principles and procedural standards are suitable for purposes of negotiating between cross-cultural and interdependent aspects of human rights and population health.

(ii) A Combination of the Three Models

This dissertation suggests Mixed Interests Ethics Model (MIEM) as criterion to negotiate a balance between conflicting individual and population interests generated by libertarian, epidemiological, and, social justice models in pandemics and epidemics. The combination of these models needs to be made practical by addressing related principles and standards.

The principles address substantive issues; and standards address procedural issues to negotiate conflict between the principles. Hence, both substantive and procedural components are involved. These basic principles will vary from case to case. But this dissertation illustrates a major principle aligned with each model, such as: libertarian model and the principle of autonomy, epidemiological model and the principle of solidarity, social justice model and the principle of common good.

The interpretation of substantive ethical principles concerns two interrelated aspects. The first is a consideration of the meaning and range of scope of the substantive ethical principle, so as to determine what interpretation increases or reduces conflict. The second aspect is the determination of the strength of the principle, so as to identify considerations that yield to others in case of conflict.\textsuperscript{87} Negotiating balance between conflicting
principles, in concrete cases, necessitates the application of generally agreed upon standards of necessity, reasonableness, proportionality, and harm avoidance.

Because MIEM seeks to respect and promote rights (individual and human), the model functions within the general tension of individual and universal rights as explained by the UDBHR. Insofar as the UNESCO declaration places MIEM within the context of the general ethical tension between individual and universal rights, it provides a hermeneutical context for applying MIEM.

B. Substantive Ethical Principles Deriving from the Intervention Models

Beauchamp and LeRoy Walters define a principle as “a fundamental standard of conduct from which many other moral standards and judgments draw support for their defense and standing.”88 Substantive ethical principles imply robust and meaningful criteria, such as autonomy, justifying ethical decisions, and actions.89 It is in this sense that the four biomedical principles by Beauchamp and Childress have demonstrated moral worth and depth in clinical practice and research ethics. But ethicists have determined that in public health, moral consideration additional principles, such as the substantive principles of solidarity and common good, are of considerable significance.

(i) Autonomy

The substantive principle of individual autonomy implies sets of individual interests in self-governance (determination), liberty rights, informed consent (knowledge, comprehension, and voluntariness), freedoms of (decision-making and choice), confidentiality, and privacy.90 In medicinal practice, autonomy has traditionally been discussed in relation to paternalism.91 In research ethics, modern medical ethics codes
and international ethical guidelines are formulated with a goal of deterring hazardous research and the exploitation of individual human participants. The Nuremberg Code, the Helsinki Declarations, the CIOMS-WHO, and other subsequent ethical codes, underlined the need for voluntary consent and ethics review committees.92

The United States government, through multiple commissions, emphasized the ethical obligation to adhere to safety standards in medical research involving human subjects, and respect of the individual’s choices in medical practice.93 Most distinguishable is the Belmont Report that heralded the birth of bioethics following the forty years of the involuntary and inhumane Tuskegee Syphilis Study on black men in Alabama. The three ethical principles from the Belmont Report were developed into four biomedical principles by Beauchamp and Childress as autonomy, beneficence, non-maleficence, and justice. Of the four principles, critics point to autonomy as tending to override all other moral considerations in the United States biomedical discourse. However, Beauchamp and Childress disagree with this characterization.94

The practice of clinical medicine was historically paternalistic until modern developments, though the physician was obligated to protect and not to harm the individual patient. This foundational ethos of not harming the patient is coded in the Hippocratic Oath. The ethical shift in favor of individual self-determination was prompted in part by a renewed attentiveness to Kantian ethics and Stuart Mill’s exposition on the individuality of autonomous agents. Stuart Mill’s ethics rejects society’s paternalistic tendencies to control the individual’s preferences and behavior. According to Stuart Mill, the only justifiable limit to individual’s liberty and freedom is harm to others.95
Kantian moral philosophy provides that the autonomy of the will is the supreme principle of morality.\textsuperscript{96} For Immanuel Kant, “autonomous persons are ends in themselves, determine their own destiny, and are not to be treated as merely means to the ends of others.”\textsuperscript{97} The principle of autonomy, according to Kant, is: “Always so to choose that the same volition shall comprehend the maxims of our choice as a universal law.”\textsuperscript{98} Hence, the freedom of the will is autonomy, which in turn is understood as the property of the will to be law to itself.\textsuperscript{99} Consequently, actions are permitted in so far as they are consistent with autonomy of the will, “one that does not agree therewith is forbidden.”\textsuperscript{100}

In the United States’ legal system a connection was made, in the 20\textsuperscript{th} Century, between autonomy and the notion of the right to bodily integrity. As a legal doctrine, bodily integrity is the determination that “a person of adult years and sound mind has a right, in the exercise of control over his body, to determine whether or not to submit to lawful medical treatment.”\textsuperscript{101} Justice O’Connor explained that the right to bodily integrity is grounded in American common law, and firmly entrenched in American tort law.\textsuperscript{102} Courts have expounded that “the notion of bodily integrity has been embodied in the requirement that informed consent is generally required for medical treatment.”\textsuperscript{103}

As a legal doctrine with an ethical foundation, informed consent is based on the ethical value of individual autonomy. According to Beauchamp and Childress, “to respect an autonomous agent is at a minimum, to acknowledge that person’s right to hold views, to make choices, and take actions based on personal values and beliefs.”\textsuperscript{104} Fiduciary duty and informed consent obligates the physician to the disclosure of information that enables a competent person to weigh benefits and risks, and make an informed decision to submit to, or refuse, medical treatment.\textsuperscript{105}
In research ethics, as evidenced in both clinical medicine and public health, in order to be ethical, research must be conducted with the informed consent of the individual participant. Ezekiel Emanuel, and colleagues, detail a number of controversial unethical research studies since the 19th Century conducted without the voluntary authorization of the participants. For instance, as part of the yellow fever research in 1897 in Uruguay, Giuseppe Sanarelli injected five people with a harmful *bacillus incteroides* agent in an experiment to induce yellow fever. But the most deplorable violations of individual autonomy were the exploitive Nazi medical experiments that subjected vulnerable people to compulsory sterilization, euthanasia, and eugenics. The Nuremberg Code of 1947 established a requirement for voluntary consent in research practices.

Even after the enactment of the Nuremberg Code, principles of respect for persons and voluntary consent were not always adhered to in medical experiment protocols. In 1963, Chester Southam, with the collaboration of Dr. Emanuel Mandel, conducted a non-therapeutic immunological study of cancer cells in chronically elderly patients at the Jewish Chronic Disease Hospital in Brooklyn, New York. Twenty two debilitated patients were injected with live cultured cancer cells without soliciting for their informed consent. Though Dr. Southam believed that cultured cancer cells posed no risk to the subjects since they were eventually to be rejected by the immune system, his paternalism was incompatible with new developments requiring informed consent and patient’s decisional autonomy.

Probably no controversial public health research drew such intense public outrage over disregard for individual autonomy than the Tuskegee Syphilis Experimentation. For forty years, physician Taliaferro Clark, and colleagues, subjected 600 black men in a non-
therapeutic scientific study to document the effect of untreated syphilis in black males. The United States Public Health Service (USPHS) did not seek informed consent, and never informed the men that they had syphilis. The participants were instead told they were being treated for “bad blood.” To entice them to stay in the study, the men were promised the benefits of a certificate of appreciation: a dollar a year; hot meals and free transportation on days of examination; and burial stipends. According to James Jones, the USPHS engaged in deception “by withholding critical information about the nature of their (victims’) illness and the true purpose of study.”

The notion of disrespect for individual autonomy is not only linked to disregard for bodily integrity, but also a violation of the dignity of a person. The 1948 Universal Declaration of Human Rights (UDHR) affirmed the inherent dignity of persons as the basis for freedom, justice, and peace, and as a reason for non-discrimination, as well as a course for respect for cultural diversity. As Donald Evans explains, in the formulations of the articles of the UDBHR, autonomy provided a convergence point between the Nuremberg Code (bioethics) and the prominence of autonomy in the UDHR.

(ii) Solidarity

Whereas autonomy, as understood in the narrow sense in liberal individualism, is consistent with the pursuance of individual interests, the substantive principle of solidarity in population health is associated with responsibilities and obligations to collectively foster the well-being of humanity. Solidarity is “the desire to make common cause with those in need.” In the Report of the International Bioethics Committee of UNESCO (IBC) on Social Responsibility and Health, solidarity inferers membership in a group and a shared human destiny.
The principle of solidarity is formulated in the UDBHR, article 13, as a basis of advancing the principle of international co-operation. The notions of solidarity and co-operation are construed as issuing from fundamental individual freedom, as opposed to the interpretation of freedom as individualism. This freedom is considered as “personified in a concrete real individual, who is at the same time agent, (and) is displayed in its singularity and complementarily with the freedom of others.” In this context, it is a freedom that is consistent with the notion of solidarity among human beings “prior to articulating private interests.”

According to Howard Brody and Eric Avery, recent pandemic threats and bioterrorism have drawn attention to the principle of solidarity as an important ethical indicator towards the kinds of moral responsibilities and commitments physicians, and other members of society, owe to each other. These scholars interpret the physician’s duty to care as grounded in the concern of social solidarity. Since pandemics pose significant risks to physicians and health providers due to the inadequacy of scientific data regarding rates of transmission and mortality, the duty to care should be justified on the basis of the substantive principle of solidarity rather than on a rigid stance of the traditional *prima facie* physician duty to treat. As defined in the American Medical Association (AMA)’s 1847 code, the physician’s duty to treat “is the duty to face the danger (when pestilence prevails), and to continue their labors for the alleviation of the suffering, even at the jeopardy of their own lives.”

The 2001 *AMA Principle of Medical Ethics*, article VIII, stipulates that the physician’s responsibility to the patient is paramount. However, article VI of the code also strikes a compromise by requiring a delicate balance. In so far as it is within the
provision of appropriate care, Principle VI provides the physicians freedom to choose whom to serve, and the environment in which to provide medical care, with the exception of emergencies. Ethicists Rosamond Rhodes regards the AMA’s compromise, which limits the duty to treat, as an unnecessary softening of the assertion of professional ideals and commitments. For Rhodes, AMA Principle VI “takes back with one hand” what the statement of professional duty “appears to have given with the other.”

The principle of solidarity is an alternative way of thinking through the professional duty to treat, especially during pandemics and epidemic. Since the commitment to this obligation of rendering treatment in disaster emergencies varies according to proximity, capability, and level of need, so does the level of commitment vary. Accordingly, “the greater the need the greater the obligation to assist.” Moreover, the basis upon which physicians are expected to adhere to a professional acceptance of risks in pandemic disease is the relevant expert knowledge. Such knowledge may be absent in the initial stages of a pandemic disease, thereby rendering the physician’s acceptance of risks a matter of heroism rather than a professional moral mandate.

The Pandemic Influenza Working Group of the Joint Center for Bioethics – University of Toronto invoked the substantive principle of solidarity for purposes of addressing the health professions’ duty to treat. The Group further identified the procedural values of reasonableness, open and transparency, inclusivity, and accountability for balancing the competing values to formulate effective pandemic policy. In this sense, solidarity entails open and honest collaboration, communication, and cooperation between professionals and the community for the wellbeing of the vulnerable.
When the notion of the professionals’ duty to treat is grounded in the substantive principle of solidarity, the duty to care entails “solidarity (among staff) within the institution, between health professionals and the community, and the community as a whole, to the vulnerable members.”\textsuperscript{130} This interpretation accommodates the diverse obligations professional groups such as physicians, nurses, kitchen staff, housekeepers, and other service and support personnel, owe to vulnerable persons and the community during the pandemic outbreak.\textsuperscript{131} These commitments pertain to open and honest communication, and collaboration, in a spirit of common purpose, within and between health care institutions. Moreover, the spirit of solidarity requires the sharing of public health information, and the effective coordination of health care deliveries, as well as the deployment of human and material resources.\textsuperscript{132}

The notion of solidarity as “a communal responsibility to help others,” originates from “socialist and religious roots.”\textsuperscript{133} Specifically, the nineteenth century was characterized by a political philosophy that construed the notions of freedom and liberty by way of “a clash between (liberal) individualism and socialist collectivism.”\textsuperscript{134} In Marxist socialist moral thought, the collective classless humanism, born of socioeconomic interdependence, was the unit of moral discourse.\textsuperscript{135} The Marxist socialist tradition understood rights as social objectives which the state was obligated to secure, as well as social means, which the state must commit to providing in pursuance of the material ends.\textsuperscript{136}

For Marxist socialism freedom means liberation of the working class by the abolition of the exploitive capitalist system, sustained on (liberal) individualism, and replacing it with economic collectivism. In this regard, equality would mean social rights
of members to being guaranteed basic needs, and the contribution to collective goal of production. Collectivity implied not “merely an aggregate of social individuals but represented in its significance a social and economic interdependence with far-reaching implications.” Specifically, the individual members are understood as “creatures of social circumstances, acquiring social rights through community affiliation.”

The liberal position has roots in the Lockean views in which rights are alienated from the notion of shared responsibilities. Accordingly, “the person enters civil society with rights, but not bound by a fabric of social responsibilities.” Connectedly, in the liberal Kantian view of the 19th Century, freedom meant “the right to determine one’s own affairs (self determination).” In the new liberalism of Stuart Mill and Thomas Hill Green, emphasis is put on “both negative and positive freedoms in the context of capitalist society.” So, freedom is “freedom from interference in the exercise of one’s rights,” and, “the function of the state is to facilitate the individual exercise of his or her rights.”

In Catholic moral thought, the concept of solidarity found its clear articulation in Catholic social teaching. Pope John XXIII, in the encyclical *Mater et Magistra* (1961), taught that “both workers and employees should regulate their mutual relations in accordance with the principle of human solidarity and Christian brotherhood.” He characterized Marxist class warfare, and, “unrestricted competition in the liberal sense,” as contrary to the nature of man. Pope John XXIII’s teaching followed Pope Pius XI’s instruction in *Quadragesimo Anno* (1931) that: “ownership of property must avoid two extremes: individualism, denying or minimizing the social and public character of the
right to own property; and collectivism, rejecting or minimizing the private and individual character of the right to own property. \(^{145}\)

As defined by Pope John Paul II, in the Encyclical *Sollicitudo Rei Socialis* (1985), solidarity means “a firm and persevering determination to commit oneself to the common good; (meaning) the good of all and each because we are all really responsible for all.”\(^ {146} \) In this sense, solidarity in Catholic moral teaching is in conformity with justice and charity as the basis of social order. Justice and charity complement each other since, “charity cannot substitute for justice and justice alone cannot bring people together in social harmony.”\(^ {147} \)

The 1994 Synod of Bishops in Africa used the metaphor of “Church as family of God” to symbolize the self-understanding of the Church in Africa.\(^ {148} \) This model emphasizes solidarity in compliment with other notions, such as care for others, acceptance, dialogue, and trust.\(^ {149} \) The 2003 Symposium of Episcopal Conference of Africa and Madagascar (SECAM) invoked solidarity to forge collective actions towards the amelioration of the threat of HIV/AIDS on the African continent.\(^ {150} \) The SECAM Bishops elucidated that solidarity entailed a plan of action which involves making available the Church’s resources for health care education and social services, encouraging change of behavior, and personal and shared responsibility.\(^ {151} \)

The Bishops of Uganda called on all people to respond to the victims of HIV/AIDS, and their families, with special care, generosity, and courage. They viewed the initiative to alleviate HIV/AIDS as a call for solidarity, interior purification, and personal salvation.\(^ {152} \) Solidarity with victims of HIV/AIDS is not about feelings only, but engagement in a variety of ministries to aid the victims. Michel Kamanzi calls this
For personal identity in sub-Saharan Africa occurs in the context of family interdependence where the “we’ comes before the “I.” If family is synonymous with marriage relationships in the African context, some rights advocates in global HIV coalitions argue that such relationships diminish the decisional autonomy of vulnerable persons in HIV/AIDS prevention. For these critics, marriage relationships, in so called poor countries, subordinates women rights, and provides no pathway to gender equality, or effective prevention of HIV/AIDS. For instance, the development of microbicides has been identified as one way of enhancing women’s decisional autonomy and gender equality. Accordingly, the development of user-controlled tools “must expand dramatically and quickly.” However, in the absence of concerted efforts to harmonize autonomous claims with the principle of solidarity as sustained in interfamily relationships, scientific endeavors alone have not resolved the vulnerability problem, as demonstrated in the failure of the candidate microbicides CS clinical trial.

(iii) Common Good

The common good implies “the sum of those conditions of social life which allow social groups and their individual members, relatively thorough and ready access to their own fulfillment.” According to Benedict Ashley and Kevin D. Rourke, the common good is the signature fundamental demand of social justice. For the common good entails love, mercy, and communities of mutual concern and responsibilities. The foundational basis for the common good in Catholic social teaching is the intrinsic value and dignity of persons created in God’s image.
As observed by Lisa S. Cahill, the encyclical tradition appeals to the notions of basic equality and dignity of each and every person so as to strike a balance between individualism and social responsibilities. For Cahill, this vision provides the cornerstone of social justice in HIV/AIDS crisis, for the individual is construed in terms of having “inviolable value in himself or herself, while strongly affirming the inherently social nature of the person.”

In the Encyclical *Pacem in Terris* (1963), Pope John XXIII affirms the rights and duties of each person that are universal, inviolable, and inalienable. This acceptance further leads to the recognition of an imperative to provide the individual person with the necessary social services.

Common good also requires a commitment to the principles of subsidiarity. The notion of subsidiarity implies the sharing of decision-making power at all various (vertical) level of local, state, and national (Federal), as well as among other (horizontal) sectors representing other functions. Pope John XXIII expounded that the principle of subsidiarity “governs the relationship between public authority and individuals, families and intermediate societies.”

Communitarian theorists, such as Michael Walzer, and Dan Beauchamp, attach great importance to the principle of common good, particularly for the safeguard of the communal needs of health and safety. In this sense common good means interests held in common by the people (or the public). Beauchamp draws this definition from the interpretation of the US Constitutional tradition whereof common good refers to “the welfare of individuals considered as a group, the public or the people generally, the body politic or the commonwealth ...” Common good is then the basis for the regulatory police powers that subordinate individual liberty interests to “protect compelling
community interests.”166 Subsequently, public health and safety are community or group interests, and not simply aggregates of each individual’s interests in health and safety.167

C. Procedural Standards of Necessity, Reasonableness, Proportionality and Harm Avoidance

(i) Specification of Substantive Principles

The Rev. David Jacobson controversy arose because he was unconvinced of Massachusetts’ public health authorities’ arguments for imposing compulsory vaccination to protect population health and safety against smallpox. All that mattered to Rev. Jacobson was whether there were safeguards in place to protect his liberty interests. He regarded the compulsory vaccination law as an invasion of his right to self determination.168 He argued that “the execution of such a law against one who objects to vaccination ... is nothing short of an assault upon his person.”169

The tension between the promotion of individual interests, such as of Rev. Jacobson’s liberty claims and the population interests prioritized by the public health initiatives, cannot be resolved by appealing to solely foundational ethical theories, such as libertarianism or utilitarianism. The most effective pathway is to seek balance between conflicting principles that accrue from a commitment to these foundational ethical theories.

The balancing of conflicting principles, for instance, involves the interpretation and specification of individual autonomy issuing form libertarian approaches and common good resulting from a commitment to population welfare. When it is established that a commitment to individual autonomy prioritizes privacy and confidentiality, while a
commitment to common good prioritizes collaboration and communication, there is a
need to explore the scope and meaning attached to these notions for purposes of
determining aspects that increase or decrease conflict.\textsuperscript{170}

In the 2005 PA’s IPRP draft, the Pennsylvania Department of Health justified
invoking the police powers of the state to prevent and suppress pandemic disease (for the
common good) as a constitutional mandate.\textsuperscript{171} Following this reasoning, the Pennsylvania
State’s 2005 pandemic influenza draft guideline provided for the imposition of restrictive
control measure, in certain circumstances, such as mandatory reporting of contact
persons, isolation, quarantine, and civil confinement.\textsuperscript{172} Those measures restrict the
individual’s freedom of assembly, consent, and privacy. In the context of conflicting
principles such as these, the importance of interpretation, and specifying the meaning of
competing substantive principles, cannot be underestimated.

Let us, for instance, take Hans Haugen’s specification and interpretation of the
concept of reduced autonomy as increased vulnerability. The understanding that
“autonomy can defer considerably between individuals” means that “those with reduced
autonomy have the highest vulnerability.”\textsuperscript{173} The implication regarding public health
coercive policy, in the event of the influenza pandemic, is that these decisions impact
people at different levels of vulnerability. According to Hans Haugen, vulnerability is
“person-specific, condition-specific and situation-specific.”\textsuperscript{174} Therefore, interpreting
vulnerability is useful for purposes of understanding and demonstrating insufficient
autonomy.\textsuperscript{175}

In the absence of concerted effort to minimize individual vulnerability, the use of
coercive measures is incompatible with the goal of promoting the common good. The
justification for overriding legitimate interests of the individual should be by way of a substantive (good reasons) and procedural process. Even then, the Supreme Court in the United States has provided guidance with three levels of scrutiny in constitutional law to assess the importance of the individual interests at stake.\textsuperscript{176} The categories are strict scrutiny (most rigorous), intermediate scrutiny, and the minimum rationality (least rigorous). A strict scrutiny applies when coercive laws classify by categories such as gender, race, or national origin. Of importance here is the need to prevent the advancement of public health statutes that are reflective of prejudice and antipathy.

The process of negotiating balance between individual and population interests does not only require the understanding and interpretation of competing substantive principles, but also benchmarks, such as procedural standards of necessity, reasonable, proportionality, and harm avoidance. An example of the application of these standards is the \textit{Jacobson v. Massachusetts} (1905) case that defended the population health interests, while imposing constitutional limitation on public health authority.\textsuperscript{177} Other sources, such as the Toronto Joint Center for Bioethics, included these standards in their listing of substantive and procedural values.\textsuperscript{178}

(ii) Application of the Procedural Standards

The procedural standard of public health necessity, reasonableness, proportionality, and harm avoidance are suitable tools for negotiating balance between the conflicting substantive principles. When utilized, either on their individual merit or complimenting each other, these procedural standards provide benchmarks for the process of interpretation and balancing of conflicting principles.
Public health necessity infers that the use of coercive and mandatory restrictive public health measures can only be justified, in limited application, when essential to protect the health and safety of the public. Even in this case, moral considerations require the least infringement reasonably adequate for the control, and containment, of the contagious disease.\(^{179}\) If a general moral consideration is to be infringed upon, there should be a strong reason for not adopting alternative strategies that are less invasive.\(^{180}\) Reasoning must be evidence-based on plausible, and consistent, credible scientific data, as well as political, and ethical considerations.

Necessity here implies “the necessity of the case.” In his critique of the original 2003 MSEHPA, George Annas invoked the necessity argument questioning what problem the proposed mandatory laws of isolation, quarantine and confinement sought to resolve given that “proposed laws should respond to real problem.”\(^{181}\) Annas argues that the authors of the proposed coercive laws assumed that physicians and citizens are not likely to cooperate with public health authorities when bioterrorism attack occurs. Moreover, the effectiveness of these coercive measures is assumed for all forms of public health emergencies involving bioterrorism and pandemics. Annas’ point is that “trade-offs between civil rights and public health measures are (case specific), not always required and can be counterproductive.”\(^{182}\) For Annas, better planning, coordination and cooperation is more helpful than targeting the restriction of civil liberties.\(^{183}\)

In Uganda, the ABC-PEPFAR program attracted foreign and domestic proponents of competing principles (individual autonomy and common good) bent on introducing unnecessary measures. The enactment of laws that punish gay activities for the purpose of preventing HIV/AIDS is not a necessary public health measure since there are other
effective means such as education, collaboration and coordination. Likewise, the imposition of punitive measures such as withholding foreign-aid to cause Uganda to prioritize gay interests, are unnecessary measures for purposes of HIV/AIDS prevention.

The procedural standard of reasonableness refers to “reasonable means.” Negatively, measures are unreasonable if they do not diminish the public health emergency threat. Probably the most recent example of unreasonable means is the 2001 nevirapine case in South Africa. The South Africa government restricted the use of nevirapine for the prevention of mother-to-child HIV transmission though the manufacturers were willing to avail it for free, given a high annual mother-to-child HIV infection rate of approximately 70,000 infants.\textsuperscript{184} The government’s 2001 policy that limited access to nevirapine to two study sites in each province prevented physicians elsewhere from prescribe a medically indicted HIV preventive drug.\textsuperscript{185}

In 2001, the High Court of South Africa ruled that government’s restriction of nevirapine to a limited number of pilot sites was “not reasonable and is an unjustifiable barrier to the realization of the right to health care.”\textsuperscript{186} The court ruling was in accord with the South African (post-apartheid) constitution which states that “The State must take reasonable legislative and other measures, within its available resources, to achieve the progressive realization of each of these rights (access to health care, water, food, and social assistance).”\textsuperscript{187}

In poor countries, such as Uganda, where in 2010 as many as 540,000 people were eligible for antiretroviral therapy but only 240,000 received treatment, donor funding makes a difference. Thankfully, the United States’ PEPFAR program contributed to about 70 per cent of the HIV programs in Uganda.\textsuperscript{188} Without donor funding many
people with HIV/AIDS would remain untreated. For this reason, the anti-funding campaigns that seek to restrict donor funding, so essential for the alleviation of HIV/AIDS suffering in Uganda, is an unreasonable population health strategy.¹⁸⁹

The procedural standard of proportionality is a balancing ethical tool that renders a public health measure permissible if the benefit outweigh the infringed interest.¹⁹⁰ Public health measures that impose excessive burdens, yet offer comparatively little benefit, ought to be avoided. Mandatory measures ought to be by the least restrictive means necessary to manage the public health danger. The Toronto Joint Center for Bioethics pandemic working group referred to proportionality as a requirement that “restrictions to individual liberty and measures taken to protect the public from harm should not exceed what is not necessary to address the actual level of risk to or critical need of the community.”¹⁹¹

In research ethics, an intervention is proportionate when sufficient evidence has been adduced that the study is consistent with sound scientific design, and the potential for clinical benefit, or social value outweighs the risk to participants. The Nuremberg code disallows research whereby there are prior reasons to believe that “death or disabling injury will occur.”¹⁹² But regarding minimal risks, Institution Review Boards (IRB) are generally tasked with the responsibility of ensuring that “research interventions do not pose excessive net risks” to participants.¹⁹³

Research regulating bodies generally rely on two types of standards for assessing risk benefit standards. One standard categorizes research as therapeutic or non-therapeutic. The second standard uses the direct benefit standard. In the case of therapeutic interventions, only those interventions that satisfy clinical equipoise are permitted. For
non-therapeutic research (even of no interest to the participant), net-risk (reasonable risks) is justified on the basis of social values to be gained.\textsuperscript{194}

Research regulating bodies that rely on the direct benefit standard, rather than the therapeutic/non-therapeutic standard, mandate additional safeguards in research that do not offer a sufficient prospect of direct benefit to participants.\textsuperscript{195} For instance, the U.S. federal regulations that govern human-subject research, “Common Rule” require that the IRB not only ensures fair subject selection and informed consent, but also that risks to subjects “are minimized,” and “are reasonable in relation to anticipated benefits.”\textsuperscript{196}

The United States Public Health Services (USPHS), for instance, requires additional protection for children participants in research that offers no prospect for direct benefit to them, yet could yield generalizable knowledge regarding the subject’s condition. The additional safeguards include the requirement that IRB’s establish that “the risk represents a minor increase over minimal risk,” and the adequate provisions for seeking children assent and parent permission.\textsuperscript{197}

According to Alex London, if an “IRB finds that the risks associated with a particular study are not reasonable then it is unethical even to offer participation to potential subjects.”\textsuperscript{198} Risks are considered to be reasonable “when they are offset or outweighed by the anticipated benefits of the research.”\textsuperscript{199} The two types of benefits considered important enough to justify tradeoff are potential benefits to the individual participant, and potential benefits for other individuals, or the community.\textsuperscript{200} However, in the absence of clear criteria for determining the specification and the value of knowledge that override individual participant’s interests, critics have pointed out the danger of arbitrariness.\textsuperscript{201}
London’s proposed criterion for establishing reasonable risks to individual participants is:

…. the least amount of intrusion into the interests of participants that is necessary in order to facilitate sound scientific inquiry and … are consistent with an equal regard for the basis interests of study participants and the members of the larger community whose interests that research is intended to serve.\(^{202}\)

This consideration addresses the need for scientific rigor, and justification for subjecting participants to only what is necessary for sound scientific inquiry. Moreover, the motivation for securing best interests of others (research endeavor), versus the best interests of the individual, is determined with the same moral concern.\(^{203}\)

London provided helpful guidance towards what counts as a reasonable balance between the interests of individual research participants, and interests in potential future science benefits. He proposes “conceptual and operational clarity,” in addition to “an appropriate balance of relevant moral concerns,” and, “theoretical unit in scope of applicability.”\(^{204}\) Conceptual clarity entails clearly defining what is meant by reasonable risk, and a normative justification of the definition. In addition, there is a need for delineating the boundaries that separate reasonable from excessive risks, and set practical benchmarks to assess favorable outcomes.\(^{205}\)

The procedural standard of harm avoidance implies that public health providers should seek the least infringement. The goal of the proposed intervention should be the promotion of wellbeing, and not the overburdening of individuals. The control measures “should not pose an undue health risk to its subjects.”\(^{206}\) The CS microbicide trial case is an example of a public health research initiative that caused undue harm to the
participants. The non-therapeutic Phase III clinical trial exposed HIV sero-negative women to a high risk of HIV sero-positive conversion. Though the research was justified on the basis of its potential social values, there were questions regarding scientific rigor and whether the risks to participants were reasonable.

Ezekiel Emanuel and Christine Grady identified a trend by research activists, beginning in the 1980s, of asserting “an autonomous right to try risky but potentially beneficial treatments” – a right that they claimed should trump regulatory protectionism and paternalism. Starting particularly with HIV experimental interventions, the model of “protectionism” was categorized as an injustice that should be replaced with ensuring (the right to) individual access. The harmful outcome of the candidate CS microbicide trial underlines the dangers of absolute rights claims against protected, experimental scientific endeavors. The development justifies a need for a new approach that harmonizes the rights and safety interests of individuals with society interests, by way of negotiating between the underlying substantive and procedural principles.

D. MIEM and The UNESCO Universal Declaration on Bioethics and Human Rights

(i) Human Rights Advocacy and Reductionism

The concept of human rights derives from the inherent and inviolable dignity of a person. Human rights are considered to be equal and inalienable rights of all human beings. In this context, a human right is defined as “a principle of justification with respect to what is due each person and which each person must dutifully respect in others, in virtue of being a human being.” But, as commented on by Alan Rosenbaum, the determination of the meaning of a human rights concept hinges on the security of the
foundation (moral or otherwise) on which it is developed. Consequently, in global human rights discourse, the interpretation of the concept of human rights, particularly from the philosophical and political perspectives, “is not univocal.”

There is convergence in international human rights philosophical discourse on the justification of the universal relevance of human rights based on the inviolability of the dignity of a person. But the common misnomer is assuming that “human rights are synonymous with natural rights, individual rights, social rights, or community rights.” This confusion happens because of the interconnectedness of the philosophical features of human rights with political considerations. Even though these terms are products of the evolutionary history of human rights philosophy, and politics, they are component rights-categories conforming to “different facets of the human rights idea.”

Human rights are “rights held on the basis of one’s nature as a human being.” From a philosophical perspective John Locke’s natural rights theory was vital to the evolution of the human rights concept. But Locke was influenced by the natural law tradition which has roots in Thomas Aquinas. Though Thomas Aquinas did not specifically develop a concept of human rights, his explication of the natural law ethics in *Summa Theologiae, I-II qq. 90-7*, inspired future development of the foundations of moral and legal rights.

Having defined law as “an ordinance of reason, for the common good, made by him who has care of the community and promulgated,” Thomas Aquinas went on to distinguish between natural law, eternal law, human or positive law, and divine law. Accordingly, natural law is “the participation of the eternal law in the rational creature.” But human reason can only grasp certain general principles of the perfect divine reason, thereby restricting natural law to general precepts. This requires
supplementation by human laws, which “are particular specifications of the general precepts of natural law.” This distinction is important because Thomas Aquinas considers an act to be right “because it is in accord with the requirements of human nature, not because it is reducible to a divine command.”

The transition from the understanding of natural law as “merely a natural set of objective norm,” to natural law as “protective of subjective interests and rights of individual interests,” occurred in Locke’s rationalism. Unlike Thomas Hobbes, for whom the state of nature prior to any form of government was ungoverned by moral law, Locke claimed that in the state of nature, “the individual possesses by nature, the right to life, liberty and property.” This law of nature, according to Locke, is given by God. These natural rights, however, “must be exercised within the substantive moral limits set by natural law.” In the state of nature, the natural (human) rights are morally inviolable, but enforceable only in a civil society that is obligated to protect those rights through the social contract.

The European Enlightenment through the 1700s was characterized by dominance of natural rights theory that underscored the individual’s autonomy of reason and morality. The French and the American revolutions gave prominence to the idea of “equality before the law.” Fuelled by the “Age of reason,” the European philosophy had a single mission of “the liberation of the individual from absolute authority and of human reason from dogma.” This development is more explicitly demonstrated in Kantian moral thought, following in the tradition of the Enlightenment rationalism of philosophers such as Hugo Grotius and Locke.
For Kant, the moral worth of an action lies not on the effects expected (utilitarian) or pragmatic consideration, but *a prior* in the virtuous will of a rational individual.\textsuperscript{226} If the principle that rational nature exists as an end in itself holds true for the individual, then it applies universally to all rational beings. This principle has implications for our responsibility to others, as a duty, to treat them as ends in themselves, and not as means to an end. Kant thereby regards autonomy (self-determination) as “the basis of the dignity of human and of every rational nature.”\textsuperscript{227}

Stuart Mill’s liberal formulation of individualism has had strong influence on the civil and political components of the evolution of human rights theory.\textsuperscript{228} For Stuart Mill, if liberty means anything, the individual is absolute in pursuit of his own interests, such as freedom of thought and feelings, opinion, speech, and assembly. Moreover, “each (individual) is the proper guardian of his health, whether bodily or mental and spiritual.”\textsuperscript{229}

Stuart Mill argued that in the era of expansive political communities and the separation of spiritual and temporal authority, there was no justification for society’s encroachment on the power of the individual.\textsuperscript{230} The limits of the sovereignty of the individual over himself, and to which society is justified to impose its jurisdiction, is conduct that prejudicially affects the interests of others. Society’s disinterested, benevolent actions to promote the well-being of one another are encouraged, if they are by means of conviction and persuasion, and aimed at promoting self-regarding virtues.\textsuperscript{231}

Nineteenth century socialism introduced an aspect of collectivism which conflicted with liberal individualism in the natural rights discourse. Karl Marx characterized the natural rights idea as “the ideological expression of bourgeois egoism and social
antagonism.”232 Accordingly, the declaration of the universal rights of man by modern states established an instrument of partiality in favor of the bourgeois rights.233 Equal rights here meant rights of inequality, since “the equality consists in the fact that measurement is made with an equal standard, labor,” for unequal individuals.234

Thus Marx rejected the abstract individualism of human rights because he perceived those rights as based on antagonistic relationships. The proletarian socialist revolution would establish egalitarian relationships and remove the need for human rights. But before that accomplishment, the abolishment of human rights would not serve a good purpose since society will revert to a worse stage of despotism.235

According to Jack Donnelly, the post-Marx socialist critique of the Western interpretation of human rights focused on the Western emphasis on civil and political rights, and how those rights are practiced regarding the relationship between rights and duties.236 The argument is against severing the two human rights sets of ICCPR and the ICESCR. Some critics in Asian and developing countries lambast the sole use of Western standards of liberalism and democracy to determine human rights performance in those countries. The approach is seen as advancing a reductionist overemphasis of legal rights, and narrow benefits that ignores the socio-cultural aspects of human rights. Moreover, developing countries are mischaracterized as too pre-occupied with survival and development issues to afford individual rights.237

In the 1990s, as observed by Kieran Donaghue, humanitarian international organizations such as Medecins San Frontier, and developmental international organizations such as Oxfam, began to explore and incorporate rights-based approaches to development. Likewise, international human rights organizations, such as Amnesty
International and Human Rights Watch, became attentive to the importance of reconciling civil and political rights with social, economic and cultural rights.\textsuperscript{238} The shift came as a response to the HIV/AIDS epidemic when consensus begun to emerge that health and human rights conditions are interrelated.

Since their founding and before the global HIV epidemics, international human rights organizations, such as Amnesty International and the United States-based Human Rights Watch, advocated for civil and political rights of vulnerable people, particularly in less developed countries; though, the ICCPR was ratified only in 1992 by the United States.\textsuperscript{239} Of concern were the right to liberty, and freedoms of: movement, association, expression and religion. The sister treaty ICESCR was largely ignored by conventional human rights movements for its perceived disregard for private property. Since economic rights were suspect, the prevailing advocacy methodology and strategies were deemed as not suitable for pursuance of economic goals.\textsuperscript{240}

As evidenced in the ABC and PEPFAR tension, the harmonization of the political and civil categories with the social, economic, and cultural components of human rights is still an elusive goal. Much of the tension in Uganda’s HIV/AIDS prevention strategy, as prioritized by Western advocates, hinges on emphasis on the political perspective of human rights as civil and political rights.\textsuperscript{241} This development is consistent with Alan Rosenbaum’s explication that some political theorists think of human rights in a political sense, independent from other considerations. Others consider human rights as “broader than its political signification.”\textsuperscript{242} Still other political theorists “generally consider the political perspective on human rights as derivative from, but as important as, one or more of the other foundational principles.”\textsuperscript{243}
Right from their founding, organizations, such as Human Rights Watch, used a confrontational approach of “investigate, expose and shame” that targeted mostly governments in developing countries to pressure them into compliance with, and promotion of, civil and political rights.\textsuperscript{244} The approach was in some cases effectively used to secure the rights of vulnerable persons in oppressive regimes. When HIV/AIDS became a global menace, human rights advocates reversely used the shaming strategy on pharmaceutical companies, and the United States government, to secure funds and drugs for HIV prevention and treatment in resource-challenged countries.\textsuperscript{245}

For instance, the Global Access Project (HealthGAP) compelled President Clinton’s administration to support the production of low-cost, generic alternative drugs for HIV treatment in poor countries. This was done by exposing the administration’s role in “protecting U.S. pharmaceutical companies from actions by foreign governments to obtain access to low-cost generic alternatives for treating HIV/AIDS.”\textsuperscript{246} One of the in-your-face confrontation scenes, as pointed out by Holly Burkhalter, was the taunting at Vice President Gore’s campaign events with “flinging blood-drenched pills, waving signs, and chanting.”\textsuperscript{247}

In the global multi-cultural community, particularly poor countries that lack health resources and infrastructure, a solely narrow strategy of generating outrage and shaming do not guarantee the goals of equality and adequate access to HIV treatment. Starting in the 1990s, health and human rights advocates made a strategic shift by making a compelling argument to developed countries to share resources for the provision of needed care for those afflicted with HIV/AIDS in poor resource countries.\textsuperscript{248} Gavin Yamey and Rankin argued that wealthy countries must act justly, to address the economic
imbalance in poor countries devastated with HIV, by providing the money needed to fight the epidemic. These measures involve scaling up antiretroviral drugs, vaccine research, empowerment of women, and the care of the AIDS orphaned children.$^{249}$

The United Nations, in 2001, established a Global Fund to Fight AIDS, Tuberculosis, and Malaria. Other international organizations, such as the World Health Organization, followed suit by scaling up antiretroviral treatment. It had occurred that by 1998 an estimated 33 million people worldwide had HIV infection or AIDS. Out of the estimated new 5.8 million HIV infections that occurred worldwide in 1998, more than 95 percent were in developing countries.$^{250}$ In 2003 President George W. Bush launched the PEPFAR initiative with a goal of expanding treatment to more people in the most HIV affected countries in Africa.$^{251}$

Despite the out-pouring of global solidarity by some donors, skeptics questioned whether all donor partners were prepared to respond to local needs of the people, rather than their own interest.$^{252}$ As it turned out, the ABC-PEPFAR program in Uganda was subjected to meticulous scrutiny by advocates of competing human rights perspectives to assess its commitment to interests such as condoms, sex orientation, and abstinence only programs.$^{253}$

Though human rights advocates rightly emphasized government responsibility to protest and promote the greater realization of human rights, some at times misrepresented human rights. As Jack Donnelly points out, “violations of human rights are denials of one’s humanity rather than deprivation of one’s needs.”$^{254}$ The focus by civil liberties advocates, in the case of Uganda HIV prevention strategy, was often on the need for
condoms supply, or legal enforcement to protect or suppress homosexuality trumping other considerations.

One of the cultural perspectives in the fights against HIV/AIDS is the role of the marriage institution. Jonathan Cohen and Tony Tate rightly addressed the issue of violation of women’s human rights in the HIV/AIDS epidemic in Uganda, but, again they viewed the civil liberties (rights) perspective of human rights as irreconcilable with the cultural perspectives of marriage. These critics argued against the focus on the institution of marriage in Uganda as protective of HIV.\textsuperscript{255} Cohen and Tate claimed that:

Indeed, the suggestion that marriage provides a safeguard against HIV may amount to death for women and girls. Uganda women face a high risk of HIV in marriage as a result of polygamy and infidelity among their husbands, combined with human rights abuse such as domestic violence, marital rape, and wife inheritance.\textsuperscript{256}

There is no justification for downplaying marital infidelity and sexual violence against women in Uganda. But, to appear to suggest that HIV infection among Ugandan women results from endemic violent and sexual proclivities of Ugandan men is depictive of a cultural bias. In fact, if most sex encounters were coerced, the HIV prevalence rate would be much higher than 6.2 percent in a population of thirty three million. The claim only served to confirm that stereotyping about Africa sexuality is still prevalent in the thought processes of some Western human rights advocates as they confront HIV/AIDS prevention strategies, in communitarian-oriented, sub-Saharan African countries.\textsuperscript{257}

The trend by some Western human rights advocates was to approach the HIV/AIDS prevention campaign in Uganda by avoiding complex moral discourse regarding the
interplay between health, human rights, and socio-cultural issues, and instead focus narrowly on condoms availability, abstinence only, or gay and anti-gay tension. Such focus has given rise to human rights reductionism. When human rights advocates turn to pursuing policies that prioritize partial, narrow benefits, or legal positivism, they abscond from the responsibility of promoting collective human flourishing.

Reductionism proceeds by the “replacement or explanation of one phenomenon by another reality of a different nature, one supposedly simpler or more fundamental.” ²⁵⁸ Richard Jones further elucidates that:

This process (reductionism) may be a direct substitution of realities or the specification of the real causes at work in the phenomenon. In either case, our picture of what is actually real in a phenomenon has to change: the “whole” is no more than the sum of its “parts,” and, indeed the ultimate “parts” alone are real. ²⁵⁹

To further explore the meaning of reductionism, let us for instance take the claim that individual autonomy is unrelated to the notion of human dignity. Dignity, then, is declared “a useless concept,” which “means no more than respect for persons or their autonomy.” ²⁶⁰ Ruth Macklin, for instance, claims that “appeals to dignity are either vague restatement of other, more precise, notions or mere slogans that add nothing to an understanding of the topic.” ²⁶¹ Accordingly, dignity is not real for the ethical analysis of medical practice or research since, there are no criteria for establishing when dignity has been violated.²⁶² For reductionists, what is reducible to something else is not fully real.

For Macklin, the use of the notion “human dignity” in religious sources, and as applied in the language of the UDHR and other European Council documents, inadequately suffice for its application and relevance in medical treatment and
research. It appears that, for Macklin, what is real should be analyzable. Subsequently, there is no criterion for analyzing human dignity in medical ethics. What is real, for Macklin, is autonomy, or respect for the persons, because these notions involve “the need to obtain voluntary, informed consent; the requirement for confidentiality; and the need to avoid discrimination and abusive practices.”

Reductionism is also evidenced in the definition of human rights as “gay rights are human rights and human rights are gay rights.” No doubt discrimination based on sexual orientation is against the dignity of persons, and subsequently a violation of human rights, but to claim that human rights and gay rights are essentially indistinguishable is to make the whole no more than the parts. The inviolability of human rights is justified on the basis of the inherent dignity of each and every person (the whole), but not on whether one is gay or heterosexual (the parts).

Let us consider another example of the claim that participation in clinical research is a right. This view is compatible with Jeremy Bentham’s utilitarian reductionism. As commented on by Jack Donnelly, Bentham argued that “rights are merely beneficial obligations.” Accordingly, “being the intended beneficiary of an obligation is a necessary and sufficient condition for the possession of a right.” Rights are thus established, or granted, by “imposing obligations or by abstaining from imposing them.”

Legal positivism commits to a form of reductionism that acknowledges no point of intersection between law and morals. The separation thesis, as proposed by Hart, implies the severing of legal orders from moral values. As Carl Schmitt, and colleagues, argues that American legal positivists “sever moral substance from form.” This is because, they see the separation thesis as having a moral payoff – “it enables the individual
citizen to decide on the merits of the law free from the constraints of an ideology which holds that law is legitimate.”²⁷⁰ Moreover, as they suggest, “the separation thesis facilitates conscientious judgment by the good liberal citizen.”²⁷¹

Legal positivism as reductionism appears to apply to the form of human rights advocacy that prioritizes the legal system over moral foundations in HIV prevention strategies in Uganda.²⁷² In this case, laws are prioritized over the moral force of empathy and altruism in HIV/AIDS prevention strategies. So the individual citizen is “free” to decide on the best course to take in HIV/AIDS prevention and treatment on the merit of the laws, rather than on moral values.

According to Richard Jones, the term “reductionism” was introduced in the mid-20th century. However, the reductionism versus anti-reductionism controversy has roots in Greek philosophical thought and in 19th century scientific revolution.²⁷³ Greek thought was more speculative in approach and focused on “what is the ultimate nature of things (the issues of substantive reductionism).”²⁷⁴ In Newtonian physics, the application of Euclidean geometry focuses more on “how things interact and what kind of parts they were composed of (the issue of structural reductionism).”²⁷⁵ This development resulted in a fundamental distinction between the speculative and experience, as well as appearance and reality.

Richard Jones further elucidates that modern philosophical thought involves issues of structural, theoretical, and methodological reductionism. This shift was motivated by interests in “analysis of phenomenon and more empirical (rather than a priori) approaches to theorizing.”²⁷⁶ In science, Charles Darwin and Alfred Wallace advanced the biological theory of natural selection, leading to the later evolutionary idea of random mutation.
within genetic material. Subsequently, reductionist controversy in science revolves around “reductive versus holistic explanations and methods in biology and the social sciences.”

Reductionism has emerged as an issue requiring attention as human rights and global health engage the global multi-cultural communities over universality and plurality, the primary and the secondary, holism, and fundamental parts. Given the plurality of cultures, and the diversity of moral vision, the most effective pathway to balancing individual and population interests in pandemic and epidemics is the use of bioethics principles approach, as suggested by UNESCO’s Universal Declaration on Bioethics and Human Rights document.

As HIV/AIDS became a global epidemic in the 1980s, and as a global coalition emerged, the harsh reality of inequalities related to economic, social, and physical infrastructures, were exposed. The goal of promoting global health was hampered by “poverty and lack of access to healthcare services.” The 1997 WHO Fourth International Conference on Health Promotion, held in Jakarta, recommended a global initiative to promote social responsibilities for health. Later WHO Conferences in 2001 and 2005 underlined the importance of clarity about responsibilities and rights, and recommended that governments make the amelioration of poor health and inequality a policy priority.

When the UDBHR was formulated in 2005, the principle of social responsibility and health was included. A consensus emerged that: “… for the improvement of global health conditions, bioethics should address at the same time the moral values that actually guide the behavior of individuals and communities and the moral values and priorities that
should guide public health on these values." A link was made in global health between inequalities, cultural and moral diversity, and the promotion of wellbeing.

Article 12 of the UDBHR acknowledged and addressed the reality of diversity and plurality of cultures. The notion of respect for cultural diversity was understood, as reaffirmed in the Universal Declaration on Cultural Diversity (UDCD) adopted in 2001. The preamble stipulated that:

… culture should be regarded as a set of distinctive spiritual, material, intellectual and emotional features of society or a social group and that it encompasses … lifestyles, way of living together, value systems, traditions and beliefs. However, though there is interdependence between cultural diversity and human rights, the universality of human rights guarantees that cultural expressions do not infringe on human dignity, for all human beings are born free and equal in dignity and rights.

Bioethics principles, as set out in the UDBHR, are considered in the context of complementariness and interrelatedness. These principles are a result of linkages between science and politics, intercultural views, and diverse religious traditions. The bioethics principles stipulated in the document represent a global perspective because they have been adopted by governments committed to their implementation. The heuristic nature of these general principles provides a framework for various interpretations, and applications, of commonly shared moral experience, in the context of human rights. The UDBHR bioethics approach seeks a balance between individualistic and communitarian moral perspectives by anchoring the principles in human dignity and fundamental freedoms.
(ii) MIEM as Balancing Criterion

Recent population health initiative towards containing threats to global health have given rise to advocacy for developing policies that promote health while providing safeguards to individual and universal rights. Article 27 and article 22 of the UDBHR require limiting conflicting principles to provide for balance between individualistic and communitarian interests, in situations such as pandemics and epidemics. This dissertation provides Mixed Interests Ethics Model (MIEM) as a criterion to balance individual and population interests when principles conflict.

The MIEM criterion draws substantive principles as provided in the UDBHR to negotiate a balance between individual and population interests in pandemics and epidemics. Mandatory vaccination, for instance, may be regarded as infringing on the individual’s autonomy interests while the measure may be considered by others in terms of solidarity for the safeguard of population health interests. Balancing autonomy and solidarity requires the specification of these conflicting principles to establish their scope, meaning, and areas of possible harmonization.

The interpretation of substantive ethical principles concern: a consideration of the meaning and range of scope so as to determine what interpretation increases or reduces conflict; and the strength of the principle so as to determine considerations that yields to others, in case of conflict. For instance, the meaning and range of the scope of the substantive principle of autonomy involves consent, voluntariness, and privacy. The meaning and scope of the substantive principle of solidarity involve equity, collaboration, communication, and coordination. Common good involves social relationships, interdependence, mutual concern, and responsibility.
For instance, the first major work the International Bioethics Committee (IBC) of UNESCO undertook after the adoption of the UDBHR was an elaborate interpretation, and specification, of the principle of informed consent, as derived from autonomy and stipulated in articles 6 and 7 of the declaration. In the narrow sense informed consent is understood as the voluntary, autonomous authorization by a person to a medical professional to initiate, or not to initiate, to proceed or not to proceed, with the proposed medical or research plan. In the broader sense, informed consent is closely connected with the principle of autonomy and dignity. Autonomy implies respect for the person’s rights to hold views, and make choices based on those beliefs.

The essential features of informed consent are adequate disclosure of information, decisional capacity, comprehension (knowledge), voluntariness, and consent of the person. The condition of being informed requires that a person is given clear information concerning, for instance, diagnosis, prognosis, the nature and process of the procedure or treatment, possible risks and benefits of recommended intervention, benefits and burdens of reasonable alternative intervention, and, anticipated outcome in terms of benefits and risks.

Comprehension requires competence, which implies the ability to communicate choices, understand relevant information, and manipulate information rationally. Information needs to be communicated in ways a person can understand, regardless of barriers. Voluntariness means being free from external coercion, or moral manipulation, over and above the limitations arising from circumstances. As for persons without decisional capacity, article 7 of the UDBHR requires the protection and promotion of their best interests, as in accordance with domestic law.
Courts in the United States established that incompetent persons have the same right of self-determination as competent individuals, since the value of human dignity applies to both competent and incompetent. A surrogate acts on behalf of an incompetent individual to exercise the right to refuse medical interventions. The *In re Conroy* (1985) case set the “subjective” (substituted judgment) standards and the “best interests” standards for determining the exercise of those rights. The substituted judgment applies when there is clear evidence that the incompetent person would have exercised it, and the best interest standards is when such judgment is lacking. All these measures are put in place to protect and enhance individual, autonomous decision-making.

But as pointed out by the UNESCO’s IBC, public health control and prevention measures, such as those in the influenza pandemic could interfere with the right of self-determination of the individual. For the protection of public health, or for the protection of the rights and freedoms of others, for instance, article 27 justifies a balance by the imposition of some limitations to the competing principles set in the UDBHR. Challenging ethical issues, as considered by World Health Organization, may involve measures, such as quarantine, and mandatory immunization that restricts individual freedoms. But, as recommended, laws that limit principles ought to be consistent with human rights laws, in respect to the fundamental freedoms and dignity of the human person.

According to Ten Have, the need for balance was underlined in the early stages of UNESCO’s IBC discussions in 2004, when it was emphasized that “it was necessary to strike a balance between the principles of autonomy (emphasizing individual decision-making) and the place accorded to family and solidarity among human beings by
particular religious and cultural traditions.\textsuperscript{302} In later discussions a distinction was made between “fundamental principles” (that cannot be derogated), derived principles (justified by one or more fundamental principles), and, procedural principles (setting frameworks or rules to follow).\textsuperscript{303} The claim of this dissertation regarding substantive and procedural principles is consistent with the IBC’s elucidation of fundamental, derived, and procedural principles.

For instance, in the influenza pandemic crisis the State of Pennsylvania included in its 2005 draft plan a mandate, in some circumstances, of the temporal isolation of influenza stricken persons or quarantine contacts.\textsuperscript{304} Those measures restrict peoples’ freedoms and liberties. In health care practice individual liberty is enshrined in the substantive ethical principle of autonomy. The scope of the meaning of autonomy is diverse, and includes notions such as self-governance, liberty rights, individual choice, consent and privacy.\textsuperscript{305} But, in the epidemiological model, the foundational principle of public health rests in the obligation to protect the health and safety of the population.\textsuperscript{306} This approach generates principles such as solidarity. The meaning of solidarity encompasses collaboration in the spirit of common purpose, openness, honesty, cooperation, and coordination.

Following the interpretation of the meaning and scope of moral determination of these substantive principles, the balancing of individual and population interests further entails negotiating between, for instance, self-governance and collaboration. This stage of negotiating between self-governance and collaboration requires the utilization of procedural standards, such as necessity, reasonableness, proportionality, and harm avoidance. Applying the procedural standards provides benchmarks, and enables the process of determining which considerations yield to others in case of conflict.\textsuperscript{307} The
importance of articulating these procedural standards to serve as benchmarks is that they put into perspective the requirements for the values of professionalism, integrity, and transparency as in article 18 of the UDBHR.308

Let us consider for instance the balancing between autonomous decision-making and community solidarity by engaging the procedural standard of necessity to effect mandatory examination, and testing, of suspected influenza infected persons. As provided in the MSEHPA, article VI, section 602 (b), and the PA’s draft IPRP, government coercive powers, or criminalization, may be applied on non-compliant individuals.309 But, such coercive measure may be unnecessary if specifications, such as information, cooperation, and coordination as in the principles of autonomy and solidarity, are harmonized to strike a balance between individual and population health interests. Restrictive measures are considered necessary if they are the least infringements essential for the protection of the health and safety of the population.

To determine actions that are of least infringement, values such as information, collaboration, and communication, as specified from principles such as informed consent and solidarity, must be adequately (in the circumstances) considered. George Annas makes a compelling argument that we live in an era of vast scientific advancement, professionalism, and better health facilities, which make coercive measures distasteful.310 The new tools of social media, including web-based and mobile technologies, have enabled easy communication and interactive dialogue. Means are at hand today to quickly disseminate information regarding available scientific data, and environmental and social determinants of pandemic diseases.
The use of ethics committees, for instance, at all levels to enhance cooperation, collaboration and communication is a more plausible approach than coercive laws compelling institutions, such as hospitals, to provide mandatory examination, and treatment, of suspected influenza pandemic persons. With the understanding that coercive laws have limited application, ethics committees play vital roles in the analysis and establishment of decisions and actions considered to be necessary, reasonable, and proportionate in the circumstances to contain the pandemic.

Ethics committees provide an appropriate forum for utilizing a principles-based framework to negotiate between conflicting values. As clarified in article 19 of the UDBHR, ethics committees are characterized by their independence, multidisciplinary nature, and plurality. Ethics committees are relevant for all categories of population health decision-making, be it for individuals, groups, committee, or institutions and corporations. The cogency of ethics committees lies in the multidisciplinary, and analytical assessment, of the relevant ethical, legal, scientific, and related social issues. Ethics committees then need to be diversely composed to include representation for individual liberty interests, health-providers obligations, and community representation to promote the population safety and health interests.

E. Summary

This chapter suggests Mixed Interests Ethics Model (MIEM) as overlapping criteria for resolving conflict between ethical principles generated by the epidemiological, libertarian, and social justice models, so as to attain an ethical balance between competing individual and population interests in pandemics and epidemics intervention.
These ethical models are made practical by generating substantive principles, and procedural standards which facilitate negotiation of balance between conflicting principles.

The UDBHR provides a hermeneutical context for applying MIEM. For, the UDBHR seeks to ameliorate individual and universal rights by anchoring the conflict between the individual and populations interests in a bioethics principles’ framework that is heuristic. By interpretation and specification of the substantive principles, MIEM innovatively applies the generally accepted sets of procedural standards of necessity, reasonableness, proportionality, and harm avoidance to balance between conflicting interests.
4. Chapter Four

The Importance of MIEM for Policy Development in the Influenza Pandemic Intervention

Introduction

Ever since the threat of bioterrorism and the possibility of a future outbreak of influenza pandemic became a global problem, bioethicists and population health agents have generated numerous literatures of ethical methodological approaches for the effective management of influenza pandemics. Some suggestions tend to give primacy to the individual-centered approaches, such as promoted in libertarianism, while other approaches prioritize ethical considerations that promote societal interests, such as utilitarianism, egalitarianism, and communitarians.

The principles approach that has been successfully deployed in clinical medicine to protect individual interests has gained acceptance as an effective variable for negotiating balance between individual and population interests. But no overwhelming consensus has emerged as to whether the principles-based approach has convincingly demonstrated sufficient critical and analytical ethical tools to override other ethical methodologies in the management of population health disasters, such as influenza pandemic.

Chapter Four of this dissertation makes the case for the principles-based Mixed Interests Ethics Model (MIEM) as robust enough to provide ethical tools that can be successfully deployed to effectively manage the influenza pandemic. The MIEM provides for argumentative rigor to exhaust, and underpin, the meaning and justification
underlying the competing substantive principles that generate conflict between individual and population interests.

A. MIEM and the Illustrative Principles of Autonomy and Solidarity

(i) Influenza Pandemic Occurrence

Influenza virus is categorized as types A, B, and C. Influenza B virus is hosted, and causes disease, in humans but does not result in pandemics. Influenza A virus is hosted by several species such as birds, pigs, horses, dogs, and humans. Of major concern to public health authority is Influenza A virus that is responsible for causing previous major outbreaks among humans, beginning with the HINI pandemic (Spanish flu) of 1918, H2N2 pandemic of 1957, H3N3 pandemic of 1968, H5N1 (avian flu) human infection since 1997, and the reemergence of H1N1 (swine flu) of 2009.

Categories of Influenza A virus vary according to subtypes that occur due to changes in proteins hemagglutinin (HA) and neuraminidinase (NA) on the surface of influenza A virus, and how the protein combine. Influenza viruses evade human immune response by utilizing “two mechanisms referred to as antigenic drift and antigenic shift.” Antigens are “the physical markings that the immune system feels and reads and then binds to.” HA and NA are the main antigens of the influenza virus that project out on its surface. For instance, antibodies bearing receptors on their surface function in a manner that recognizes and binds on a virus bearing the antigen. Sometimes, however, the HA and NA can evade the immune system by rapid mutation to change into different forms that can only be recognized by the immune system with some difficulty. This phenomenon is called antigen drift, and can create epidemics.
More worrisome is the antigen shift whereby the immune system cannot recognize antigens at all. This phenomenon is a replacement of the old with entirely new gene coding for HA, or for NA, or for both by which “the shape of the new antigen bears no resemblance to the old one.” This situation creates a pandemic that occurs “if a large proportion of the population lacks immunity to the novel HA and NA and if the virus has the ability to spread efficiently from person to person.” Moreover, “influenza viruses replicate extremely rapidly in the host” complicating health professionals’ efforts to effectively contain the subsequent high morbidity and mortality.

According to scientists, viruses generally appear in spherical form with two types of protuberances: the HA has a spikes-like shape while the NA has the appearance of a tree. So, in the event that the influenza virus collides with a cell, HA “brushes against the molecules of sialic acid that juts out from the surface of the cell in the respiratory tract.” The viral HA protein binds onto the cell surface’s sialic acid receptors in a process called adsorption. Once the virion manages to penetrate the cell membrane in a vesicle by endocytosis and fusion, the shape and form shifts, making it unrecognizable by the immune system. In a complementary function, the viral NA protein cleaves the sialic acid receptors remaining on the cell surface (membrane) disabling “the acid’s ability to bind to the influenza viruses.” Consequentially, new viruses can now freely escape from inside the destroyed cell, after it bursts, and invade new health cells.

John Barry elucidated that, “the virus is nothing more than a membrane … that contains the genome, the eight genes that define what a virus is.” Unlike bacteria that consist of one cell with metabolism, and produces by division, viruses are less than a fully living organism whose only function is to replicate by invading cells, subvert them,
and thrive on. The virulence of a virus lies in the ability to invade a cell and then, “insert is own gene in the cells genome, and the viral genes seize control from the cell’s own genes.”

Scientists explain that antibodies against the HA offer protection from infection, while antibodies against the NA may reduce the spread of the virus, but are unable to prevent infection. One effective strategy of managing human infection of influenza virus is vaccination. But there are often, and will probably always be, inadequate stockpiles of vaccines and antiviral drugs in the event of influenza pandemic outbreak. Scientists have to identify the specific influenza strain, and prepare the appropriate vaccine, which usually takes a period of at least four to six months. The challenge to vaccine development is “the ability of the virus to drift and evade immune detection.” Moreover, Kanta Subbarao and colleagues state that there is “paucity of HA conserved epitopes that include cross-reactive neutralized or protective antibodies.”

Influenza viruses attack the respiratory tract causing victims of influenza pandemics to suffer nose mucosal membranes swelling, pharynx, inflamed throat, cough, fever, headache, body aches, exhaustion, and may develop complications such as viral pneumonia and acute respiratory distress. These complications require antiviral treatment, and mechanical ventilation treatment, that will be in limited supply at the time of a pandemic. The shortages create ethical dilemmas for public health decision-makers regarding the denial of medically effective care to some who need it. Subsequently, consideration of rationing, prioritization, and triage become necessary, but highly contentious.
Most controversial, however, is the question of individual liberties and freedoms. Traditionally, public health officials have used measures, such as isolation of sick persons, quarantine of contact persons, and involuntary treatment, to manage morbidity and mortality in the influenza pandemics. Yet, these measures entail problematic ethical issues regarding the legitimacy of government’s compulsory public health interventions, and related issues of ethical justification. The most outspoken critiques of the proposed influenza pandemics plans, and other disaster intervention plans, are libertarian and liberal cosmopolitan thinkers who question the justification for public health authority powers to limit individual liberties and freedoms.19

Historically there are good reasons why the public, and the health providers, are concerned with balancing individual and population interests in the influenza pandemic outbreak. For instance, the anguish caused to the human population by the H1N1 influenza virus (Spanish flu) of 1918 is well chronicled in John Barry’s book, *The Great Influenza: The Story of the Deadliest Pandemic in History.*20 The so called Spanish flu was estimated to have killed between twenty million to fifty million people worldwide. It overwhelmed health facilities, health care resources, professional capabilities, and disrupted individual freedoms, such as of assembly, as it decimated population health and safety.21

In the city of Philadelphia, distress began to unfold barely seventy-two hours after two hundred thousand people gathered for the Philadelphia Liberty Loan Drive. The patriotic crowd was more concerned with funding the war than heeding warning of a public health danger. The influenza pandemic struck the city soon after the parade. One hundred and seventeen people died on the third day after the parade. On the eighth day,
two hundred and fifty four people died, while on the ninth day two hundred and eighty nine people died of the influenza pandemic.\textsuperscript{22}

According to Barry, the city’s thirty-one hospitals ran out of beds, and health professionals resorted to turning away influenza pandemic stricken victims, even with attempted offers of one hundred dollars bribes to nurses.\textsuperscript{23} Public health officials banned all public meetings, including public funerals. Infrastructures such as schools, churches, theaters, and courts were all closed. Arrests were made of anyone who spit in public. Soon there were no more available caskets, morgues, and undertakers in the city, as bodies stacked up and others were left in homes where the influenza pandemic victims died.\textsuperscript{24}

Horrors, such as those discharged by the 1918 Spanish flu onto the human population, have caused governments globally to invest considerable resources in preparation for a possible future influenza pandemic outbreak. The scare of the 1997 H5N1 avian influenza outbreak, and its reemergence in 2003, convinced the World Health Organization (WHO) of the need for governments worldwide to have influenza pandemic preparedness plans. Scientists became concerned that if the H5N1 influenza virus mutated and developed the ability to be transmitted from person to person, a highly pathogenic influenza A (H5N1) pandemic may occur.\textsuperscript{25}

In 1997 the world community began to engage the H5N1 avian influenza outbreak when several humans in Hong Kong became infected after exposure to infected birds.\textsuperscript{26} Six of the eighteen patients admitted to hospitals with confirmed avian influenza A (H5N1) died. The avian influenza A (H5N1) recurred in 2003 causing an outbreak of human cases, most of them fatal, in Vietnam and Thailand. Within that same period, bird
populations in Asia were dying of an epidemic of avian influenza A (H5N1). At its peak in 2006, there were four thousand outbreaks in sixty three countries. Just when epidemiologists thought the virus was eliminated in most of those countries, the United Nations expressed fear that a mutant avian influenza strain was resurging in Asian countries in 2011.

Since 2004, WHO feared the worst, and warned of a possible pandemic outbreak of a highly virulent influenza A (H5N1) pandemic, should human-to-human infection begin to occur. Working closely with the WHO, the United States federal government embarked on monitoring, planning, and preparing for a possible global influenza pandemic outbreak. Both on the federal and state levels, the strategies for preparedness and response activities were categorized according to periods of pandemic influenza surveillance, emergency response, community disease control and prevention, travel management, distribution of vaccines and antiviral, clinical guidelines, public health communication, and workforce support.

Ethicists worldwide began to collaborate with public health officials to forge an ethical pathway towards the effective management of pandemics, and other disaster occurrences such as bioterrorism. Since then, ethical frameworks suggested for the guidance of informed policy development have tended to address three interrelated areas of concern: respect for individual liberties and freedoms, restricting individual freedoms to advance population health and safety, and fair distribution of limited health resources. The 2001 draft Model State Emergency Health Powers Act (MSEHPA) issued by the Center for Disease Control (CDC) as a model for states’ pandemic preparedness, stirred a
debate over the legitimacy and justification of coercive public health powers that subordinate individual interests.\textsuperscript{32}

Mixed Interests Ethics Model (MIEM), as suggested by this dissertation, strikes a balance between a relentless commitment to individualism, and the subjugation of the individual in collectivism. Anchoring policy development in substantive ethics principles provides a way for negotiating between competing ethical theories, such as libertarianism, utilitarianism, and Kantian deontology. This strategy involves the specification of the substantive ethical principles, delineation of areas that ameliorate the tension, and articulating procedural standards to effectively manage of pandemics and epidemics.

The hermeneutical context for the application of MIEM is provided by UNESCO’s international normative standards, based on bioethics principles enumerated in the UDBHR. The UNESCO framework also sets limitations on the application of principles in conflicting situations. Specifically, article 27 of the UDBHR requires that the limitation of principles, or on human rights, be “strictly necessary for and proportionate” to the protection of societal interests such as public safety, health, and for the protection of others rights and freedoms.\textsuperscript{33}

(ii) Use of the Principles Approach in the Influenza Pandemic

While the case for the protection of individual interests in clinical medicine is well argued in bioethics literature, consensus is yet to be attained regarding an effective overlapping ethical strategy in population health. Ethical considerations in clinical medicine tend to promote and protect individual interests, such as autonomy, privacy, and confidentiality. In the early 1970s, principilism emerged as the most dominant ethical
approach in clinical medicine, edging out approaches such as casuistry, and comprehensive ethical theories such as virtue ethics, utilitarianism, and ethics of care.

The strength of the principles approach lies in the flexibility to overlap different ethical theories. Popularized by Tom Beauchamp and James Childress, the biomedical principles of autonomy, beneficence, non-maleficence and justice were meant to serve as an analytical framework “through which we can reason about problems in bioethics.” Beauchamp and Childress suggested a method of specification, justification and balancing of principles, and rules and rights, as a strategy for dealing with moral conflicts. Accordingly, specification addresses the dimension of range and scope of a principle, and the balancing addresses the dimension of weight and strength. These scholars further elucidate that the determination of weight and strength calls into play values, such as reasonableness and necessity.

Though the strategy of specifying, justifying and balancing principles has proved to be fairly successful in clinical medicine, and in the domain of individual interests, its application in population health interventions is not yet properly articulated. Population health presents a new paradigm in which the population good is prioritized over the individual’s preferences. Moral considerations in population health are pluralistic, and applied in a multidisciplinary and multifaceted manner, since the population good takes primacy over individual preference. Subsequently, ethical approaches such as utilitarianism and egalitarianism gain prominence over ethical approaches that promote individual interests such as libertarianism.

But, despite the differences between clinical medicine and population health, ethicists think that the principles approach is suited to the goal of balancing individual and
population interests. Since the application of principles in clinical medicine is well suited to the needs of the individual, ethicists have developed additional principles that are applicable in population health.  

UNESCO’s Universal Declaration on Bioethics and Humanities Rights (UDBHR) document sanctioned the bioethics principles approach, and expanded the principles to accommodate societal interests such as solidarity, cooperation, and social responsibilities.

UNESCO acknowledged the moral complexity associated with public health measures that alleviate public health threats, while also interfering with the self-determination of the individual. The primary aim of the Declaration was to provide “a universal framework (a normative standard) of principles and procedures to guide States in the formulation of their legislation, policies or other instruments in the field of bioethics.”

The UDBHR declaration is a non-binding, legal instrument but human rights advocates attribute the moral weight of the principles approach to the fact that governments have adopted, and committed to the principles therein, and their applications. But probably the strongest justification for the principles approach in public health and human rights connection comes from philosophical reflection. Stephen Holland explains that “public health principlism is very promising because it is a relatively accessible and practical way of doing public health ethics.” Moreover, public health principlism has double attributes of clarifying the nature of the dilemma and resolving dilemma in public health.

The UDBHR enumerated principles found application in public health when UNESCO became concerned about a potential influenza pandemic outbreak, as was
warned by the WHO. UNESCO guided that compulsory measures, such as quarantine, require strict regulation “in accordance with Article 27 of the Declaration on limitation of the principles.”

Article 27 lays out instances, such as protection of public health and the protection of the rights and freedoms of others, as reasons for limiting the application of principles. But the Declaration does not provide concrete guidance on how the balance is to be achieved in the real situation of a pandemic outbreak, such as influenza pandemic.

(iii) Autonomy and Individual Interests

The substantive principle of individual autonomy is the most appropriate ethical variable for the practical application of individual interests associated with individual liberty and freedoms. In clinical practice, the primary responsibility of the provider is to implement the informed, autonomous decision of a competent person, or the patient’s surrogate. Likewise, in research ethics, the investigator is obligated to seek the informed consent of the individual research participant.

Beauchamp and Childress explain that autonomy connotes “meanings as diverse as self-governing, liberty rights, privacy, individual choices, freedom of the will, causing one’s own behavior, and being one’s own person.” In clinical medicine and research, autonomy is enshrined in the concept of informed consent. It is in this sense that Beauchamp and Childress refer to personal autonomy as “at a minimum … self-rule that is free from both controlling interference by others, and from limitations … that prevent meaningful choice.”

Informed consent then, is the patient’s “voluntary, autonomous authorization to proceed with the proposed intervention.”

While the focus of clinical medicine is the individual’s health interests, the influenza pandemic presents a paradigm shift from prioritizing the individual to the emphasis on
protecting populations. This change is clearly attested to in the *Pennsylvania’s Influenza Pandemic Response Plan* (IPRP), which adopted the federal draft *Model State Emergency Health Power Act* (MSEHPA). The 2005 draft IPRP asserts the State’s duty to protect the public from serious harm during a public health emergency through disease prevention and suppression.\(^{48}\)

As stipulated in the IPRP, the Governor is invested with the powers to protect citizens of the commonwealth against a health disaster. Those powers include the declaration of a disaster emergency, suspension of regulatory statutes that may hinder or delay emergency response, and appropriation of some public and private property for state use in disaster intervention.\(^{49}\) The IPRP grants the Governor, in consultation with the Department of Health, powers to order the isolation and quarantine of an individual, or groups of individuals, for purposes of limiting the transmission of a contagious disease.\(^{50}\) The Secretary of Health has powers to issue warrants for apprehending and arresting “persons who disobey the quarantine orders or regulations of the Department of Health.”\(^{51}\)

For hospitals, and other healthcare institutions, the requirement to implement mandatory coercive intervention could interfere with the ordinary standard of care. Compulsory control measures may be incompatible with the strictly guarded, autonomous decision-making authority of individual patients. In a public health emergency, the individual’s decisional authority is subdued, since health care officials take over the control of the population health emergency response.

Hospitals may be required to limit access to some services such as elective surgery, and impose infectious control measures, such as wearing masks. They could be required
to enforce control measures such as culling, isolation, and quarantine, as well as reporting suspected persons. Additionally, health care institutions may receive orders from the state to carry out compulsory medical tests and diagnostic procedures. A person who refuses to comply could be committed to civil confinement.

Coercive measures may be ethically justifiable if balance is struck between individual and population health interests. From the legal perspectives, due process provides that no person shall be deprived of liberty, or property without due process of the law. Courts have established that “the parameters of due process require an analysis of both the individual and government interests involved and the consequences, and the avoidability of the risks of errors and abuse.” Due process as guaranteed in the Fourth Amendment of the United States Constitution, limits police power. Even in cases in which confinement is justified “the terms of confinement must minimize infringement on liberty and enhance autonomy.”

In this context, therefore, hospitals and other healthcare institutions ought to have in place ethically sound administrative policies, and procedures, to provide for ethical guidance in decision-making during the pandemic influenza outbreak. Concerned about this need, Alison Thompson and his Canadian colleagues developed a pack of ten substantive values and five procedural values meant to ensure the safeguarding of individual and societal health interests. However, these experts do not offer an in-depth discourse to demonstrate a coherent methodology for balancing conflicting principles, such as autonomy and solidarity.

Ethicists differ in their conceptual analysis of autonomy. For libertarian-oriented experts, such as Griffin Trotter, legitimacy for public health powers issues from
individual authorization via public (democratic) deliberation. Cosmopolitan liberalism, as espoused by George Annas, commits to a rights-based approach that defends individual interests, and civil liberties against government and corporate overreaching, by drawing legitimacy from the interpretation of constitutional rights and universal human rights.\(^{57}\)

Communitarians, such as Michael Walzer and Dan Beauchamp, regard the individual as “being part of a well regulated society that seeks to prevent risks that all members share.”\(^{58}\) The implication of these diverse perspectives on the role of autonomy is enormous for policy development, particularly in hospitals during the pandemic influenza preparedness and response.

If one concurs with Trotter’s libertarianism, the question of population interests, as common good, does not arise. From Trotter’s perspective, balance is necessary where liberty interests of the individual clash with the aggregate security interests regarding decisions about coercion. The means off striking the balance is by “proper exercise of practical judgment,” and not by “moral principles (substantive) … applied like recipes to produce distinct and singularly correct solutions.”\(^{59}\) Trotter argues that decisions are about, and affect, individuals, who then should be the legitimate source of authorization.

Trotter appears to be more concerned with limiting government involvement and ensuring the primacy of individual rights. Accordingly, “In so far as possible, citizens should cultivate advance agreements about terms of coercion in such events.”\(^{60}\) Health professionals, for their part, should cultivate the art of practical judgment through guiding principles (procedural standards) and training regimens.\(^{61}\) In this sense then, autonomy assumes the meaning of individual self-governing.
This vision of autonomy as embraced by Trotter is fully defended by Tristram Engelhardt in its strictest sense of individualism. The only moral basis for one to transfer one’s goods to another is consent and permission. Emphasis is put on the primacy of individual preferences, and on limiting the governing powers of the state, or any other social institution over the individual. The legitimacy of the minimal state is strongly defended by Robert Nozick who was influenced by Kantian views that individuals are ends in themselves, and not merely means.

According to Nozick, more than a minimal state is unjustifiable. People are so different that imposing a single utopian vision would be absurd. Only the minimal state provides a framework for utopia by respecting people’s rights, freely allowing them to choose their lives and realize their ends, and, “aided by the voluntary cooperation of the individuals possessing the same dignity.” The distribution of resources in society is not based on a patterned central distributive or allocating agency, but on individual holdings. The principle of transfer is “from each as they choose, to each as they are chosen.”

On the contrary, the communitarian vision as explained by Daniel Callahan, subordinates individualism and prioritizes the needs of the community. For Callahan, any initial questions raised about ethical problems “should focus on the social meaning, implications, and context, even those cases which seem to affect individuals only.” In this sense, the state is primarily obligated to guarantee the security and health of the populations.

Not surprising, if the influenza preparedness and response committee is comprised of a libertarian, a utilitarian, a liberal cosmopolitan, and a communitarian, there will, most likely, be diverse perspectives regarding autonomous decision making. Yet no single
principle accruing from these theories, such as “the greater good for the greater number,” is sufficiently suited, on its own, to the purpose of resolving complex ethical problems. Attempts to strike balance between protecting the individual and ensuring societal well-being, should involve procedural values such as necessity, proportionality, reciprocity, mutuality, and solidarity. Subsequently, UDBHR considers autonomy, and individual responsibility for self and others, as mutually connected. Article 10 stipulates that, “the autonomy of persons to make decisions, while taking responsibility for those decisions and respecting the autonomy of others, is to be respected.”

A policy statement based on MIEM criterion, and protective of individual autonomy, ought to emphasize both aspects of responsibility to self, and the autonomy of others. Such a policy could be stated as follows:

In a public health crisis of the magnitude of the influenza pandemic, Y Hospital respects the substantive principle of individual autonomy and solidarity in implementing guidelines that restrict individual liberty and freedom. The restrictions need to be indispensable, applied equitably, and employ the least restrictive means necessary for the prevention of the influenza pandemic, and the amelioration of the individual and universal rights.

This sample ethical policy statement is coherent and robust enough to provide for the safeguard of the individual’s autonomous interests in liberty and freedom, as well as the population health interests in health and safety. The goal is to anchor decisions and actions in a universally accepted ethical standard that requires consistency with respect for “the dignity of human person, and respect for, and observance of human rights and fundamental freedoms.”
The International Bioethics Committee of UNESCO delineated their vision of autonomy by expounding the notion of informed consent. Accordingly, in clinical medicine or medical research, a person has a right to make autonomous decisions if they provided with adequate information, comprehend the information, and voluntarily make the choice. In population health, the application of the principle of informed consent needs to be applied within the context of article 27 of the UDBHR declaration, which allows for the limitations on the application of the principles, for instance, in danger of a public health threat.

(iv) Solidarity and Protection of Populations

Respect for the autonomy of others and the promotion of others’ wellbeing calls into play the substantive principle of solidarity. To comprehend the contrast between autonomy and solidarity one needs to analyze the connectedness of solidarity to the notion of common good. When solidarity is understood as common cause for the wellbeing of those who are in need, the notion necessarily implies the promotion of the common good of all. Trotter explains that utilitarianism, egalitarianism and communitarianism (broadly) entail the three varieties of the fulfillment model of the common good. Though, Trotter himself does not find these approaches very helpful since his interpretation of the notion of common good is merely an aggregation of the individual’s goods.

The substantive principles of solidarity and common good are notions that are mutually connected with each other. Solidarity requires proactively taking measures to protect those in danger of a public health threat. The intervention may involve justification of some legitimate coercive measure that limit individual freedom and
liberty, as well as prioritizing and rationing scarce community resources. But, as explained by Alison Thompson and colleagues, solidarity requires coordination as well as “good, open and honest communication.”

One recognizes a pattern of overlapping values such as information, open communication, and collaboration that mutually inform both autonomy and solidarity.

A group of ethicists assembled by the Greenwall Foundation in the year 2002 to “map out the public health ethics terrain” established that there are areas in competing moral considerations that either decrease or increase conflict. James Childress and colleagues recommended that for practical guidance to resolving conflict, general moral considerations, such as autonomy and liberty, need to be made more specific and concrete. In this regard, there should be a consideration of “the meaning and range of scope” as well as their “weight or strength.” This exercise is important, since no general moral consideration can be taken to be absolute.

These scholars elucidated that a consideration of meaning and range of scope determines the extent of conflict among the conflicting general moral considerations. Subsequently, “if their range of scope is interpreted in certain ways, conflict may be increased or reduced.” Moreover, by determining their weight and strength we can establish when “different considerations yield to others in case of conflict.” A combination of meaning, scope, context, and circumstances provide the ethical trajectory for determining practices, features, and actions that qualify as prima facie consideration when moral considerations conflict.

Applying this standard in the MIEM context, the substantive principles require specification and interpretation to delineate their meaning and scope. To determine
considerations that yield to others, one needs to apply procedural principles such as necessity, reasonableness, proportionality, and harm avoidance. This is the context in which, for instance, one engages autonomy and solidarity to negotiate balance between individual and population interests. The essential features of autonomy, such as knowledge, comprehension, and voluntariness, are compatible with the essential features of solidarity such as open communication, collaboration, coordination, and a sense of common purpose.  

B. Meaning and Scope of Autonomy and Solidarity

(i) Specification of Autonomy (information, comprehension, and voluntariness)

The Pennsylvania 2005 draft IPRP is a bold statement of proactive, strategic planning for the future influenza pandemics; incomparable to the sloppy response to the horrendous 1918 Spanish Flu. Nevertheless, one of the most controversial features of the IPRP is the sanctioning of the exercise of mandatory and intrusive public health powers, such as culling, isolation, quarantine, and possible confinement. Moreover, the state may limit the individual’s freedom of movement and assembly. These measures could lead to ethical and legal questions about restrictive public health intervention that disrupt personal freedoms and liberties, such as those enshrined in the substantive principle of individual autonomy and the related values of privacy and confidentiality.

Another ethical problem is the subordination of the individual’s autonomous preferences in the allocation of limited health resources, such as vaccines, antiviral medication, or hospital beds which raises the question of distributive justice. The individual’s interest in self-determination, as understood in libertarian ethics, prioritizes
the free market system as the appropriate variable for attaining distributive justice. The main actors in the market system are the individual consumer, private investor, insurers, and business corporations. The government’s role is understood as the protection of the individual by applying limited regulation to prevent unfair practices, and incentives to encourage investment and competition.84

But even pro-libertarian ethicists acknowledge that, in population health emergency, success is measured not on individual preferences, but on the state’s ability to reduce morbidity and mortality in the population.85 The paradigm shift from emphasis on the individual to community preferences results in the rationing, and prioritization, of resources whereby specific individuals may be legitimately denied care, or subjected to involuntary treatment. Most ethicists now concur that respect for individual autonomy requires that public health authority ought to apply the least restrictive (infringement) means necessary for achieving population health goals.86

Attentive to the legal and ethical requirements to protect the autonomous individual, Pennsylvania’s 2005 draft IPRP included, among its recommendations, the use of “the least restrictive means necessary” and the granting of due process protection by providing for the petitioning of courts for the extension of quarantine, or isolation, as required by Pennsylvania’s Counterterrorism Planning, Preparedness and Response Act (CPPR).87 Under the CPPR, the Governor has authority to order the immediate isolation or quarantine of contacts for a designated period, beyond which, a court proceeding and permission is required.88

Informed by ethical reflection, courts in the United States have developed a legal framework for determining what legitimately counts as a least infringement on the
individual’s liberty, and freedom for purposes of pursuing the common good. The courts distinguish between substantive and procedural kinds of restrain on police power of the state. The substantive requires strong justification (good reason) for infringing on individual liberties and freedoms. The procedural requires fair process if individuals are to be deprived of their liberties and freedoms.89

The interference with the substantive, autonomous decision-making right of an individual requires strong justification commensurable to a fundamental level of a threat, or risk of contagiousness to others. Even then, coercion may not be necessary unless there is credible proof that the affected individual poses such risk, and would not cooperate, thereby putting others at risk for infection.90 Autonomous decision making is synonymous with the notion of informed consent, which requires that adequate information is given and comprehended, and that the decision is voluntarily made. One important piece of reliable knowledge in public health emergencies is scientific information arrived at by way of rigorous analysis and replicable method.91

Experts have argued that the dissemination of information also entails public health accountability. According to Childress and colleagues, public health accountability refers to the responsibility of the public health agents to involve “the public and scientific experts to identify, define, and understand at a fundamental level the threat to public health, and the risks and benefits of ways to address them.”92 To be voluntary, the individual’s action requires adequate information, absence of controlling influence, and competency. Non-voluntary actions are defined as those that occur in circumstances of inadequate information, a controlling influence and incompetence.93
Most ethicists agree that the standard of autonomy as set in clinical medicine is not a perfect fit in population health intervention. Health care experts have come to the conclusion that planning for health care disasters emergencies can entails undertakings that alters the accepted standards of care. But ethicists insist that even in situations where altering standards is justified, safeguards must be put in place to protect against unnecessary overreaching into the rights of the autonomous individuals. One helpful approach is to think of decisional autonomy as also “taking responsibility for those decisions and respecting the autonomy of others.”

It is important to emphasize that responsibility is not compatible with coercion. Ruth Faden argued for persuasion as a strategy of communicating public health information. Persuasion enhances individual autonomy while manipulation compromises autonomy. In persuasion, “the reasons that comprise the persuasive appeal exist independent of the persuader.” Persuasion is an appeal to reason so that a person “freely accepts – as his own – the beliefs, attitudes, values, intentions, or actions advocated by the influencing agent.”

Contrasting persuasion with manipulation, Ruth Faden finds manipulation to be a threat to individual autonomy. For, manipulation of information aims at deliberate modification of a person’s perception of the available options to affect what that person believes. Because of the manipulation of information, the targeted person is rendered ignorant. For example, Dr. Taliaferro Clark and his colleagues who conducted the Tuskegee Syphilis Study relied on manipulation to render the participants ignorant of the whole purpose of the study, and thereby, deprived them of decisional-autonomy.
Connected with persuasion are the notions of transparency and openness. Concurring with Normans Daniels, Allison Thompson and colleagues argued that “decisions must be publicly defensible.” Decision-makers have a responsibility to let the public, and particularly the affected stakeholders, access and scrutinize the process, and to understand the basis upon which decisions are made. One strategy to demonstrate transparency is the involvement of all affected parties. In the influenza pandemic planning and response, committees should be comprised of stakeholders such as ethicists, clinicians, lawyers, public health officials, and representation from the community that will be affected.

Epidemiologists make a connection between increased vulnerability and reduced autonomy. In determining risks, they also focus on the level of vulnerability. A distinction is made between vulnerability resulting from the interplay of virology factors and the individual’s biological susceptibility, and vulnerability that occurs due to unfavorable social, economic, and political factors. To minimize vulnerability resulting from biological susceptibility, the IPRP identified specific groups of persons to be targeted first to benefit from the limited supply of vaccination. These people include aged persons with high risk medical conditions, pregnant women, persons above age 65, and in certain circumstances, infants aged 6-12 months.

But, more ethical oversight may be required when decisions and actions affect persons who are vulnerable due to socio-political and economic problems. Ethnic minority populations are often subjected to discrimination and stigmatization during infectious disease outbreaks. Moreover, individual persons in minority populations
rarely receive adequate health care, making them highly susceptible to contagious
diseases and easily targeted for coercive intervention during pandemics.

Elaine Vaughan and Timothy Tinker explained that, from a public health perspective,
vulnerability means “an increased potential for loss in a hazardous situation, including
reduced capacity to respond effectively.”105 The link between vulnerable individuals, or
groups with disproportionate care, and reduced autonomy during the influenza pandemic
partly accrues from health disparities such as living conditions, health literacy,
immigration status, and language.106

The judiciary in the United States is attentive to the problem of reduced autonomy
resulting from vulnerability in population health intervention. For instance, government
statutes that identify people by race, class, alienage, or gender, are subjected to a standard
of strict scrutiny. Courts have established that these categories are often likely to be
subjected to unequal treatment, bias, and antipathy.107 To enhance trust, and increase the
prospects for effective management of influenza pandemics, public health authorities
need to have better ethical oversight in dealing with vulnerable individuals and groups.108

When the joint advisory group of the Massachusetts Department of Health and the
Harvard School of Public health recommended the utilitarian principle of maximizing
benefit in allocating limited resources, they also included safeguards against
discrimination based on gender or class.109 The principle stated that:

Limited resources be allocated so as to maximize the number of lives saved
(determined on the basis of the best available medical information, implemented
in a manner that provides equitable treatment of any individual or group of
individuals based on the best available clinical knowledge and judgment, and

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implemented without discrimination or regard to sex, sexual orientation, race, religion, ethnicity, disability, age, income, or insurance status).\textsuperscript{110}

In the domain of universal rights, according to Roberto Andorno, “human dignity is specifically invoked as an argument against discrimination (article 11), as well as the framework within which cultural diversity is to be respected (article 12).”\textsuperscript{111} As affirmed in the Universal Declaration of Human Rights, “all human beings are born free and equal in dignity and rights.”\textsuperscript{112} Glenn Rivard explains that the injunction against discrimination and stigmatization, in article 11 of the UDBHR, “is in reference to the resolution of ethics issues related to medicine, life science and associated technologies as applied to human beings.”\textsuperscript{113}

Some of the most effective strategies employed by epidemiologists for enhancing autonomy and reducing societal vulnerability are effective communication; partnership and collaboration; and coordination.\textsuperscript{114} Ethicists consider communication, along with collaboration and coordination, as the essential features of the substantive principle of solidarity.\textsuperscript{115} These values are essential for the abridgement of the tension between the principles of autonomy and solidarity for effective prevention, containment, and treatment of influenza pandemic.

(ii) Specification of Solidarity (communication, collaboration, co-ordination)

Communication, collaboration (cooperation), and co-ordination enable the dissemination of the information that individuals, and populations at risk, require to comply with the population health intervention. Good communication, as proposed by Elaine Vaughan and Timothy Tinker, aims at successful instruction, information, and motivation, as well as updating risk factors, building trust, and dispelling rumors.\textsuperscript{116}
Pennsylvania’s IPRP underpins the importance of communication in the pandemic influenza by outlining strategies for a wide range of communications about risks, ranging from those related to virology and environment to, various social factors. Accordingly, the goal of public health communication in an emergency or disaster is to provide accurate, consistent, and timely messages to the public. These messages are coordinated and disseminated on federal, state, and local levels.\textsuperscript{117}

The IPRP identified various means of communication, such as news conferences, media updates, public education campaigns, and providing education materials to the public. Other ways are Public Health Department websites, script resources for response to telephone calls, establishment of hotlines and central sources of public information, the use of local communication channels, and providing staff as resources to manage any surge in the demand for public health information.\textsuperscript{118} Individuals are most likely to cooperate with public health officials when adequately informed, rather than when they luck such information. Cooperation from diverse parties helps reduce negative consequences.\textsuperscript{119}

Public cooperation with health officials in population health emergency occurs within the context of collaboration. The notion of collaboration in influenza pandemic intervention refers to participatory approaches, in which public health agencies, systems, emergency managers, and the communities are involved in planning and response.\textsuperscript{120} While exploring the role of low-skilled and paraprofessional home care providers in the influenza pandemic preparedness and response, Sherry Baron and colleagues underlined the importance of collaboration. This is because when faced with surge capacity, the
effective management of the influenza pandemic requires reinforcing staffing by, for instance, the mobilization of home care providers.  

Effective collaboration and cooperation between public health officials and home care providers will be essential for soliciting the cooperation of vulnerable individuals in population health emergency. Though many of these homecare providers lack some clinical competencies, they could assist with the “distribution of information, infection control supplies, food and medication.” Collaboration will be key, since some of the home care providers, such as those employed and certified or licensed by Medicare, are required by federal law only to pass a skills competency test. Other home care providers, employed directly by agencies or clients, are not required to undergo national standard training.

The notions of cooperation and collaboration have also gained increased attention as ethicists explicate the meaning of the duty to care, as stipulated in all health care professionals’ codes of ethics. The increased risk that comes with caring for patients during the influenza pandemic makes health professionals weigh obligations to self, their families, and against their professional duty. Additionally, as Alison Thomson observed, physicians may also need to assess the implication of complying, for instance, with mandatory vaccination, or antiviral regimens for prophylaxis with their interest in individual liberty.” Rather than understanding the physician’s duty to treat as overriding all their personal concerns, even to the jeopardy of their lives, emerging ethics literature emphasize solidarity. Collaboration, rather than a rigid stance on uncompromising obligation, provides a pathway to easing their moral burden.
One way of distributing the burden of the professional duty to care is to consider the need for priority setting, and fair allocation, of limited resources within the context of solidarity. In this sense, decision-makers work in advance, and collaboratively, with all involved parties to establish priority guidelines for the influenza pandemic intervention. The provisional guidelines must establish fair and accountable processes, such as triage protocols, and means for resolving interparty complaints.

When, for instance, physicians and health care providers in Minneapolis, Minnesota developed a “tiered, scalable framework for restricting mechanical ventilation” in an epidemic, one of the objectives was to ease the burden of the individual physician in his duty to the individual cases (patients). They argued that the criteria for resource allocation, or withdrawal, “will reduce the potential for each physician to have to design and defend individual strategies for individual cases and improve consistency.” This strategy is compatible with values of care and stewardship and is much needed in medical professionalism.

Care within the context of solidarity, entails a moral response to a human need and suffering, as characteristic in medical conditions. One dimension of care is compassion, which is the ability of the health care provider to be empathetic to the patients in their pains and sufferings. More closely related to care is the notion of stewardship, which means “the prudent and careful use of resources necessary to sustain life.” Stewardship infers “trust, ethical behavior, and good decision-making.” According to Alison and colleagues, the notion of stewardship should guide individuals and institutions that will be entrusted with the governance and allocation of scarce
resources, such as “vaccines, antivirals, ventilators, hospital beds, and even health care workers.”

One practical way of being good stewards of insufficient health resources in the influenza pandemic is the development and implementation of a triage protocol. Triage is meant to ensure that critical care resources are rationed in an equitable manner and offers opportunity for a greater number of people to survive. Usually, when the object to be triaged is limited critical care resources, a determination is made regarding the inclusion criterion, exclusion criterion, minimum benefit for survival, and prioritization pool.

According to Michael Christian and colleagues, inclusion criterion identifies patients who may benefit from admission to critical care with focus on ventilatory failure, while hemodynamic support and other advanced care modalities are provided in areas with appropriate monitoring, but not at the level of ventilatory support care. Exclusion criterion identifies patients with: poor prognosis, despite care in ICU, those who require resources that are inaccessible in a pandemic, and advanced medical illness with poor prognosis and a high likelihood of death. The minimum qualification for survival criterion sets a ceiling on the amount of resources that can be used on any one person in comparison to the chances and opportunities to save others.

For instance, the Minneapolis group of experts developed a triage of mechanical ventilation based on three tiers of criteria. Then, they adopted the Sequential Organ Failure Assessment (SOFA) measuring system, as a validated reliable tool for comparing mortality predictability. The adoption of the triage protocol, and the SOFA criterion, underlines a practical commitment to the promotion of collective wellbeing of the all people and a solid sense of solidarity.
The three-tiered triage critical care protocol, developed by the Minneapolis group of experts from their drills experience, restricts inadequate mechanical ventilations in an epidemic disaster. The first tier is comprised solely of patients in “respiratory failure with shock, and multiple organ dysfunctions.” Physicians are not to initiate, and can withdraw, ventilator support from patients meeting these conditions of respiratory failure and poor prognosis “based on current and underlying disease.”

The Minneapolis group of experts detailed the conditions as follows:

- Respiratory failure requiring intubation with persistent hypotension …
- unresponsive to adequate fluid resuscitation after 6-12 hours of therapy and signs of additional end-organ dysfunction … Failure to respond to mechanical ventilation … and antibiotics after 72 hours of treatment for a bacterial pathogen … Laboratory or clinical evidence of >4 organ system failing … pulmonary … cardiovascular … renal … hepatic … neurological … hematological.

Tier two is comprised of criterion “related to high potential for death, prolonged ventilation, and high level of resource utilization.” If the restrictions imposed in tier one adequately meet resource demands, tier two is unnecessary. Tier three involves “additional restrictions or numerical scores” to standardize assessment of patient care and “further restrict demand on resources.” The first and second tier criteria differ from the third tier criterion in that they largely depend on “respiratory failure and poor prognosis based on current and underlying disease” and not on “familiarity with scoring system.”

The conditions in tier 2 were detailed as follows:

- Known congestive heart failure with ejection fraction <25% … Acute renal failure requiring hemodialysis … Several chronic lung disease including
pulmonary fibrosis, cystic fibrosis, obstructive or restrictive diseases requiring continuous home oxygen use before onset of acute illness. Acquired Immunodeficiency Syndrome (AIDS), (and) other immunodeficiency syndromes at stage of disease susceptibility to opportunistic pathogens … with respiratory failure requiring intubation … Active malignancy with poor potential for survival … Cirrhosis with ascites, history of variceal bleeding, fixed coagulopathy, or encephalopathy … Acute hepatic failure with hyperammonemia … Irreversible neurological impairment that makes patient dependent for personal care.  

The third tier criterion entails the application of specific protocols that could be agreed upon by the guideline development committee. The Minneapolis group of experts suggested the following possibilities:

Restriction of treatment based on disease-specific epidemiology and survival data for patient subgroups (may include age-based criteria) … Expansion of preexisting disease classes that will not be offered ventilatory support … Applying Sequential Organ Failure Assessment scoring to the triage process and establish a cutoff score above which mechanical ventilation will not be offered.  

The Sequential Organ Failure Assessment Score system is generally accepted as a useful scoring system “generating a numerical score that offers good predictive accuracy based on a few clinical and simple … laboratory observations.” SOFA was originally developed by the European Society of Intensive Care Medicine as Sepsis-related Organ Failure Assessment (SOFA) Score. The reason for the SOFA score development was “to find an objective and simple way to describe individual organ dysfunction/failure in a continuous form, from mild dysfunction to severe failure, that can be used over time to
measure the evolution of individual (or aggregated) organ dysfunction in clinical trials on sepsis or for clinician at bedside.”

John Hick and colleagues argue that predictive survival instruments such as SOFA in tier three, “allows for more efficient allocation of available resources to institutions in greatest need and provides us a consistent level of care (as possible) across the community and region.” In much as it is possible, the Minneapolis tiered protocol puts emphasis on “objective determination of the effectiveness of care affecting survival, and of resource utilization, rather than subjective determinations regarding the value of either the intervention or the value of the patient’s life.” Physicians are also guaranteed a rational and quantitative guidance in population emergency critical care.

Some ethicists have cautioned that solely scientific evidence cannot be the basis for fair allocation of limited critical care resources. Alison Thompson and colleagues have pointed out, for instance, that though science offers guidance to decision-makers regarding “maximizing benefit in the allocation of ventilated beds,” it does not account for whether “the initial decision to maximize benefit is just.” Maximizing benefit is a notion that arises from reflecting on values. This further raises the question of why a utilitarian approach of maximizing benefit was selected as the preferred principle of distributing rights, burdens, and benefits over other moral considerations.

The contrast to utilitarianism, offered by John Rawls, is the egalitarianism maxim that “social and economic inequalities are to be arranged so that they are both (a) to the greatest benefit of the least advantaged and (b) attached to the offices and positions open to all under conditions of fair equality of opportunity.” The goal of John Rawls’ is to ensure that “each person benefits from any social inequality.” In a fair setting, it is “the
requirement that the least advantaged benefit under the stipulation of maximin in the original position.\textsuperscript{157}

What the utility approach, and Rawls’ egalitarianism, remind us of is the need to have fair and well balanced community mechanisms that empower the physician’s patient-advocacy role (where patients compete for resources), and enables the physician to make impartial allocation decisions.\textsuperscript{158} In this sense, the notion of the physician’s duty to care is correlative with the notion of solidarity. As observed by the Council on Ethics and Judicial Affairs of the American Medical Association, “the physician role as a patient advocate would be jeopardized, and trust between physician and patients would be undercut” if out of loyalty, and not objective allocation mechanism, physicians feel pressured “to choose their own patients over others.”\textsuperscript{159}

The list of philosophical perspectives that could influence the trajectory of policy development in the influenza pandemic is, in fact, longer than libertarian, liberalism, utilitarian and communitarian, but there are principles that overlap. Catholic social teaching, for instance, defines justice and social structures by prioritizing the notions of human dignity and man’s social nature.\textsuperscript{160} According to Karen Lebacqz, the teaching puts emphasis on three basic affirmations: “the inviolable dignity of the human person, the essential nature of human beings, and the belief that the abundance of nature and social living is given for all people.”\textsuperscript{161}

Man is understood as created in God’s image. Thus, the demands of justice and social structures are based on the fundamental affirmations of the transcendental human dignity, and on man’s social nature.\textsuperscript{162} These affirmations result in practical application at the level of moral principles, such as the common good, solidarity, stewardship, and
subsidiary. But as observed by Karen Lebacqz, the common good advocated by the Catholic teaching is not the utilitarian “greater good for the greater number.” The plight of the worst off is the standard for justice in the society.

(iii) Ethical Justification

As demonstrated so far, the substantive ethical principles such as autonomy and solidarity are appropriate variables for decision making in the effective management of the influenza pandemic. Although these principles do conflict in some circumstances, they also yield sufficient ground for negotiating the safeguard of individual rights, while effectively managing population interests in health and safety. Through critical analysis and specification, it can be established that the notions of information, comprehension, and voluntariness that inhere in the principle of autonomy are not exclusively disharmonious with the notions of communication, collaboration, and cooperation that are inherent in the principle of solidarity.

Nevertheless, effectiveness in rendering information or collaboration does not substitute for the need to make an inquiry into the ethical justification of the decisions or information being communicated. There is need for a critical analysis and deeper investigation of the ethical ground that gives prominence to some specific decisions and actions over others. One needs to establish, for instance, why a particular approach that maximizes and distributes benefit is ethically preferable, even though it excludes from benefit certain individuals and groups of people.

Each of the approaches of utilitarianism, egalitarianism, and communitarianism contribute, in a unique way, toward the realization of a commitment to solidarity and the common good. Libertarianism, on the other hand, uniquely contributes toward a
commitment to individual autonomy. It is impossible not to notice, in various pandemic preparedness literatures, how these pluralistic ethical theories influence the trajectories of proposed ethical guidelines of different pandemic preparedness committees.\textsuperscript{167}

Several experts have advanced a number of ethical criteria for resource allocation in public health emergency that are helpful, but not often easily agreeable. The Council on Ethical and Judicial Affairs of the American Medical Association (CEJA) distinguished between ethical considerations that are appropriate, and those that are inappropriate, in certain circumstances.\textsuperscript{168} Likewise, the Ethics Subcommittee of the Advisory Committee to the Director of the Centers for Disease Control and Prevention explicated on a number of morally diverse considerations that have been proposed for allocating scarce resources, such as ventilator treatment.\textsuperscript{169}

Most experts regard as inappropriate, in public health emergency, those criteria that allocate resources based on ability to pay (free market system), as preferred in libertarian ethics, or based on the patient’s social worthiness, as is the case with meritarians. The criteria that are most favored are those that allocate based on “the likelihood of benefit to patient, the impact of treatment in improving the quality of the patient’s life, the duration of benefit, the urgency of the patient’s condition, and the amount of resources required for successful treatment.”\textsuperscript{170}

The meritarian criterion based on social worthiness, and instrumental value in resources allocation in pandemics, has been cautiously embraced by most ethicists. The approach “involves summary judgments about whether an individual’s past and future contributions to society’s goals merit prioritization for scarce resources.”\textsuperscript{171} Related to the person’s social value is the instrumental value that “refers to an individual’s ability to
carry out a specific function that is viewed as essential to prevent social disintegration or a great number of deaths during a time of crisis.”

This utilitarian “multiplier effect” refers to the practice of “prioritizing certain key individuals” through whose work “more many lives are ultimately saved.” The IPRP sanctioned this approach, in the case of limited supply of vaccines, so as to “maintain essential public services and the health care infrastructure.” Some of the prioritized groups that are targeted first to receive vaccination include healthcare personnel involved in treatment, research personnel, emergency medical services providers, medical supply transporters, and their family members. Other beneficiaries include those who maintain essential public services, such as those responsible for community safety and security.

A utilitarian criterion based on “likelihood of benefits to the patient” is favored by many decision-makers who want to “maximize the number of lives saved as well as the length and quality of life.” But some egalitarians accept the maxima of maximizing the number of lives saved, “not because this approach produces the best good, but, because each life has an equal claim on being saved.” However, the challenge of knowing those lives that will be saved is the uncertainty in outcome-predictions. Though, generally it is possible to distinguish care that offers no physiological benefit to the patient, and is thus futile, from care with a low likelihood of benefit.

Resource allocation based on the change in the quality of life of the patient means that treatment is provided to those “who will have the greatest improvement in the quality of life.” The CEJA preferred an approach that determines quality of life in terms of functional status to allow for comparison between patients. In this utilitarian sense, “improvements in quality of life would be measured for each patient by comparing
functional status with treatment and functional status without treatment. The approach allows for the use of resources, where they will do the most good, without discriminating against those with preexisting disabilities.

Another egalitarian approach gives primacy to the urgency of need. Resources are prioritized to benefit the urgent cases in hopes that the less urgent cases will have timely access as scarcity is addressed. This approach attempts to give equal chances to all to survive. However, experts worry that the conditions of patients set aside may deteriorate, to the point of requiring emergency care and treatment, which then may not be as effective as it would have been if the interception was made earlier.

Decisions that subordinate individual interests for the common good, whether utilitarian, or egalitarian, are not always indisputable. No matter how a single principle strategy, or ethical theory for allocating limited resources in a pandemic, seems to satisfy targeted population health outcomes, there are always individual interests that are undermined. Take, for instance, the triage protocol that requires physicians to allocate mechanical ventilation to some patients by withholding, or withdrawing, the care from other patients against their wishes. In attempting to promote the collective good, individuality is ignored.

With the emerging moral consensus of applying multi-principle allocation strategies, the most important question is how to ethically balance individual and population health interests, and not about which ethical theory or criteria is definitive. Solely the fact that some particular ethical considerations are chosen over others in pandemic intervention does not necessarily make them right. Aware of that ethical quandary, John Rawls
proposed “reflective equilibrium” as a reliable method of procedural assessment.\textsuperscript{186} The method ensures that our considered conviction of justice is tested and verified.

As mentioned previously, the specification of the competing substantive principles, and the harmonization of areas that decrease tension, such as information and communication, is the first steps towards the effective management of the influenza pandemic. The MIEM approach puts in practical terms the proposal by Douglas White and colleagues that a multi-principles approach requires treating “each principle as a continuous variable and weigh them according to judgments about their relative importance.”\textsuperscript{187} This strategy then requires a procedural standard, as provided in MIEM.

C. Application of Procedural Standards (Illustrative procedural standard of necessity)

(i) Limiting Public Health Powers

The UDBHR document recommended that the balancing of conflicting principles, that entail engaging ethical and legal considerations, be done in a spirit of “professionalism, honesty, integrity and transparence.”\textsuperscript{188} Previous experiences with population health interventions exposed some instances of antipathy towards ethnic groups, or individuals. One such case is the 1900 ordinance by the Board of Health of the City of San Francisco to quarantine a whole district for purposes of containing a bubonic plague, and yet enforce the restrictions only on “people of Chinese race and nationality and not against persons of other races.”\textsuperscript{189} The court determined that the manner of administration of the ordinance was “with an evil eye and an unequal hand.”\textsuperscript{190}

It takes a leap of faith to expect that once public health authorities are provided with the relevant substantive and procedural ethical tools, they will all act as guided by their
moral compass of honesty and integrity. Cases of betrayal of trust in public health interventions are not unknown. There are two outstanding examples in public health literature: the negative eugenics of the early 1900s in the United States, when vulnerable people were involuntarily sterilized to prevent procreation and promote social degeneration, and the Tuskegee syphilis study that subjected participants to deceitful experimentation instead of offering them treatment.\(^1\)

Antipathy aside, even well intention health resources allocation policies may result in unfavorable outcomes based on underlying socio-political conditions of ethnic, race, gender, or economic disparities. The individual liberties and freedoms at stake are so important that public health decisions and actions that subordinate individuals ought to be clearly delineated with practical benchmarks, such as the procedural standards of necessity, reasonableness, proportionality, and harm avoidance.

Attentive to this problem, the *American Public Health Journal* issued a supplement in February 2009 to highlight important information on influenza pandemic preparedness and response. Several articles focused on health policy and ethnicity, as well as, on vulnerability based on gender, women, ethnic minorities, immigrants and refugees, and people with disabilities.\(^2\) Sonja and colleagues explain that health disparities based on racial, or ethnic minorities, may result in high morbidity and mortality among these groups during influenza pandemics.

Ethicists warn that minority groups are economically disadvantaged and lack financial resources, “including economic assets to use during protracted pandemic.”\(^3\) They are at high risk because “they cannot stockpile food and clean water or pay for
utilities, transportation, and shelter if they cannot work while complying with some
isolation or quarantine recommendations.”

To effectively manage pandemics, public health powers cannot be exercised in an
absolute manner in situations of vulnerability. There are factors, such as the
aforementioned individual vulnerability and protected liberty interests that mollify public
health powers to necessitate balance. For these reasons, efforts to develop influenza
pandemic preparedness and response policies need to include the question of limiting
public health powers. In the United States one of the legal mechanisms for limiting public
health powers is stipulated in the U.S. Constitution and was defended by the U.S.
Supreme Court in *Jacobson v. Massachusetts (1905)*. The constitutional parameter of
limited public health coercive powers entails the application of public health procedural
values, such as necessity, reasonableness, proportionality, and harm avoidance.

These legal procedural standards of necessity, reasonableness, proportionality, and
harm avoidance are also recognized in bioethics as ethical procedural standards. Tom
Beauchamp and James Childress in their treatise on biomedical principles outlined
conditions that restrict the balancing of principles. Accordingly, the conditions of a better
reason, necessity, least possible infringement (proportionality), and minimizing the
negative effects of the infringement (harm avoidance), must be met to “justify infringing
one prima facie norm in order to adhere to another.”

From a legal perspective, government is required “to have a good reason for public
health intervention,” and that “individuals subjected to coercion receive procedural due
process.” The due process clause of the Fourteenth Amendment requires “that
deprivation of life, liberty or property by adjudication be preceded by notice and
opportunity for hearing appropriate to the nature of the case.\textsuperscript{198} Accordingly, “the parameters of due process requires an analysis of both the individual and government interests (substantive) involved and the consequences and avoidability (procedural) of the risk of error and abuse.”\textsuperscript{199} The norm here is that “the state may regulate in the name of public health, but it may not overreach … may act on the basis of scientific evidence, but not arbitrarily or with animus.”\textsuperscript{200}

In accordance with the constitutional standards set by the Supreme Court in the \textit{Jacobson v. Massachusetts (1905)} case, the state overreaches when it uses public health powers unnecessarily. The necessary use of public health powers is when the least restrictive means are used to “to prevent an avoidable harm.”\textsuperscript{201} The method used must be by “reasonable means” that “prevent or ameliorate a health threat.”\textsuperscript{202} The burden imposed should not be “wholly disproportionate to the expected benefit.”\textsuperscript{203} Public health authority must also ensure that intervention “does not pose an undue risk to its subject.”\textsuperscript{204}

(ii) Illustrative Procedural Standard of Necessity

In the United States, the Supreme Court determined that states possess police power to compel individuals to submit to compulsory public health interventions for the common good.\textsuperscript{205} The procedural standard of necessity ensures that the exercise of police power remain in the parameters of what is reasonably required to prevent avoidable risks to the safety and health of the population.\textsuperscript{206} Though, at stake is the individual’s bodily integrity and privacy, neither individual autonomy nor police power is construed to be absolute. The most cited example of the states coercive laws sanctioned by courts on
necessity grounds is public health laws that require compulsory vaccinations or school attendance.\textsuperscript{207}

The necessity to protect other vulnerable children against crippling, and yet preventable diseases has often been regarded by courts as important enough to override even exceptions based on the First Amendment rights of religious beliefs.\textsuperscript{208} In \textit{Brown v. Stone} (1979), the Supreme Court of Mississippi ruled that:

\begin{quote}
(The Mississippi statute) requiring immunization against certain crippling and deadly diseases particularly dangerous to children before they may be admitted to school, serves an overriding and compelling public interests, and that such interest extends to the exclusion of a child until such immunization has been effected, not only as a protection of the child but as a protection of the larger number of the children comprising the school community and with whom he will be daily in close contact school rooms … \textsuperscript{209}
\end{quote}

Vaccination laws for school attendance may be regarded as least intrusive in the sense that “they do not institute an illegal search and seizure” as protected in the Fourth Amendment.\textsuperscript{210} Moreover, as determined also in \textit{Adams v. Milwaukee} (1913), “vaccination laws do not discriminate against school children to the exclusion of others in violation of the equal protection clause of the Fourteenth Amendment.”\textsuperscript{211}

According to James Childress and colleagues, necessity and least infringement are corollaries. For, “a proposed coercive measure must be necessary in degree and in kind.”\textsuperscript{212} These experts argued that it is not enough for a policy to satisfy the justificatory conditions of effectiveness, to realize the goal of public health; it is essential that “agents should (also) seek to minimize the infringement of general moral consideration.”\textsuperscript{213}
Public health agents also have a moral responsibility to “explain and justify that infringement, whenever possible, to the relevant parties, including those affected by the infringement.”214 Offering public justification, or transparency, is essential for creating and maintaining trust” and establishing accountability.215

The moral justification of the infringement depends on whether it leads to a realistic achievement of the objective and “no morally preferable alternative action can be substituted.”216 According to Beauchamp and Childress, “the infringement … must be the least possible infringement, commensurable with achieving the primary goal of the action.”217 When, for instance, the moral consideration of confidentiality is to be infringed, Childress and colleagues suggest that public health agents should “only disclose the amount and kind of information needed, and only to those necessary, to realize the goal.”218

The Pennsylvania public health statutory authority, as incorporated in the draft 2005 IPRP regarding confidentiality of reports and records, puts emphasis on adherence to the necessity standards. Statute 35 P.S. #521.15 restricts disclosure of confidential records and reports obtained as a result of intercepting communicable diseases, pursuant to the act, only to members of the Department, or the local board of health. Only where necessary to realize the purpose of disease prevention and control, could the confidential information be divulged to any other party.219

Balancing conflicting ethical principles can be a complex endeavor, but ethics committees are an effective strategy for clarifying and providing guidance in complex moral issues. As acknowledged by the IBC, ethics committees have proved their worthiness in three decades of existence and have considerable experience as “guarantors
of respect for ethical conditions” in human experimentation and medical practice.\textsuperscript{220}

Because ethics committees are characteristically pluralistic, and multidisciplinary in nature, they provide clarity to ethical decisions and practices by demonstrating diversity of competences, independence, and transparence.\textsuperscript{221}

(iii) Procedural Standards and Relevance of Ethics Committees

Probably the precursors to ethics committees in hospitals are the “medico-moral” committees, in Catholic Hospitals, that were sanctioned by the Catholic Hospitals Association in the \textit{Ethical and Religious Directives} of 1949.\textsuperscript{222} The medico-moral committees were composed of physicians, nursing sisters, and at times a hospital chaplain. The role of the committee members was to ensure adherence to “Catholic teaching on matters such as contraceptives, sterilization, abortion, and euthanasia.”\textsuperscript{223} But before the emergence of ethics committees, the Advisory Council of the National Institute of Health and Regulation of Research in the United States endorsed the formulation of Institutional Review Committees. These independent, peer review boards were meant to “ensure an independent determination of risks and benefits and assure the voluntary informed consent of the subject.”\textsuperscript{224}

In the \textit{Karen Ann Quinlan} (1976) case, the New Jersey Supreme Court endorsed the establishment of Institutional Ethics Committees that would be better suited to resolving conflicts in the field of medical competency than the courts.\textsuperscript{225} The President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research endorsed the establishment of Hospital Ethics Committees in 1983.\textsuperscript{226} The President’s Commission recommended three functions for ethics committees, namely, education, policy development, and case consultation.\textsuperscript{227}
The United States Congress, in 1991, passed the Patient Self-Determination Act requiring that all health care institutions that receive federal funds for Medicare or Medicaid inform patients, upon admission, of their right to participate in health care decision-making, and in particular, about advance health care directives. According to Albert Jonsen and colleagues, the Patient Self-Determination Act inspired the engaging of ethics committees and professional organizations in community education. As currently understood in clinical ethics, Institutional Ethics Committee refers to a group of individuals of diverse backgrounds tasked with supporting the health care institutions with ethics services that include ethics education, ethics consultation, and policy development.

In the global community, member states of UNESCO are signatories to UDBHR whose article 19 recommends that States “should encourage the establishment of independent, multidisciplinary, and pluralistic ethics committees.” This strategy is undertaken to “establish a pluralistic dialogue about bioethics issues between stakeholders and within society as a whole.” According to Claude Huriet, the attributes of ethics committees “are the evaluation of ethical problems linked to scientific and technological progress, formulation of advice on ethical dilemmas, educating and mobilizing the public.”

The influenza pandemic creates a situation that necessitates the evaluation of ethical considerations emerging from both clinical medicine and public health interventions. In clinical medicine, ethics committees partake in important decisions, by both patients and physicians, only by invitation of the principle parties. Public health ethics, on the other hand, pertains to decisions and actions, by government or public health agents, that
prevent disease and promote health populations even when it entails overriding individual autonomy.\textsuperscript{235}

While ethics committees have gradually gained ample competencies for engaging clinical ethics, organizational ethics, professional ethics, business ethics, and research ethics, the integration of ethics in clinical medicine and public health is still a slow work in progress. But lessons drawn from the experience of harmonizing clinical ethics, and organizational ethics can inform ethics committees in the new paradigm shift to public health ethics.

Haavi Morreim explains that, in clinical medicine, the free market system created “a competitive environment where marketing is virtually as important as medicine.”\textsuperscript{236} Market approaches introduced value conflicts that tend to be outside the competencies of clinical ethics. Economic influences by payers and providers led to conflicts of interest in areas of billing practices, access to health care, financial incentives and penalties to influence clinician’s decisions, and restriction on access to specialists.\textsuperscript{237} This development meant that the hospital’s obligation to the patient derived from two relationships. One is the patient-provider trust relationship, based on clinical ethics, and the other is the customer-supplier relationship governed by business ethics.\textsuperscript{238}

To ensure that business practices are ethical, the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) expanded its patient’s rights standards in 1995. The “Patient Rights and Organization Ethics” linked good management policy with good ethical practice.\textsuperscript{239} Accordingly, ethics committees began to draw from business ethics to address values-laden organizational ethical issues, and on clinical ethics to address patient-provider clinical issues. A consensus gradually emerged among ethicists that
clinical ethics and organizational ethics are components of one entity. The preferred approach became one that provided structures and processes that integrate rule-based and values-based approaches to yield practical ethical solutions, and address ethics quality in the health care organization, at all levels and across the full range of domain.\textsuperscript{240}

For instance, over the last decade, hospital ethics committees in the United States worked towards the harmonization of clinical ethics with business, or organizational, ethics. By the year 2009, the American Society for Bioethics and Humanities (ASBH) was no longer recognizing “clinical ethics and organizational ethics, as distinct entities.”\textsuperscript{241} The Veteran’s Health Administration, of the United States Department of Veterans’ Affairs (VA), undertook the in-depth integration of clinical ethics, and organizational ethics, in secular bioethics in the United States.

In an initiative that created the \textit{IntegratedEthics} Model, the VA expressed dissatisfaction with a clinical ethics approach that left non-clinical concerns unaddressed.\textsuperscript{242} They critiqued the clinical ethics approach for tending to be primarily reactive and case-based (responding to ethical questions that arise), and not “proactively indentifying, prioritizing, and addressing concerns about ethics quality at the organizational level.”\textsuperscript{243} Moreover, leaders tended to become aware of problems after a crisis occurrence.

The VA embarked on developing an ethics model that addresses ethics quality at all levels of the healthcare organization, taking into account both rule-based, and value-based approaches to ethics. The approach involved defining core functions of ethics committees as consultation, prevention ethics, and ethical leadership. These core functions are used to improve three targeted levels of quality, namely, decisions and
actions (consultation), systems and processes (preventive ethics), environment, and culture (ethical leadership).\textsuperscript{244}

The VA explained preventive ethics as concerned with addressing “the underlying systems and processes that influence behavior” rather than just waiting to respond to the arising individual ethics questions. The aim of preventive ethics is to “produce measurable improvements in an organization’s ethics practices by implementing system-level changes that reduce disparities between current practices and ideal practices.”\textsuperscript{245} A step-by-step ISSUES approach is used to address the ethics quality gap in health care. “I” stands for “identify the issue;” “S” stands for “study the issue;” “S” stands for “select a strategy;” “U” stands for “undertake a plan;” “E” stands for “evaluate and adjust;” and, “S” stands for “sustain and spread.”\textsuperscript{246}

Ethics Consultation, according to the VA, is a service that responds to individual ethics concerns arising out of people’s decisions and actions.\textsuperscript{247} Integrated ethics ensures high quality consultation through a step-by-step CASES approach. “C” stands for “clarify the consultation request;” “A” stands for “assemble the relevant information;” “S” stands for “synthesize the information;” “E” stands for “explain the synthesis;” and, “S’ stands for “support the consultation process.”\textsuperscript{248}

Integrated ethics utilizes ethical leadership as a tool for improving ethics quality at the level of the organization’s environment and culture. The VA supposes that leadership plays a critical role in “creating, sustaining, and changing the organization’s culture” when “they undertake behaviors that foster an ethical environment.”\textsuperscript{249} The ethical leadership role also involves ensuring that “employees throughout the organization are supported in adhering to high standards.”\textsuperscript{250} The VA outlines four “compass points” that
ought to be made clear, in words and actions, that state: “ethics is a priority, communicate clear expectations for ethical practice, to practice ethical decision making, and, support the facility’s ethics program.”

The VA’s approach is an example of a robust approach that integrates diverse competencies, and could provide guidance to ethics committees addressing population health on how to effectively strategize in the influenza pandemic preparedness and response. For instance, in 2006 when the VA began to hold staff discussion forums on ethics issues in influenza pandemic preparedness, they based their moral considerations on substantive values, such as individual liberty, protection of public from harm, solidarity, equity, and duty to provide care. The focus on these substantive values was not unconnected to the VA’s goal of improving ethics quality in the organization by targeting the three levels of actions and decisions (consultation), systems and processes (preventive ethics), and environment and culture (ethical leadership).

(iv) Role of Ethics Committees in Influenza Pandemic

Article 19 of the UDBHR document, which explicitly recommend the establishment of ethics committees, is necessarily connected with article 18 that specifies the spirit by which decision-making and addressing of bioethics issues ought to be approached. In article 19, the UDHBR sets out four constitutive attributes of ethics committees:

assess the relevant ethical, legal, scientific and social issues related to research projects involving human beings; provide advice on ethical problems in clinical settings; assess scientific and technological developments, formulate recommendations and contribute to preparation of guidelines on issues within the
scope of this Declaration; foster debate, education and public awareness of, and
engagement in, bioethics.\textsuperscript{254}

Ethics committees are useful strategies in pandemic preparedness and response if they
are pluralistic and multidisciplinary, and if they can demonstrate competence,
independence and transparence.\textsuperscript{255} They provide the diverse competencies needed to
engage logistical and scientific needs with moral dimensions, such as ethical principles,
norms, values, interests, and preferences in allocation of scarce resources.\textsuperscript{256} The cost of
not explicitly engaging and balancing these values, as the Canadian public health
providers learned in the SARS experience, is “loss of trust, low hospital staff morale,
confusion about roles and responsibilities, stigmatization of vulnerable communities, and
misinformation.”\textsuperscript{257}

Ethics committees are very effective tools in handling ethical problems in clinical
medicine, but they can also be successfully deployed on both state and local levels in
pandemic planning and response. The ethics committee members help to clarify issues
and delineate substantive and procedural principles required for the successful
management of the influenza pandemic. In some states, pandemic planning committees
used (implicitly) the model of ethics committees by involving people of diverse
backgrounds, such as ethicists, clinicians, lawyers, local and state public health officials,
and the local community, in decision-making regarding strategies for allocation of scarce
resources.\textsuperscript{258}

Article 18 of the UDBHR document provides that affected persons, professionals, and
society should engage in dialogue for the appropriate sharing of knowledge and
reviewing bioethics issues. The basic ethical features “of decision-making and addressing
bioethics issues,” as explicitly stated in the UDBHR document, are “professionalism, honesty, integrity, and transparency.” These features inform ethics committees in their role of evaluating ethical problems, advice formulation, and the mobilization and education of the public.

The Pennsylvania’s IPRP document, for instance, provides guidance that requires application of diverse clinical, and non-clinical, competencies in hospitals in concrete influenza pandemic situations. Discussions of these guidelines in hospital ethics committees could propel more effective, and more ethical, strategizing. The hospital ethics committee could be comprised of representation from administration, medical staff (physicians and nurses), emergency department staff, other departments, community representation, ethicist, lawyer, and public health personnel trained in disaster preparedness.

Due to the pluralistic and multifaceted ethical issues in the pandemics, the ethics committee may function better when divided into subcommittees to focus on the different specific interests of individuals, and the population. Each of the subcommittees could be tasked with focusing on ethical considerations in specific domains of moral complexity, such as a subcommittee on individual liberties (autonomy and individual responsibility), a subcommittee on protection of the population good (mandatory measures, allocation of limited resources, solidarity and community participation), and a subcommittee on the duty to care (clinical competence and solidarity).

Minimally, the subcommittee on individual liberties, or autonomy, should be comprised of a representative from the community, an attorney, a public health official, a staff member with clinical competence, and a person trained in ethics. This committee
would be tasked with the analysis and interpretation of how the IPRP statutory guidelines affect individual interests in the influenza pandemic response. This segment of the IPRP guides the use of coercive powers of quarantine, isolation, compulsory examination and treatment, mandatory reporting, and commitment to confinement. The subcommittee may need to debate the relevant application of ethical notions such as least restrictive means, equal treatment, necessity, proportionality, and reasonableness.

The ethics subcommittee on the protection of the population good (protection of the public from harm) could be tasked with promoting shared decision-making, reasons for public health control measures, communication strategies, mechanisms for effective engagement of all stakeholders, and providing justification for impinging on individual liberties. These discussions could be anchored in substantive principles such as solidarity. This committee should at least have representative from the community, a person trained in ethics, a public health official, a medical staff, and a representative from hospital administration.

The subcommittee on the duty to care need to address the clinical challenges associated with patient surge, resource allocation, additional professional demands, and personal and family safety. The reflection on the professional duty to care will necessitate focusing beyond adherence to rule-based professional codes to a commitment to the substantive principle of solidarity. The subcommittee on the duty to care need to have, at a minimum, a representative of hospital clinicians, a non-clinical staff, a public health officials, a person trained in ethics, and a community representative.

Subcommittees are appropriate strategies for breaking down complex ethical problems into manageable component that could be studied, and analyzed, by the
appropriate entities. Some members may represent a moral vision that is strictly prohibitive of actions that are not permitted, or consented to, by individuals. Other members may be inclined to support approaches that prioritize community interests such as, greater good for the greater number, maximizing life-years, prioritizing the worse off, or social value. The opportunity to debate and engage in dialogue paves the way for committee members to clarify and abridge diverse perceptions of the notion of just allocation of resources, or the link between autonomy and responsibility. 263

The work of subcommittees should be submitted to the full ethics committee to further reconcile appropriate procedures, goals, and objectives. Subcommittees contribute to the multidisciplinary representation, and allow for a consideration of diverse competencies. The plurality of moral thinking brings rigor and balance to the ethical discourse as the ethics committee seeks to zero in on balancing the relevant substantive, and procedural, principles. But, the influenza preparedness and response plan will keep evolving as the substantive and procedural values are regularly analyzed, and reassessed, based on the most objective determination of the available scientific information, effectiveness of care, and resource capacity.

D. Summary

The influenza pandemic outbreak is likely to lead to drastic increases in morbidity and mortality. It will overwhelm public health resources and infrastructure, while prompting public health officials to resort to coercive measures and contentious allocation decisions. In the attempt to protect the interests of the population, individual interests will be subordinated. The principles approach has demonstrated its worth in
clinical medicine that prioritizes the individual’s choices and individual liberty interests. But population health presents a different paradigm that is accommodative of individual, and population, interests at different levels, and, involves pluralistic moral considerations such as utilitarian, egalitarian, and communitarian.

The Mixed Interests Ethics Model (MIEM) proposed by this dissertation provides policy-makers, and health providers in the influenza pandemic, with a set of ethical tools to facilitate a balance between individual and population interests. MIEM is consistent with the bioethics principles-approach developed by UNESCO in the Universal Declaration on Bioethics and Human Rights document. MIEM enhances the amelioration of individual and human rights in the influenza pandemic intervention, by requiring the subjugation of substantive and procedural principles, to a rigorous analysis of specification, meaning, scope and justification. The individual-oriented substantive principles of autonomy, as protected in libertarian ethics, is contrasted with the population-oriented substantive principle of solidarity, as promoted in utilitarianism, egalitarianism, and communitarian ethics.
5. Chapter Five
The Importance of MIEM for Policy Development in the HIV/AIDS Epidemic

Introduction
The global fight against HIV/AIDS is probably the most recognizable altruism-driven public health intervention in the last three decades. Uganda in particular has been the beneficiary of immense generous monetary grants and volunteer HIV/AIDS experts from international organizations, such as the Joint United Nations Program on HIV/AIDS (UNAIDS), United Nations Children’s Fund (UNICEF), and the U.S. Agency for International Development (USAID). Other contributions of resources, health volunteers, and researchers came from individual countries all over the world. Likewise, numerous international faith-based organizations, academic institutions, and philanthropist such as Bill Gates, made the global fight against HIV/AIDS a priority.

The global HIV/AIDS movement for networking, participation, and monetary contributions arose out of the shared urgent need for a concerted intervention effort. HIV/AIDS was understood as one of the worst global threats to the safety and health of populations and the overall wellbeing of people in the twenty-first century. By 1997 an estimated 30.6 million people worldwide had been infected with HIV, or advanced to the AIDS disease. Of these, 30.6 million, “an estimated 21 million were residing in sub-Saharan Africa.”

The stark difference in the distribution of HIV/AIDS among the world’s populations, and the contrast in intervention capabilities, came to be seen in terms of the economic imbalance between the wealthier developed nations, and poor resource nations. Some
ethicists began to argue that wealthier nations, with an aggregate national income exceeding $21 trillion, had a moral obligation to contribute the estimated $7 to $10 billion needed annually for global HIV/AIDS intervention. The initiative was eventually framed as a safety and health issue, as well as a social justice and human rights issue.

One of the most successful, and yet most criticized foreign sponsored HIV/AIDS program in Uganda, was the President’s Emergency Plan for AIDS Relief (PEPFAR) that commenced in 2003. The U.S. funded program adopted Uganda’s behavioral change policy known as Abstinence, Faithfulness, and use a Condom (ABC). The PEPFAR initiative remarkably reduced mother-to-child (PMTCT) HIV transmission, increased access to anti-retroviral treatment, and improved counseling services and palliative basic care.

However, not much of these success stories impacted global public health ethics literature and discourse as strongly as the controversies regarding condoms, abstinence-only, and minority rights. The disputes emerged from a pushback against a provision in the PEPFAR that allocated a small portion of the funds to promoting abstinence-only programs. But, as the controversial discourse, often referred to as the “ABC debate,” intensified the HIV prevalence began to rise.

While many public health and human rights experts agree that a human rights framework is the appropriate strategy for addressing HIV/AIDS policy and prevalence, the interpretation and application of human rights is not univocal. In some instances, human rights claims have been expressed in a language that is overly high-pitched and divisive on the issues of HIV intervention, human rights, and social-cultural diversities. HIV/AIDS intervention in Uganda needs a human rights-based ethical guidance, such as
suggested by the bioethics principles approach of UNESCO’s Universal Declaration for Bioethics and Human Rights (UDBHR), and as made practical, by engaging the Mixed Interests Ethics Model (MIEM).

Engaging and critiquing the aforementioned diverse perspectives regarding HIV prevention in Uganda necessitates the deployment of the Mixed Interests Ethics Model. MIEM requires balance between the underlying individual interests and population interests through a critical analysis of the moral conviction informing the competing belief systems. This normative analysis approach is necessary for purposes of enhancing communication, coordination, collaboration, and cooperation, as well as the amelioration of health and human rights.

This chapter identifies and applies two substantive principles relevant to Uganda’s ABC and PEPFAR initiative to fight HIV/AIDS. The principles are non-stigmatization and non-discrimination, and the principle of the common good. The UDBHR document included the principle of non-discrimination and non-stigmatization in article 11. Balance is negotiated through the strategy of specification, justification, and limiting the application of the principles by considering procedural standards such as reasonableness.

A. MIEM and the Illustrative Principles of the Common Good, and Non-discrimination and Non-stigmatization

(i) Behavioral change, Civil Liberties, Human Rights, and HIV/AIDS in Uganda.

Uganda, a country that gained global prominence for its behavioral change-based HIV prevalence reduction from 18 percent to about 6.2 percent in the 1990s, stands to lose its gains as HIV/AIDS prevalence rose from 6.5 percent in 2009 to 7 percent in
The civil societies’ umbrella organization – Uganda Network of Aids Services Organization (UNASO) – blamed the regress on unqualified staff, and inadequate services in Uganda’s district health centers and hospitals. Some epidemiologists denounced the uncoordinated responses by pro-gay and lesbian civil societies as obstructive to the goals of HIV prevention. The Uganda AIDS commission attributes the HIV rise to complacency. Other voices attributed the problem to Uganda’s failure to scale up biomedical intervention of prevention of mother-to-child transmission (PMTCT), safe male circumcision (SMC), and universal access to antiretroviral medication (ART).

While it may appear that all of these measures were essential for HIV prevention, parties chose to overemphasize different key drivers to foster the narrative that best suited their preferred intervention options, be it biomedical, civil liberties, individual rights, minority rights, or behavior change (ABC). Soon after the President’s Emergency Plan for AIDS Relief (PEPFAR) was initiated, disagreements emerged between global AIDS experts who favored advancing the behavioral change approach (partner reduction, age of sex debut, condom use), and those for the scaling up of scientific tools and broad structural factors, such as the economic empowerment of vulnerable populations and protection of minority’s rights.

For Jonathan Cohen and colleagues, the very idea of focusing on the A, B, and C in Uganda’s HIV prevention was a sanctioning of discrimination and stigmatization. These researchers argued that:

For too many Ugandan, especially women and girls, ABC is not enough. In 2003, we interviewed Ugandan women who described how domestic violence caused or
contributed to their HIV infection. These women could not “abstain” from being raped by their spouses; much less insist on their fidelity or condom use. Nor is ABC an effective strategy for girls who face rape or sexual coercion … Programs should focus on empowering vulnerable populations to achieve economic independence, protecting their legal rights, and providing them with the information and tools they need to prevent HIV – not preaching abstinence until marriage.\textsuperscript{17}

Several studies, including the World Health Organization/Global Program on AIDS (WHO/GPA) survey, established that AIDS-related behavior change occurred in Uganda in three areas: “increase in the age of sexual debut by adolescents, reduction in number of non-regular partners, and increase in condom use, especially after 1993.”\textsuperscript{18} According to Edward Green and colleagues, Uganda’s behavioral change-based approach to HIV prevention, that led to a dramatic decline in HIV prevalence in the 1990s continued to generate considerable interest and debate among researchers and policymakers in global public health.\textsuperscript{19}

By the year 2006, some public health experts, such as Rand Stoneburner and Daniel Low-Beer, had come to the conclusion that “a decrease in casual/multiple sexual partner behavior” rather than “mainly condom use or increase in mortality” was the overriding factor that led to the HIV prevalence decline. Other analysts such as Bob Roer, Jonathan Cohen, Rebecca Schleife, and Tony Tate insisted on the scaling up of scientific tools, and an array of broader structural factors, such as reduction of poverty, gender violence, and conflict.\textsuperscript{20}
Neither proponent of A or of C explicitly took an extreme position that negated any relevance of condoms or partner reduction. Yet the discourse developed into the intense ABC debate that gradually narrowed down to an A (abstinence) versus C (condoms) controversy—a development, these writers suggested, that may have occurred “perhaps inadvertently.” But a careful analysis of diverse literatures on the topic reveals that these developments were not random, but an inevitable upshot from the ethos of the early HIV/AIDS discourse in the United States, that shaped the tension between civil liberties (or individual interests) and the public health’s focus on the common good.

In the 1990s when Uganda used the socio-cultural tools of behavioral change to successfully reduce the rising HIV prevalence rate, global public health ethics, was also undergoing a metamorphosis. The evolution started in the early days of HIV/AIDS in the United States when public health, civil liberties, and social justice were linked. The initial strategy was the identification of homosexual men, bisexual men, and intravenous drug users (IDUs) who were labeled as risky groups, before the focus shifted to risky behaviors.

When identifying those “with asymptomatic HIV infection” became a matter of clinical urgency in the United States, gay organizations “began to argue homosexual and bisexual men to have their antibody status determined under confidential or anonymous conditions.” Physicians maintained that HIV-antibody tests be considered just like any other blood tests that required only a presumed consent of the patient. Using rights-based arguments, advocates also sought to “preserve the (autonomous) right of pregnant women to undergo HIV testing only after special informed consent.” But the prospects of saving the newly born babies from HIV infection, through the administration of
zidovudine to pregnant seropositive women, caused many to argue for routine testing of pregnant women, and mandatory screening of newborn babies.29

New developments in global public health ethics in the 1990s led to an explicit linkage of public health with social justice and a focus on human rights.30 This was thought of as a new way of “defining and advancing human wellbeing.”31 But, while some saw the economic, social and cultural rights asserted in the International Covenant on Economic, Social, and cultural rights (ICESCR) as complimenting the civil-political rights in the International Covenant on Civil and Political Rights (ICCPR), others considered ICESCR as optional.32

Even as public health and human rights were being linked, some epidemiologists and ethicists could not overcome the division that characterized the two human rights treaties in the mid-20th century. Those committed to advancing the interests of liberal states were inclined to emphasize civil and political rights. Those who saw governments as obligated to “meet basic economic and social needs” of people tended to emphasize the ICESCR.33 These two approaches appear to have been in play as the Uganda ABC and PEPFAR debate engaged individual rights and freedoms, and diversities of beliefs and cultural-social values.

As the transnational, global civil societies assumed the responsibility for global HIV/AIDS and human rights advocacy, as well as the role of advancing democratic practices, tension began to re-emerge regarding conceptual issues about human rights, and cultural diversity.34 Not all human rights claims advanced a balanced and more realistic view of human rights. Tom Hadden referred to this phenomenon as the “The pendulum theory of individual, communal and minority Rights.”35
According to Hadden, those who promote the individualistic understanding of human rights hold the view that “human rights can be deduced from, or at any rate linked to, the nature of the human individual.”\textsuperscript{36} The absolutists regard human rights as “absolute and unchanging and can therefore be used as a basis for the development of a global theory of democracy and governance.”\textsuperscript{37} Others are of the view that “all human rights are of equal status and that non-can be subordinated to any other.”\textsuperscript{38}

Roberto Andorno states that “in many Western nations there has been an excessive emphasis on rights and freedoms for the individual, sometimes to the detriment of families and community values, which are of paramount importance to most non-Western societies.”\textsuperscript{39} This scholar advances his argument in defense of the bioethics principles-approach stipulated in the UNECSO’s Universal Declaration on Bioethics and Human Rights (UDBHR) document, as the most effective way of engaging health and human rights.\textsuperscript{40} The UDBHR draws legitimacy from the universal recognition that every human being has an inherent dignity, and inherent rights, simply by virtue of being human. Subsequently, “human rights emerge from international law instrument with sufficient flexibility to be compatible with full respect for cultural diversity.”\textsuperscript{41}

Tony Barnett and Priers Blaikie were among the first researchers to explore the link between the AIDS epidemics and the socio-cultural, economic and political dynamics that prevailed before, and during, the 1980s in Uganda. The two researchers made an inquiry into the societal structures of sexual relations, such as marriage expectations, cohabitation and kinship, and how they impacted on the vulnerability to HIV/AIDS epidemic.\textsuperscript{42} The study contributed to the understanding of behavioral change, in terms of addressing the conditions and environment in which risky behaviors occur rather than
focusing solely on the individual behavior, as had been done in the early days of
HIV/AIDS in the West.\textsuperscript{43}

The high rate of HIV/AIDS infection, in the 1980s, was largely attributed to civil
wars that created an environment of economic inequality, and disruption of social identity
and property relationships.\textsuperscript{44} After the civil war in 1986, President Yoweri Museveni
sought to combat the spread of HIV/AIDS by reviving traditional societal structures to
harness their social cohesion and the power of community mobilization, as well as
interpersonal communication.\textsuperscript{45} Through a behavioral change strategy, articulated in
slogans such as “Zero Grazing,” “Love Carefully” and “Abstain, be Faithful, use a
Condom (ABC),” the HIV prevalence rate was reduced from a high of 18 percent in 1992
to 6.2 percent in 2004.\textsuperscript{46}

The approach involved partner reduction, delay of sex-debut, condom use, and
improvement of women’s rights, such as the education of girls.\textsuperscript{47} Despite improvement,
however, issues of discrimination and stigmatization still occur in Uganda. With the
availability of donor funds, such as PEPFAR and the Global Fund to fight AIDS, one
would expect the HIV prevalence rate in Uganda to have dropped to lower than 6 percent
in the last nine years. Instead, HIV prevalence stabilized at a rate of 6.1 percent to 6.5
percent before it began to rise in 2006. By 2011, the prevalence rate had risen to 7
percent.\textsuperscript{48}

The set back did not come as a surprise to some scholars and experts who had all
along argued that parties advancing competing interests were undermining Uganda’s
behavioral change-based program.\textsuperscript{49} The abstinence-until-marriage provision in the
PEPFAR program triggered a divisive debate among donors, and involved parties who
cast doubt on the whole idea of the effectiveness of the behavioral change, particularly the ABC-based approach in Uganda. Some United States-based evangelical groups teamed up with their colleagues in Uganda to prioritize the abstinence and fidelity part of the ABC strategy while discrediting condoms.\textsuperscript{50} The counter-criticism, led by Human Rights Watch, sought to discredit the ABC while retaining the condom component.\textsuperscript{51}

Jonathan Cohen and colleagues initiated a paradigm shift when they framed the Uganda ABC-based behavioral change strategy as a human rights issue.\textsuperscript{52} They argued for a new direction that would guarantee the rights of vulnerable minorities such as children, lesbian, gay, and transgender persons. They sought to ensure that these groups of people “are explicitly recognized in national and local HIV prevention policies and programs.”\textsuperscript{53} As the support for homosexual rights in Uganda gained support in the international community, the government of the United States counteracted the resistance in Uganda with a policy of attaching foreign aid to improving gay rights in developing countries.\textsuperscript{54}

Global initiatives were also being undertaken to advance women’s rights. It is generally accepted that gender imbalances in sub-Saharan Africa influence men’s violation of women’s rights, and also increase women’s risks of acquiring HIV/AIDS.\textsuperscript{55} According to Jacques du Guerny and Elisabeth Sjoberg, the economic dependence of women, coupled with their lack of decisional power, makes it impossible for women to have influence over sexual matters, such as demanding their partner use of condom.\textsuperscript{56} Some studies have also established that girls who marry in adolescence have higher rates of HIV because an increase in coital frequency, along with a decreased use of condoms, result in girls’ diminished abilities to abstain from sex.\textsuperscript{57}
While the parliament of Uganda passed the Domestic Violence Bill in 2009, the more comprehensive Domestic Relations Bill tabled in parliament in 2003, was still shelved by 2010. The involved parties were reluctant to accept the necessary tradeoff between cultural rights and individual rights. The bill sought to initiate reforms in marriage, separation, and divorce, as well as property rights. The targeted issues were polygamy, co-habitation, dowry, wife inheritance, early marriages, marital rape, and domestic violence against women. The most contentious issues on which agreement could not be reached were property rights, co-habitation, and restriction on polygamy.

Muslims, and some traditional cultural societies, objected to restriction on polygamous marriages. The 2008 revision of the Domestic Relations Bill, which was issued in two drafts, included a provision for customary marriages within the law. It was provided that for Muslims, legally constituted lower Qadhic courts under the High Court would be established to deal with marriage, divorce, guardianship, and inheritance of property, in accordance to Islamic law. The provision to regard partners who had cohabitated for ten years or more as married was dropped in the new draft because Christians and Muslims alike objected to it.

It is likely that not many Western human rights advocates and ethicists are aware of the role played by the government, and faith-based organizations, in Uganda, in the fight against gender-based HIV/AIDS stigma and discrimination. In 2003, the Catholic Bishops of Africa and Madagascar (SECAM) directly addressed the issue of stigma and discrimination in their workshop on HIV/AIDS in Dakar, Senegal. According to Michael Czerny, the SECAM bishops pledged to work “tirelessly to eradicate stigma and discrimination and to challenge any social, religious, cultural and political norms and
practices which perpetuate such stigma and discrimination. The bishops of East Africa emphasized the need for all people to respect the dignity and rights of people living with HIV/AIDS, and to care for them.

According to Sofia Gruskin and Daniel Tarantola, “adverse discrimination occurs when a distinction is made against a person which results in their being treated unfairly or unjustly.” Those groups that “do not share the characteristics of the dominant group within a society” are targets for discrimination. This implies “social inequality and a denial of equal opportunities.” For this reason, gender or class based-discrimination is prohibited in all major international treaties, and international declarations.

UNESCO’s Universal Declaration on Bioethics and Human Rights (UDBHR) document included a principle prohibiting discrimination or stigmatization in violation of human dignity, human rights, and fundamental freedoms. This bioethics principle was derived from article 7 of the Universal Declaration of Human Rights (1948) which asserts that:

All (human beings) are equal before the law and are entitled without any discrimination to equal protection of the law. All are entitled to equal protection against any discrimination in violation of this Declaration and against any incitement to such discrimination.

With the ABC and PEPFAR ethical discourse increasingly focusing on human rights, the argument was no longer whether discrimination occurs in Uganda, but whether parties could reconcile their differences regarding the meaning and interpretation of human rights. This challenge is a reminder of the question Jonathan Mann and colleagues raised, but did not satisfactorily address, regarding how to negotiate an optimal balance.
between public health goals and human rights norms, given the inevitability of conflict.\textsuperscript{68} This challenge has become even more urgent given that public health and human rights are understood to be enabled by the pragmatic-oriented global transnational HIV/AIDS advocates.

From a political-philosophical analysis, globalization affected public health at the level of human rights. The implication of globalization for democracy meant a global dimension of “the democratic recognition of a broader range of human needs” that set “a gradual trend for international recognition of justice and human rights.”\textsuperscript{69} Another related development of globalization, according to Deen K. Chatterjee, is the “surge of pluralistically oriented social and political movements within both democratic and nondemocratic countries.”\textsuperscript{70} These two developments “share the common democratic ideas of autonomy, equality, and political participation, as well as the spur of globalization.”\textsuperscript{71}

In this new way of conceptualizing global interconnectedness and participation, communities are conceived and empowered as “cross-border localities.”\textsuperscript{72} In question, however, is the relevance, or irrelevance, of the old democratic principle of autonomous self-government. Likewise, the diversity of culture, social and political formations presents a complex problem in the application of cosmopolitan norms to different localities. But, of significant importance to some advocates of liberal cosmopolitanism is the idea that solidarity entails “cross-border interactions among members.”\textsuperscript{73} While the link between public health and human rights has been fairly well argued in the normative analysis of public health, the specific modalities of liberal cosmopolitan-biopolitics are inconclusive.
As provided for in MIEM, the discourse over HIV prevention and human rights protection in Uganda must be subjected to an in-depth ethical analysis of the specification, meaning, scope, and justification of the competing moral claims, so that a balance via the appropriate procedural standards such as reasonableness and necessity can be successfully negotiated. Attempts to balance competing interests ought to engage the link between public health, human rights, and the new component of liberal cosmopolitanism that involves networked transnational advocates.

(ii) Human Rights and Reductionism in Uganda HIV/AIDS Intervention

In his assessment of the policy trajectory of the heterosexual prevention of HIV in Uganda, Edward C. Green, in the year 2003, boldly questioned the ethical objectives of some international agents. He framed his concern as follows:

We who work in AIDS, as in other fields, fall into thinking and operating within certain paradigms which become mindsets, which in turn erect blinders to ideas and evidence that fall outside – or contrary to – the prevailing paradigm.\(^74\)

He was frustrated with the Western approaches that he characterized as advancing embedded ethnocentric interests over public health goals of the health and safety of populations in Uganda, and other developing countries.\(^75\)

The main target of Edward Green’s criticism was donor agencies, such as UNAID and USAID, that allocated the billions in AIDS prevention funds worldwide based largely on what they thought they knew about AIDS in America in the mid-1980s, and not on the facts on the ground in those developing countries.\(^76\) Green’s observation was later to be supported by Helen Epstein, in 2007, who claimed that UNAID and USAID had for years ignored the hard evidence, presented by researchers such as Maxine
Ankrah, that partner reduction was largely responsible for HIV reduction in Uganda in
the 1990s.\textsuperscript{77}

Green’s criticism could not be ignorable following the divisive, and partisan, debate
over the policy priorities of the President’s Emergency Plan for AIDS Relief (PEPFAR)
initiatives. The 2003 PEPFAR act by the U.S. Congress required that 55 percent of the
funds be spent on treatment of individuals with HIV/AIDS, 15 percent on palliative care,
20 percent on HIV/AIDS prevention, and 10 percent on helping orphans and vulnerable
children. Of the 20 percent designated for HIV/AIDS prevention, Congress further
directed that 33 percent (approximately one billion dollars) be used on abstinence-until-
marrige programs. Moreover, a “global gag rule” prevented funding any organization
that engaged in abortion services.\textsuperscript{78}

The move to insert the abstinence-until-marriage provision superimposed the already
explosive United States’ moral discourse regarding condoms, abstinence until marriage,
women’s rights, and gay rights onto the Uganda behavioral change-based prevention
strategy. The once effective behavioral change model, known by the acronym of ABC in
Uganda, succumbed to the relentless demands for change. Critics insisted that it was
insufficiently suited to the task of HIV/AIDS prevention. This verdict emerged right from
the moment the PEPFAR plan included the abstinence-only requirement, endorsed by
Conservatives, but drew the ire of critics who otherwise preferred condom use.\textsuperscript{79}

The confrontation gradually transformed into a divisive and stifling debate among
donors, activists, politicians, and ethicists over whether HIV/AIDS prevention in Uganda
should be a behavior change issue, a civil liberty issue, or a human rights issue. But,
following the persistent criticism of the “abstinence until marriage” provision, the
PEPFAR reauthorization of 2008, which also tripled the fund, did not include directives on how the funds were to be spent.\textsuperscript{80} President Obama’s administration that came to power in 2009, sought to change the controversial aspects of PEPFAR by replacing what he called “ideology” with “best practice.”\textsuperscript{81}

According to Andrew Green, the lynchpin for U.S. President Obama’s goal for an “AIDS-free generation” comprised “prevention of mother-to-child transmission (PMTCT), safe male circumcision (SMC), and access to universal treatment.”\textsuperscript{82} While these biomedical instruments are proven interventions, HIV/AIDS is also a social-cultural encounter. One of the initiatives of President Obama’s government to address the socio-cultural component was the 2011 policy of attaching foreign aid to the promotion of gay rights abroad. This policy, however, did not help to abate the tension surrounding the PEPFAR and ABC related controversies.\textsuperscript{83}

Critics of the behavior change ABC strategy in Uganda had argued that it was discriminative and against human rights since it gave unfair advantage to the choices of men over women, and was repugnant to the sexual preferences of gay people. There were those who dismissed the whole notion of marriage as useless for purposes of HIV/AIDS prevention in sub-Saharan Africa. They argued that “to the extent that abstinence-only-until-marriage approach promotes marriage as a safeguard against HIV infection, it potentially endanger the lives of individuals who face a high risk of HIV infection from their spouses.”\textsuperscript{84}

But there were also people that did not apportion blame for increased HIV infection among women on the institution of marriage, per se, but on the overall female-male gender relation. They pointed out that different cultures assign different gender-based
roles to women and men. While men are assigned more economic and political power, “women are more likely to be in economic dependent positions, implying a lack of power, lower status, and limited influence on decisions concerning themselves and families.” So, the heterosexual spread of HIV, particularly as relates to the vulnerability of women, results from, an inability for self-protection “because of their lower cultural and economic status and their lack of influence on sexual relations.” For these experts, the way forward for women’s rights and wellbeing is to improve, or change, their social status.

Those who put the blame on marriage appeared to be of view that African heterosexual men are prone to predatory sexual lifestyles of rape, marital infidelity, and domestic violence while African women are reluctantly forced into marital submissions sanctioned by oppressive cultural bondages. This perspective is reconcilable with an old western missionary view of African sexuality as an “exotic, traditional, irrational and immoral practice.”

But, some scholars and ethicists who, although they agree that marriage infidelity and sexual violence against women occur in Africa, maintain that predatory sexual life is not an endemic feature by which Sub-Saharan heterosexual relationships should be characterized. Africa, retorted Helen Epstein, is not “the Sodoma and Gomorrah depicted by nineteenth century missionaries.”

Most of the studies that put the blame on marriage tend to treat Africa as a culturally homogeneous society. Ignored are the significant differences in cultural practices pertaining to ill health, adolescence initiation, courtship and marriage, family, and kinship affiliation. Absent from these literatures is mention of the basic characteristic
features and relationships in marriage, such as the notions of love, husband, wife, mother, mother-in-law, daughter, son, brother, sister, and sister-in-law.\textsuperscript{91} It is incomprehensible that sub-Saharan African people could be perceived as so different from their Western counterparts to such an extent that marriage, in their case, is seen as profoundly and miserably devoid of love and kinship relations.

Despite disagreements over the scope and nature of human rights violations against minority groups, ethicists and public health agents agree that HIV/AIDS prevention in Uganda ought to change course, and address human rights issues concurrently with public health goals.\textsuperscript{92} Both in Uganda, and in the global community, it is acknowledged that some forms of discrimination based on gender, or sexual orientation, occurs in Uganda.\textsuperscript{93} But, as to whether the anti-marriage stance is the most appropriate human rights response is questionable. Debatable also is the wisdom of cutting foreign aid as a punitive measure to enforce the recognition of gay rights, instead of utilizing ethical tools, such as empathy, education, cooperation, coordination, and collaboration, with all involved parties.

For some transnational advocates in the West, the stakes are high for protecting the sexual freedoms of some minority groups in developing nations. A systemic change of the cultural, political, and religious beliefs that infringe on the individual rights and freedoms of private citizens should take priority over any other procedural considerations.\textsuperscript{94} Accordingly, there is an urgent need for involving the global civil society, born of systems of democracy that gives voices to the undermined, such as the sexual minorities in countries like Uganda.\textsuperscript{95} Global civil society, according to Graham
Long, “incorporates transnational social movements, NGOs and less formalized individual or socially embedded activism.”

The combating of HIV/AIDS gave rise to the new field of health and human rights that engages social justice issues. Accordingly, “civil libertarians turned to the language of human rights to defend persons living with HIV/AIDS from stigma and discrimination.” In this sense, scholars such as Amartya Sen considered the task of improving health as also entailing improvement in participatory politics that involves the public, who see themselves as both patients and agents of change. The justification for political participation in the establishment of health populations has given rise to transnational global advocacy networks for the advancement of human rights.

But some scholars have drawn attention to the possibility that advocates use human rights language in different and overlapping ways. Lawrence O. Gostin explains that:

Some use human rights to mean a set of entitlements under international law.

Others use human rights to mean a set of ethical standards that stress the paramount importance of the individuals. Still others use human rights language for its inspirational, or rhetorical, qualities.

It appears that all three aspects of the use of human rights language were in play in the manner advocates attempted to engage diversity and human rights for purposes of influencing the trajectory of the ABC and PEPFAR initiatives in Uganda.

The justification for invoking human rights rests on inviolability of the inherent dignity of human beings, irrespective of their gender or sexual-orientation. But, depending on whether the goal is to emphasize individual rights over social rights or vice versa, parties involved in the PEPFAR/behavioral change ethical discourse in Uganda at
times invoked the language of human rights in ways that made them appear synonymous with civil rights, legal rights, and social rights. These approaches gave rise to human rights reductionism, which manifests in forms of legal positivism or in the thinking that what is beneficial is a right.

Legal positivism was manifested in Uganda’s anti-homosexual, private member’s parliamentary bill, and in the Western response that attached foreign aid to the demand for reform, or enactment of laws, promoting gay rights. The justification for non-discrimination is the inherent dignity of being human, and not differences such as heterosexual or homosexual. Policies that are based on formulations such as, “human rights are gay rights and gay rights are human rights,” appear to suggest that human rights and gay rights are synonymous. The cause of harmonizing global health with human rights is advanced by conceptual clarity, and not with ambiguity.

At least by the year 2011 it was clear Uganda had lost its focus on the behavioral change HIV prevention strategy. Some blamed policies of abstinence-only, marriage or anti-marriage, scarcity of condoms, and discrimination against sexual minorities, as responsible for the rise of HIV. Other critics blamed activists who had consistently campaigned against behavioral change approaches. There were also those who attributed the problem to complacency, and the new understanding that HIV had become a chronicle condition, rather than an acute fatal condition, due to the availability of antiretroviral drugs.

Some ethicists argue that ideology drove the debate on whether HIV/AIDS intervention in Uganda is a behavioral change issue, a civil liberties issue, or a human rights issue. Although, as believed by ethicists, ideology does not account for all
aspects of the agent’s response to HIV initiatives, but it shapes and guides the trajectory of the agent’s perceptions and objectives. To unravel the genuinely ethical issues from some of the deceptive elements therein, it is necessary to engage in an analytical ethical inquiry that goes beyond ideological identity.

The ethical inquiry ought to start with the early days of HIV/AIDS in the United States, when the country struggled to find balance between the public health goals of wellbeing, and political ideologies associated with race, ethnicity, gender, and sex orientation. This is precisely because the first phase of HIV/AIDS intervention in the early 1980s focused on risky behaviors, such as gay activities and prostitution. The focus on behavioral change was partly due to limited therapeutic intervention, but also largely because of prejudice based on gender and differences in sexual orientation.

Because the first cases of what was then regarded as an unusual immune deficiency were identified in gay men, it was erroneously thought that HIV/AIDS was a disease of gay people and prostitutes. Worse still, women were underrepresented in the first attempts to find treatment for HIV/AIDS. As Nancy Kass explained that, even by 1991, “no large studies of the effect of HIV infection on women’s health” had been undertaken. Yet, eighty million dollars had been spent “on a single study of the natural history of HIV in gay and bisexual men.” Discrimination and stigmatization of gay people resulted in activism and advocacy for civil liberties.

Public health agents acknowledged the need to balance between population health-based behavioral change priorities and the individual’s need for civil liberties and freedoms. For the objective of the overemphasis on behavioral change was the promotion of population interests while those that overemphasized civil liberties tended to promote
individual interests. When the global fund to fight HIV and the PEPFAR programs were implemented in Uganda, donor agents projected the experience and lessons learnt in the first phase of HIV in United States onto Uganda’s HIV/AIDS ethical discourse.113

While Uganda’s first phase of HIV prevention, in the 1990s, focused on behavioral change, the PEPFAR intervention in 2003 marked the beginning of a second phase of an ethical discourse that prioritized individual rights and civil liberties. In 2005, Human Rights Watch protested to the government of Uganda demanding that HIV policies and programs incorporate the special needs of affected children, displaced persons, lesbians, gay, bisexual, transsexual, and transgender persons. Human Rights Watch insisted that Uganda abandon support for the PEPFAR’s behavioral change provision of abstinence-until-marriage.114

The tension, which negatively impacted on the PEPFAR and ABC program, played out in a manner that pitted pro-abstinence against anti-abstinence, and pro-gay against anti-gay activists.115 The pro-abstinence and anti-abstinence fight was evident in the U.S. Congress between some Republicans and Democratic congressmen at the launching of the PEPFAR program before the tension extended to Uganda.116 In Uganda, the pro-abstinence First Lady, Janet Museveni, started a chastity scholarship program to encourage girls to remain virgins until marriage as a means of HIV prevention.117 An evangelical church group also started an abstinence club by the name of Glory of Virginity Movement (GLOVIM).118

The pro-gay and anti-gay tension was as contentious as the abstinence fight. An article provided by the U.S. Center for Disease Control and Prevention, in 2007, stated that “the New York-based Human Rights Watch sent a letter to the U.S. officials
demanding that United States reconsider funding HIV/AIDS programs in Uganda, where it claimed recipients of such money violate the rights of homosexuals.”

In Uganda, Pastor Martin Ssempa of the faith-based organization Campus Alliance to Wipe Out AIDS (CAWA) became the most outspoken anti-homosexuality, anti-condoms, and pro-abstinence only religious figure.”

By 2006 divisions among HIV/AIDS experts in the global community were beginning to emerge between those who attributed much of the HIV prevalence decline to a decrease in multi-partner sexual behavior rather than merely condom use, and those who credited the success to scientific tools and “broader structure factors.” According to Edward Green and colleagues, one school of thought “concluded that a decrease in casual or multiple sexual partner behavior, rather than mainly condom use or increase in mortality, was primarily responsible for Uganda’s success.” Other HIV/AIDS experts argued “in favor of the more prevailing prevention approach that has centered on condom promotion and HIV testing as well as an array of broader structural factors, such as poverty, gender violence and conflict.”

According to Green and his colleagues, the Uganda behavioral change analysis, at least as published in leading scientific journals, “has not argued that such broader factors, as well as condom use were unimportant.” Likewise, those also who criticized the partner reduction theory did not take an extreme position, such as – condoms only with no role for partner reduction. Regrettably, the arguments focused on the relative importance of the different ABC factors (Abstaining, Being Faithful and Condom use), and perhaps inadvertently drove the ABC debate to the polarizing arguments of A versus C.
Gradually the debate began to evolve from the condom-abstinence discourse to rights-based arguments. By the year 2011 international, non-government organizations, such as Human Right Watch had intensified their criticism of the discrimination and stigmatization of people in Uganda based on their sexual orientation and gender identity. The controversies evolving around the Uganda anti-homosexuality private bill, and gay rights activism, appear to have dominated all other considerations relating to the HIV/AIDS prevention discourse in Uganda.¹²⁷

There was also another important initiative associated with the notion of justice for women with HIV that had focused on HIV microbicides research. One such clinical research study was the 2007 candidate cellulose sulfate clinical trial, in Uganda and other developing countries. The ethical justification for conducting this research was the felt need to urgently make scientific tools (HIV inhibitors) available to assist women who were at greater risk of HIV infection due to social vulnerability.¹²⁸

The microbicides research conducted in Uganda was not unrelated to the campaign in the United States, in the late 1980s, to include women in biomedical research as a matter of justice.¹²⁹ Women were harmed by the exclusion from HIV research, since medical professionals could not acquire knowledge of women vulnerability or manifestation of HIV infection. Women were often undiagnosed, and consequently untreated, for HIV and AIDS.¹³⁰ Likewise, the new initiative to intensify HIV research in Uganda, and other developing countries, was understood as an issue of justice to remedy the powerlessness of women in matters of sexual choices and HIV susceptibility.¹³¹

These initiatives to improve minority rights in Uganda’s HIV/AIDS intervention program resembled the phases of the HIV/AIDS ethical intervention in the United States.
The HIV/AIDS discourse in both countries appears to have progressed from an overemphasis on behavioral change, to civil liberties, and to human rights. The outstanding ethical issues driving this progress pertained to distributive justice, stigmatization, and discriminations based on gender, race, and sexual-orientation.

In between the transition from emphasis on civil liberties to human rights was the phase of “the resurgence of public health traditionalism,” in the United States. This period was characterized by increased support for mandatory HIV preventive measures, and less resistance to the inversion of the individual’s liberties where populations were at risk. As scientific evidence increasingly indicated that early detection of HIV infection was good for effective preventive measures using antiretroviral therapy, ethicists began to interpret measures such as prenatal routine testing, as beneficial.

As HIV research and other potential beneficial therapies, such as antiretroviral intervention, became available, the issue of equitable access to health resources was raised. Distributive justice was understood as entailing abandonment of over-protective stances, particularly relating to research participation. Advocacy initiatives targeted the inclusion of women and minority groups that had been ignored on the basis of their race or economic status. According to Charles McCarthy, the 1980s feminist movement scrutinized the concept of justice, particularly in research, and brought about new meanings by the identification of “the many forms of discrimination against women.”

Because of the need for equity, and access to scarce resources, a new thinking began to emerge in the global community in the 1990s that linked public health with social justice (or human rights). Lawrence Gostin and Lesley Stone made reference to the sound epidemiological research which established that “social economic status is correlated
with morbidity, mortality, and functioning.” Some experts came to the conclusion that inferior health status is predominant in the societies that were experiencing more inequalities between the rich and the poor. Normans Daniels rightly asserted that “social justice is good for our health.”

Martha Nussbaum developed Amartya Sen’s capability approach relating to social justice, and “focusing particularly on women’s poverty and the relationship between poverty and sex inequality.” Nussbaum envisions the ideas of *Women and Human Development* as beginning with “the conception of the dignity of human beings, and of a life that is worthy of that dignity” which is enabled with human functioning. She made a link between capabilities and human rights when she argued that “my list of capabilities include many of the liberties that are also stressed in the human rights movement.”

Similarly, Jonathan Mann and colleagues linked the language of disease, morbidity, and mortality in the populations with addressing social injustices associated with poverty, racism, gender violence and inequity, and discrimination. These experts suggested the human rights approach as the most appropriate variable for underpinning social justice for individuals, and populations, in pandemics such as HIV/AIDS. They justify the human rights-based approach on the basis that nations reaffirmed, in the Universal Declaration of Human Rights (UDHR) treaty, their faith in the “inherent dignity and of the equal and inalienable rights of all members of the human family.”

The UDHR was adopted in 1948 “as a Universal or common standard of achievement for all peoples and all nations.” The UDHR was a statement of aspiration, and not a legally binding document. However, governments were to derive the legal obligations from the two human rights charters of the International Covenant on the Civil and
Political Rights (ICCPR) and the International Covenant on Economic, Social, and Cultural Rights (ICESCR) adopted by the General Assembly in 1966. Surprisingly the United States has never adopted the ICESCR while Uganda adopted it in 1987.

The ICCPR is the preferred charter in modern liberal political theory, as held by countries such as the United States. In this vision, the rights framework reflects and institutionalizes “the existence of a political community of equal rights-bearing subjects.”146 David Chandler explains that, “the liberal political ontology has the autonomous rights-bearing individual as the foundational subject of legal and political spheres of formal equality.”147 Subsequently, “the rule of law and legitimacy of government were derived from the consent and accountability of rights-holding citizens.”148

Not adopting the ICESCR is not an irrelevant detail, in the case of the United States. This is because the tendency by some United States-based transnational HIV advocacy groups is to overemphasize individual rights and civil liberties as the most important key drivers for human rights protection.149 This is a reasonable demand if one understands human rights as universal, and ascribing a single set of rights to all humanity in the global diversity.150 African countries, such as Uganda are characterized by diversity of culture, forms of life, or different circumstances. Human rights are relevant even in diversity, since all are entitled to the same minimum of concern and respect by virtue of being human beings.151

As cautioned by Peter Jones, certain types of diversity, such as belief and values, are different and may pose uniquely complex moral questions.152 For instance, the diversity of religious beliefs, such as pertains to Catholicism, Hinduism, and Islam, should be
considered a normal part of the human condition.\textsuperscript{153} But, the implication, according to Peter Jones, is that a theory of human rights not only accepts diversity, but must provide for the diversity by telling us “something about how we should relate to one another as people with diverse beliefs and values.”\textsuperscript{154} Accordingly, “acceptable diversity is reasonable disagreement,” which means “reasonable doctrines held by reasonable people.”\textsuperscript{155}

Peter Jones further argues that the doctrine of human rights is different in the sense that it is discontinuous with the doctrines of beliefs and values. The doctrine of human rights is more concerned with “the people who hold the beliefs”, as humans, “than the beliefs they hold,” and, “how people of diverse beliefs and values ought to relate to one another.”\textsuperscript{156} As the new transnational application of democracy and human rights within a liberal cosmopolitan vision gains prominence, Jones explication of diversity is important for purposes of exploring the link between public health and human rights in the new globalized post-territorial political communities.

Global cosmopolitians are dissatisfied with the old view of state sovereignty, whereby democracy and human rights are regarded as embodied in national constitutions, and understood as having application exclusively within national states.”\textsuperscript{157} Liberal cosmopolitanism advocates envision the development of cross-border, post-territorial global communities, and forms of democratic decision-making that are superior to “bonds of citizenship, constituted by modern liberal rights frameworks.”\textsuperscript{158}

The notion of cosmopolitanism as meaning “citizen of the world” is as old as Diogenes’ Greek thought.\textsuperscript{159} But the connection of liberalism to cosmopolitanism was inspired by Kantian philosophy, and articulated in terms of post-territorial politics in the
1990s “mainly by theorists who argues that liberal democratic politics could no longer be meaningfully practiced within the confines of the nation-state.” The birth of liberal cosmopolitanism, initiated by political theorists such as Mary Kaldor, David Held, Daniel Archibugi, and colleagues, meant that democracy and political communities should transcend territorial limits of national states and be asserted on the global level.

Having attributed the liberal cosmopolitan theory to Mary Kaldor and colleagues, David Chandler explicates:

The advocates of the cosmopolitan community in the 1990s were the first to distance themselves from state-based politics, finding a freedom in the free-floating rights of global advocacy. It was under this banner of global liberalism and ethical policy-making that political elites sought their own “exodus from sovereignty” – justified on the basis of a critique of the liberal right subject – and in the process, further attenuated the relationship between government and citizen.

Accordingly, the new forms of political communities ought to be constellations of global civil societies constituted by many institutionalized structures, associations, and networked agents “within which individuals and groups actors are interrelated and functionally interdependent.” Civil society is understood in terms of “the most minimal and negative sense,” as “involving the idea of society organizing itself separately from and set against the state.” In this regard, the transnational civil society “refers to a set of interactions among an imagined community to shape collective life that are not confined to the territorial and institutional space or state.”
This post-territorial political vision has its critics. Chris Brown argues that the more negative definition of civil society simplifies the relationship between civil society and the state. This argument holds that, civil society cannot exist to limit state activities if the state is not strong enough to guarantee peace and mechanisms enabling arbitration.\textsuperscript{166} David Chandler is of the view that since (liberal) cosmopolitan political community “further attenuated the relationship between government and citizens,” it should be understood as “a discourse that sought to respond to the collapse of political communities rather than one that reflects the birth of a newer or more expansive one at a global level.”\textsuperscript{167}

If there are lessons to be learned from the current HIV/AIDS prevention dilemmas in Uganda, it is that the linking between public health, human rights, and global HIV advocacy is a complex ethical interlock. The conflicts relating to notions of abstinence-only-until marriage, condoms, anti-marriage, and gay rights that appear to have obstructed the fight against heterosexual transmission of HIV was a multi-layered, and multifaceted, ethical quandary. Epidemiologists are not often prepared to safely navigate the complex encounter between global biomedical, \textit{biopolitical} and \textit{biosocio-cultural} drivers.

When Dr. Zainab Akol, coordinator of the Uganda national AIDS Control Program, attributed the high 6.5 percent to 7 percent HIV prevalence rate in the country between 2009 and 2011 to the uncoordinated interference of gay and lesbian civil societies in the HIV/AIDS control program, she underpinned the intricate relationship between public health, human rights, the state, and the new post-territorial civil societies.\textsuperscript{168} Akol further stated that those in the health professional did not discriminate between sick homosexuals
or heterosexuals. She, therefore, saw no justification for civil societies lobbying The Global Fund to cut financial grants on which many sick people depend for HIV/AIDS services.  

Godfrey Tumwesigye, of Human Rights Network Uganda (HURINET-U), refuted claims that the organization was responsible for derailing the public health prevention initiative by dragging it to “human rights issues of homosexuals.” However, HURINET-U’s allied New York-based Human Rights Watch had, in 2009, asked the government of the United States to “reconsider funding for HIV/AIDS programs in Uganda, where it claimed recipients of such money violated the rights of homosexuals.” Human Rights Watch got their wish when the government of the United States attached foreign aid to “fighting discrimination against gay people abroad.” The policy was based on the conceptual framework that “Gay rights are Human Rights and Human Rights are Gay Rights.”

In fact, Human Rights Watch began the HIV anti-funding campaign, as recommended in the report by Jonathan Cohen and Tony Tate. The recommendation to “all other donors to Uganda AIDS programs” was to deny funding to individuals or groups that do not provide to young people “factual information about HIV prevention, discriminate against marginalized communities such as sexual minorities, or use HIV prevention funds to engage in religious proselytizing.” These are genuine human rights concerns, but Cohen and Tate did not satisfactorily demonstrate that public health strategies, of balance through collaboration, communication, and cooperation, had failed before recommending harsher measures.
The 2005 Human Rights Watch report also sought the repel of Uganda’s law, sections 140, 141, and 143 of the *Penal Code* that criminalizes homosexual activities and “at times used as justification for failing to provide life-saving HIV prevention information and services to lesbian, gay, bisexual, and transgender.” Reversely, the anti-homosexual coalition in Uganda that sought to severely punish homosexual activities in Uganda was equally obstructive to HIV prevention campaign. The Uganda anti-homosexual campaign also had external networked allies among some conservative religious groups in United States.

The focus of liberal cosmopolitanism is the spread of democracy, and human rights, globally by individuals and groups of people, who are supposedly freed from the shackles of state sovereignty. Since “the poor and the excluded cannot automatically enforce their rights … an external agency needs to step in to empower them and constitute them as rights holders.” However, as Graham Long has noted, global civil societies “face conceptual and practical problems that arise from the diversity of actors and the motives present within.” As liberal cosmopolitan moralists exert their influence on HIV/AIDS prevention initiative in Uganda, the danger of advancing human rights reductionism is becoming more explicit.

(iii) Common Good, Non-discrimination and Non-stigmatization

UNESCO’s International Bioethics Committee acknowledged the need to include the principle of non-discrimination and non-stigmatization as one of the ethical instruments to protect against “violation of human dignity, human rights and freedoms” of people. This substantive principle was identified for purposes of addressing issues of particular
relevance to “healthcare, human reproduction, genetic and health care data, research involving human subjects and behavioral genetics.”

An important characteristic of this principle, and indeed to all UDBHR principles, is that they set “global minimum standards in bioethics and clinical practice,” which are intergovernmental, non-binding, and formulated generally. The principles are deliberately formulated in general terms to allow for flexibility and “balance between the universalism of some bioethics norms and respect of cultural diversity.” Moreover, the goal is not “to oblige states to enact enforceable rules inspired by the common standards but to encourage them to do so.” The strength of these formulations lies in the overwhelming “widespread conviction that people have unconditional rights simply by virtue of their humanity.”

Discrimination against sexual minorities in Uganda became a profoundly health-related issue when Human Rights Watch, and the International Gay and Lesbian Human Rights Commission (IGLHRC), demanded that Western donor countries refrain from funding HIV/AIDS programs and organizations in Uganda that discriminate against sexual minorities. Activists also sought the abrogation of a constitutional law that criminalized homosexual acts. But the 2009 private member’s bill sought parliamentary approval to impose the death penalty for gay adults who transmit HIV to minors.

The critics of homosexuality framed the tension as a cultural diversity problem. In an interview with the British Broadcasting Corporation, the president of Uganda accused the West of seeking to impose on Africa a Western culture, particularly homosexuality. He said “black Africans are very humble people; we never impose our views on anybody
He further stated that, although Uganda does not treat homosexuality as something good, nevertheless, gay people are not persecuted but tolerated.

But U.S. Secretary of State Hillary Clinton had a different perspective on the gay issue. She argued that being gay is a human reality, and should never be considered a crime. Clinton attributed the gay hatred to personal, cultural, and religious beliefs.

Theologian Russell Reno explains that there are times when our “conviction (personal, cultural, religious) become excuses for exercising our perverse love of violence.” This is “true of our violence against homosexuals.” But it is also true that “there are ways to humanize our moral horror and reduce its capacity to lead to violence and injustice.”

According to Reno, the solution in Christianity is “to hate the sin; love the sinner.” It is a call to “adopt the disposition of charity or love that allows us to see the intrinsic dignity of the human person.” The focus turns to the action rather than to the person. The liberal view, in the early modern period, was to “encouraged the virtue of tolerance, a disposition that involves enduring what one objects to.”

But the solution in contemporary liberalism (particularly in liberal cosmopolitanism) is “to get to the root cause and promote systematic change.” Humanity will overcome these obstacles erected by personal beliefs, and cultural and religious traditions, as identified by Clinton, by accepting contemporary and enlightened views of sex, and not humanizing elements of these beliefs or moderations by way of tolerance.

If Reno’s exposition is correct, then it is not difficult to see how moral views on either side of the HIV and gay rights debate have increasingly failed to accommodative values such as transparence, cooperation, coordination, and collaboration. These values are central to disease prevention in public health initiatives. Instead, it appears that
competing parties have reggressively reverted to human rights reductionism by advancing legal positivism, or by regarding human rights simply as what benefits minority groups.

To be effective, the HIV prevention program in Uganda must seek for balance between competing interests. The principles approach, as proposed by the UDBHR document, offers an international normative standard, and as engaged in MIEM, provides guidance towards effective HIV/AIDS intervention and human rights safeguards. Within this approach, the principle of non-discrimination and non-stigmatization is specified as being comprised of the notions of equality of human beings and dignity, as well as the understanding that being human is not synonymous with color, race, ethnicity, gender, or sexual orientation.

Though the principle of non-discrimination and non-stigmatization is formulated in negative language, the positive implication for public health is the promotion of the wellbeing of individuals and populations. In this sense, non-discrimination and non-stigmatization is necessarily related to the principle of common good, which is not enumerated in the UDBHR document.

Common good is a principle commonly used in the Catholic tradition, in reference to our mutual rights and responsibilities as members sharing common humanity. Within the Catholic vision of social justice, and common good, are the three basic affirmations of, “the inviolable dignity of the human person, the essential social nature of human beings, and the belief that the abundance of nature and social living is given for all people.”199
B. The Meaning and Scope of Common good, and Non-discrimination and Non-stigmatization.

(i) Specification of Non-discrimination and Non-stigmatization

The substantive principle of non-discrimination and non-stigmatization, as stipulated in article 11 of the UDBHR document, states that, “no individual or group should be discriminated against or stigmatized on any grounds, in violation of human dignity, human rights and fundamental freedoms.” Clearly, the specification of this principle of non-discrimination and non-stigmatization constitutes three notions stipulated in article 3(1): inviolable dignity, human rights, and fundamental freedoms.

This is the context in which the principle of non-stigmatization and discrimination ought to be applied to the HIV/AIDS prevention initiatives in Uganda. In the UDHR document, member states recognized and affirmed the inherent dignity of all members of the human family. Human nature was assumed as the source of this inherent dignity, which also serves as the foundation of freedom, justice, and peace in the world. It is in this sense that “human dignity is invoked as an argument against discrimination as well as the framework within which cultural diversity is to be respected.”

The substantive principle of non-discrimination and non-stigmatization is annunciated negatively. In positive language this claim infers the promotion of respect for human dignity, and protection of human rights, which necessitates “ensuring respect for the life of human beings, and fundamental freedoms, consistent with international human rights law (art.2(c).” Although the need to adopt, and include in the UDBHR, the principle of non-discrimination and non-stigmatization was identified around 2003, the standards set
by this principle appear to have been in practice in the first phase of HIV/AIDS prevention in Uganda between 1987 through the 1990s.

Several ethics scholars testify to the fact that Uganda recognized the need to confront stigma and discrimination as an important strategy for combating the HIV/AIDS epidemic, and the tragic effects, in the early days of HIV/AIDS. Helen Epstein articulated this spirit as follows:

During the early 1980s and 1990s, ..., hundreds of tiny community-based AIDS groups sprang up throughout Uganda and Kagera to comfort the sick, care for the orphans, warn people about the dangers of casual sex, and address the particular vulnerability of women and girls to infection. Yoweri Museveni’s government developed its own vigorous prevention campaigns and the World Health Organization provided funding, but much of it came from the pockets of the poor themselves. Their compassion and hard work brought the disease into the open, got people talking about the epidemic, reduced stigma and denial, and led to a profound shift in sexual norms.

Epstein herself concluded that this movement might have arisen partly because the people of the region realized much earlier that “AIDS was not just a disease of prostitutes, truck drivers and other stigmatized, high-risk groups.” She could not find a name for this social movement, but thought of it as “collective efficacy,” to connote “the ability of people to join together and help one another.” Epstein applied this term to the Uganda phenomenon, but credited it to sociologist Felton Earls who coined “collective efficacy” in reference to “a spirit of collective action and mutual aid ... rooted in a sense of compassion and common humanity.”
Bioethics, in fact, has a name for this phenomenon – solidarity and common good. Solidarity implies mutual concern for one another because of our common humanity and inalienable rights.\textsuperscript{210} In the encyclical \textit{Sollitudo Rei Socialis}, Pope John Paul II refers to the virtue of solidarity as an experience of interdependence, at all levels of human life and development that occurs within the context of our collective moral action and practical response.\textsuperscript{211} For Pope John Paul II, solidarity is not merely “a feeling of vague compassion or shallow distress at the misfortune of so many people … it is a feeling of a firm and persevering determination to commit oneself to the common good.”\textsuperscript{212}

In this sense, solidarity entails the values of collaboration, communication, coordination, and cooperation.\textsuperscript{213} When explaining the principle of solidarity and cooperation, as stipulated in article 13 of the UDBHR document, Alphonse Elungu states that:

\begin{quote}
It is through co-operation that the free human being becomes a citizen and is brought to discover what is common between him or herself and others, what he or she shares with others, and which bonds unites him or her to others.”\textsuperscript{214}
\end{quote}

The UDHR recognizes the inherent dignity, equality, and social nature of human beings, and the need for mutual rights and responsibilities as members of the human family.\textsuperscript{215} Sometimes the principles that underlie these fundamental rights conflict, particularly when tension emerges between individual and population interests. But, bioethicists understand that there are moral considerations that aggravate conflict, and also moral values that reduce conflict.\textsuperscript{216} For instance, in the 1990s Uganda chose to confront stigma and discrimination by implicitly appealing to solidarity and the common good, as well as engaging the values of communication, collaboration, coordination,
cooperation, and education as strategies for confronting HIV/AIDS-based stigma and discrimination.

It is accepted by many, in global public health, that open and effective communication, coupled with, political will for mobilization, were keys to Uganda’s success in the fight against HIV/AIDS in the 1990s. But it is also known that much of the now well developed tools of strategic communication in HIV/AIDS intervention, such as those targeting knowledge, attitudes, social norms, collective efficacy, political will, policy change, and resource allocation, had not been explicitly articulated in global public health. Surprisingly, some of the earliest and most effective communication strategies for confronting HIV stigma and discrimination in Uganda came from music artists.

When Philly Bongole Lutaaya, a famous Ugandan musician, became ill with AIDS he was ostracized by colleagues. He disregarded his fame and prestige and openly declared his HIV status. Using his musical talent and skills, Lutaaya captivated the attention of Ugandans by opening a debate on HIV/AIDS, and called on Ugandan to reject the stigmatization and discrimination of those living with HIV/AIDS. His famous song “Alone,” reminded the public of our common humanity and destiny – “today it’s me and tomorrow it’s someone else … let’s stand together and fight AIDS.” He took this message of prevention and non-stigmatization to schools and institutions around the country.

But probably no morbidity-and mortality-related, massage-driven-song has ever captivated the minds and hearts of Ugandans more than Walumbe Zaaya (meaning death the devastator), by Paul Job Kafeero. In a uniquely Ugandan traditional music lyric of Kadongo Kamu, Kafeero recounted the lamentation, horrors, and solitude associated with
issues of illness and death. For his song, Kafeero won the *Golden Boy of Africa Award* in 1994, chosen out of 7,000 contestants in Africa.\textsuperscript{221} A culturally iconic country music maestro, Kafeero died in 2007, but the song *Walumbe Zaaya* is still a very popular household song, and a regular pick for HIV-awareness conference in Uganda.

But even before some individual Ugandans took extraordinary courage to take the lead in creating HIV/AIDS awareness, in 1986 the government of Uganda had already embarked on a “decentralized planning and implementation for behavior change communication.”\textsuperscript{222} An aggressive public media campaign was launched by the National AIDS Control Program (ACP). The effort involved “print materials, radio, billboards and community mobilization for a grass-roots offensive against HIV.”\textsuperscript{223} The style of “sustained interpersonal communication intervention” strongly influenced a change of sexual behavior in the general public, and key targeted groups as high risk.\textsuperscript{224}

Apart from communication and AIDS awareness, Ugandans actively got involved in collaboration with public health agents for voluntary testing and counseling services.\textsuperscript{225} Partnership and collaboration are essential features of public health engagement with communities and vulnerable populations.\textsuperscript{226} Noerine Kaleeba, co-founder of The AIDS Support Organization (TASO), figured out in 1987 that the most effective way of fighting stigma was collaboration and partnership between affected persons, communities, and public health agents.\textsuperscript{227} TASO’s mission was to assist in “restoring hope and improving the quality of life of persons and communities affected by HIV infection and AIDS disease.”\textsuperscript{228}

To combat stigma and discrimination, TASO pledged to promote “living positively with AIDS and dying with dignity” through compassionate care, and mutual support\textsuperscript{229}
The organization started voluntary counseling and testing services as a way of encouraging people to get treatment and the promotion of positive behavioral change. Edward Green explains that by 1993, “studies in Uganda seemed to show that voluntary counseling services led to safer behavior,” whether the persons tested and counseled were found to be HIV positive, or negative. TASO eventually began training HIV/AIDS counselors, and provide medical and social welfare services.

The cooperation of faith-groups with public health agents, and the government, was a significant factor in the reduction of HIV infection, and the de-stigmatization of HIV/AIDS in the 1990s. Helen Epstein attested to the fact that, even before the 2003 PEPFAR initiative, “Catholic and Protestant Churches had been running exemplary AIDS programs since the 1980s.” Green explains that the Ugandan government strategically involved faith-based leaders and organizations (Catholics, Anglican, and Muslim) from the beginning of the struggle against AIDS.

Catholics, Anglicans, and Muslims faith-based organizations were better suited to the role of creating HIV/AIDS awareness than the mass media and other infrastructures that had been rendered less operative by the brutal dictatorship and wars. Cooperation was needed, since it was estimated that 92 percent of the population attended Anglican and Catholic services regularly. Subsequently, HIV/AIDS awareness messages would reach more people when effectively disseminated from pulpits.

Equally significant was the fact that a majority of the health facilities in Uganda were owned by faith-based organizations. It is noteworthy that, even by 2003, sixty percent of all health care facilities in Uganda were private, and majority of them operated under the auspices faith-based organizations. According to Green, and based on a 2001 survey,
44 percent of private health care facilities were owned by Catholics; 34 percent by Protestants; 8 percent by Muslims; and 14 percent by other private entities.\textsuperscript{237} The government deployed health experts from the government’s owned Makerere University to train religious leaders to be HIV/AIDS educators.

The first slogans used to articulate HIV/AIDS awareness and behavioral change-based intervention were: “Love Carefully,” “Love Faithfully,” and “Zero Grazing.”\textsuperscript{238} The Zero Grazing language was phased out and replaced with “Abstain, be Faithful and use a Condom (ABC).” However, the Catholic Church did not incorporate the condom component that was part of the national awareness and prevention initiatives. On the part of the Uganda AIDS Commission they did not adopt a non-confrontational policy, and instead opted for inclusiveness with different social and religious groups.\textsuperscript{239}

Although the Catholic bishops were opposed to condom use on grounds that condoms were not hundred percent effective, their cooperation or noncooperation was not based on a monolithic issue, but a fight against triplet threats – “poverty, ignorance, and disease (AIDS).”\textsuperscript{240} In 1987, the bishops argued for sexual behavioral change and partly attributed the rapid spread of HIV/AIDS to the loosening of family (marriage) and moral values. They explicitly expressed their stance that AIDS was not a punishment from God, and society needed to respond in solidarity with “love, understanding, and compassion” rather than with stigmatization.\textsuperscript{241}

The bishops based their instructions on HIV intervention on biblical notions of love, care, mercy, and compassion as in Mt.25: 35-36 and Lk.6: 36-37.\textsuperscript{242} On the practical level, they proposed that the Church gets involved in activities such as counseling, promote faith based-values, education, confronting risk-related traditional customs,
utilizing communication tools, value formation of the youths, and, support for widows and orphans. This engagement was understood in terms of “work, solidarity, interior purification and personal salvation.”

One of the most effective cooperation and collaborative HIV/AIDS initiatives by the Catholic Church in Uganda was carried out by the Caritas organization. In 1989 Caritas Internationalis Working Group on AIDS held a meeting in Uganda. This meeting followed a 1987 meeting in Rome, when Caritas Internationalis took “a leadership role in sensitizing Church leaders in the social-pastoral field to the needs presented by the pandemic of HIV/AIDS.” Since then the Caritas Confederations has “coordinated a program of both material and expert assistance to Church-related HIV/AIDS services in developing countries.”

Caritas saw its HIV/AIDS initiative as participating in the Church’s threefold response to all human realities: to teach, serve, and gather people in worship. This response provided for renewed reinforcement, in love and mercy, of the Church’s traditional moral teachings and values, “especially with regards to sexual behavior and marital relationships.” The service mandate meant that Caritas got involved in HIV/AIDS projects, such as expansion of medical services, social service facilities, and the supply of food, medicine, and HIV-antibody testing equipment. The worship component entails the responsibility to help those faced with the reality of AIDS to deepen their faith as they “confront the final realities of life.”

The justification of the role of Caritas’ in HIV/AIDS intervention comes from its name which is derived from the Latin word caritas, meaning charity, or “dearness” (virtue). The scope of Caritas’ work is laid out in its mission statement, namely, to reflect
the social mission of the Church and the core values of dignity, justice, solidarity, and stewardship. It is in the same spirit that the Catholic Church in Uganda was compelled to provide leadership, through its institution, in HIV/AIDS education and prevention. One concrete example of the Church’s effort was the “designing of mobile home care and special programs for AIDS widows and orphans” by Catholic mission hospitals.

Partnership and collaboration is also evidenced by contribution made by the Anglican Church to the early HIV prevention initiatives. In 1992, the Anglican Church in Uganda embarked on an HIV education program funded by USAID. The CHUSA program targeted the education of clergy and laity in HIV prevention. In less than two years 863 leaders and 5,702 community-health educators, had been trained. The campaign involved pastoral home visitations, peer education, distribution of sample sermons and other HIV/AIDS awareness materials, and the distribution of condoms. The 1995 evaluation of the campaign established that significant behavioral change had resulted. Multiple sexual partners dropped from 86 percent to 29 percent for men and from 75 percent to 7 percent for women. There was also an increase in the use of condoms, from 9 percent to 12 percent.

A significant change occurred in 2003 when several faith-based abstinence organizations emerged in Uganda, boosted by the availability of a $1 billion PEPFAR fund earmarked for abstinence-only HIV prevention initiatives. Among these organizations were the Campus Alliance to Wipe Out AIDS (CAWA), Glory of Virginity Movement (GLOVIM), and Family Life Network (FLN). These organizations, and others, received assistance from several U.S.-based faith associated groups such as True Love Waits and Family Life Network. In 2004 Human Rights Watch expressed
frustration that a Virginia based organization, Children’s AIDS Fund (CAF), with ties to Uganda’s Youth Forum, received a PEPFAR grant. Human Rights Watch was unhappy that Youth Forum was “developing abstinence material to be distributed nationally.”

According to Pastor Martin Ssempe, the new faith-based movement in Uganda (mostly Evangelicals) appears to have been driven by an overriding desire to fight off, the “attack from an agenda driven by homosexuals and Western experts who are out of touch with how the AIDS epidemic is driven in Africa.” To counteract this movement, international organizations, such as Human Rights International, invoked rights-based arguments and sought punitive measures against the rights-violators in Uganda. This confrontation initiated a new phase in HIV/AIDS discourse that subordinated altruistic ethics-talk, and hyped the ideology polemics of HIV/AIDS.

(ii) Specification of Common Good

Common good is a principle that is generally associated with Catholic Social teaching. When HIV/AIDS intervention is approached as promoting the common good, the assumption is that it is a social justice issue. For Lisa Sowle Cahill, this is an important identification since the attention shifts from overemphasis on individual behavior, such as drug abuse or condoms, to social conditions (relationships), such as power and vulnerability that strongly influence the spread of HIV. For instance, according to Cahill, poverty reduces peoples’ social access to preventive measures, and to the basic means of subsistence which in turn leads to a decline of their physical well-being.

Benedict Ashley and Kevin O’Rourke define the common good as “the sum total of those conditions of social living whereby citizens are enabled more fully and more
readily to achieve their own perfection.” Pope John Paul II explained the common good as “the good of all and each individual, because we are really responsible for all.” In the Catholic tradition, this principle is seen as deriving from biblical foundation such as in the Beatitudes (Luke 6:20-22; Mt 5:3-11). More explicitly, the principle of common good was applied in its practical terms in the early Church that required “from each according to his (or her) ability, to each according to his (or her) needs (Act 32:35).” This notion of the common good is also related to subsidiarity.

Ashley and O’Rourke elucidated that subsidiarity is an aspect of the common good that “calls upon each person or lower social unit to be given the opportunity to exercise the responsibility to achieve the goals proper to it.” Accordingly, “subsidiarity implies that the first responsibility to meet human needs rests with the free and competent individual, then with the local community.” Subsidiarity enables the sharing of decision-making power among the functional societal bodies that an individual person relates to for basic needs. The role of government is not to deprive, but “to coordinate and encourage the full development of these different organs of society.”

If the common good is understood in this sense, then it was implicitly applied in HIV intervention in the 1990s in Uganda. The government of Uganda took seriously its role of coordination and collaboration in the fight against HIV/AIDS. In the spirit of supporting all-inclusive and participatory policy, the government created the multi-sectoral Uganda AIDS Commission in 1992. The role of UAC was to coordinate and monitor the national AIDS multi-sector strategy that was adopted in 1990. By 2001, at least 700 governmental and non-governmental agencies were engaged in HIV/AIDS issues nationwide, under the Commission’s role as coordinator.
central and local governments, local and international non-governmental organizations, faith-based organizations, youth organizations, private sector components, media, experts in science, and researchers.

In addition to subsidiarity, Ashley and O’Rourke specify the common good as constitutive of love, mercy, and mutual concern and responsibility. These values are indicative of the person’s, or community’s concern for the wellbeing of others. One outstanding example from Uganda was the level of willingness by Ugandan HIV negative women to advance scientific endeavors by participating in non-therapeutic global microbicides clinical trials between 2005 and 2009, even with the awareness of the likely danger of infection.

Ugandan women participated in the microbicides PRO 2000 (0.5 and 0.2), and the cellulose sulfate (CS) clinical trials. As it turned out, HIV negative women who participated in the phase III of the cellulose sulfate clinical trial were exposed to increased risks for HIV infection. The investigators clarified that they ensured the clinical trial was approved by an Institutional Review Board, underwent the Phase II safety and tolerance trial, and sought the informed consent. But, there are other standards, such as ensuring reasonable risk that must come prior to even subject selection and informed consent.

Before individuals collaborate and cooperate in research to promote the wellbeing of the human family, U.S. federal research policy for the protection of human subjects ensures that Institutional Review Boards (IRB) are tasked with oversight to minimize risk, and that “the risks to the subjects are reasonable compared to the benefits.” The requirement for “reasonable” is important, for as established in MIEM, it is not enough to
adhere to a principle, such as the common good, and then solicit cooperation and
collaboration, without committing to the relevant limiting procedural standard, such as
reasonableness, which facilitates balance between the common good and disproportionate
risk to the individual.

C. Application of Procedural Standards

(i) Illustrative Procedural Standard of Reasonableness

Uganda’s national HIV/AIDS strategic plan, for the years 2011/12-2014/15,
acknowledged the importance of deploying the human rights approach in the fight against
HIV/AIDS and the promotion of wellbeing.276 The five years’ plan adopted a
“combination HIV prevention” which involves “implementing multiple (biomedical,
behavioral and structural) prevention interventions.”277 But the document does not
explain how the strategic plan will disambiguate the HIV prevention program already
imbued with conflicting interpretations of the meaning, scope, and application of human
rights between Western agencies and proponents of Uganda’s socio-cultural beliefs and
values.

The UDBHR, article 12, calls for the recognition and respect of cultural diversity and
pluralism. But the Declaration also explicitly states that cultural diversity cannot be
invoked to infringe “upon human dignity, human rights, and fundamental freedoms.”278
Peter Jones’ philosophical explication of the relationship between human rights and
cultural diversity can offer helpful insights for navigating this complex relation.279 Jones
explains that diversity of belief and value should be considered as an essential feature of
the human condition. Subsequently, a theory of human rights must accommodate, and provide for, the diversity of belief and value.  

According to Jones, acceptable diversity can also be described as reasonable disagreement, which means disagreement among reasonable persons. In this sense, “what persuades us to describe as reasonable the larger range of very different doctrines that we find in the world is the reasonableness of the people who hold them.” For Jones, it is not only important that a human rights theory accommodates diversity of beliefs and values, but also provide for a way for people with diversity of beliefs and values (doctrinal disagreements) to relate to one another. The reconciliation of human rights with human diversity therefore requires a discontinuous and not a continuous strategy.

A theory of human rights is understood to be discontinuous with doctrinal disagreements, if it places itself on the second-level “outside and above the arena of doctrinal disagreement.” Individuals caught up at the first-level of disagreement need a theory of human rights that is independent of the disagreement and discontinuous with those other doctrines that regulate the relationship with one another. A theory of human rights is a theory about the equal rights and equal status of human persons. Since it ascribes the same fundamental rights to human persons, it must therefore ascribe the same moral standing to persons.

John’s insights are of significant relevance to Uganda’s human rights-based HIV/AIDS policy development because of diversity of beliefs and values. A theory of human rights is not about competing in these doctrinal disagreements but about the status of a human person. A human person is owed these fundamental rights merely by virtue of
being human, and not because he or she is male or female, or heterosexual or gay. For instance, gender based roles in Uganda ought to abide by the principle of non-discrimination since all are equal, and have the same dignity by virtue of being human.

The arbiter principle, such as non-discrimination and non-stigmatization, derives from universally recognized inherent dignity, and of the equal and inalienable rights of all members of the human family. No one should be discriminated against, or stigmatized, because of their race, ethnicity, gender, or sexual orientation; for they are human persons. Dr. Zainab Akol, coordinator of the national AIDS Control Program in Uganda, was alluding to this basic truth when she said, “We in the health ministry do not want to know your sexual orientation …. We treat everyone so long as that person is sick.”

But the effective management of the conflicting doctrinal disagreements will require that the engagement of the principle of non-discrimination and non-stigmatization be mediated within the procedural values of communication, collaboration, coordination, and cooperation. Moreover, this will further entail the consideration, by all involved parties, of procedural standards, such as reasonableness.

(ii) Ethics Committees and Reasonable Risks in HIV/AIDS Intervention

One of the biomedical HIV prevention strategies since the late 1990s is the development of microbicides. Uganda’s active participation in microbicides clinical trials is a testimony to the commitment to advance science for the good of humanity. But, Uganda, as well as the global research community, acknowledges the need for an appropriate balance of the relevant moral concerns that arise in the process of advancing the good of society, and the safety of the individuals participating in research. These
concerns have, at times, been referred to as the balance between protectionist concerns and respect for autonomy.  

Research ethics is well regulated in international ethics bodies to offer the prospects of advancing science while also protecting the individual participants from disproportionate risks. One strategy, as stipulated in the Common Rule of the U.S. federal regulation of human research, is the assessment of the reasonableness of risks in clinical research. The Institutional Review Board (IRB) is required to make this assessment before enrollment of participants can proceed. As Alex London states, “the Common Rule Approach holds that risks are reasonable when they are offset or outweighed by the anticipated benefit of the research.” 

But according to London, the Common Rule lacks, “conceptual and operational clarity” of the substantive guide regarding:

- how to (a) distinguish the relative value of the various interests of research participants that may be at stake in a particular trial, (b) distinguish the relative value of the information or understanding that might be generated by the trials that study different questions and employ different methods and (c) distinguish permissible from impermissible trade-offs between these variables.

The likely outcome, then, is for those entrusted with decision making to rely on their common sense and good judgment. Uncertainty regarding what counts as unreasonable risks occurs due to the absence of, “shared set of criteria or standards that deliberators can use to demarcate reasonable from unreasonable risks.” 

In an attempt to address the question of criteria and standard for reasonable risks, Alex London defines reasonable risks as:
Risks to individual research participants are reasonable just in case they (1) require the least amount of intrusion into the interests of participants that is necessary in order to facilitate sound scientific inquiry and (2) are consistent with an equal regard for the basic interests of study participants and the members of the larger community whose interests that research is intended to serve.\textsuperscript{294}

The criterion and standard set by this definition prioritizes scientific rigor, and the reduction of risks, to what is necessary to address the research question in a manner consistent with the “current state of scientific inquiry.”\textsuperscript{295} The second aspect is the permissibility to ask individual community members “to sacrifice some of their personal interests as part of an effort to advance or secure the interest of others.”\textsuperscript{296} The participation must not pose risks to the basic interests of participants that are inconsistent with the same degree of concern that is shown for the basic interests of other community members.”\textsuperscript{297}

The phase III cellulose sulfate clinical trial met the criteria of a prior independent ethics review committee, and informed consent, as required by the United States, and all major international bodies regulating human research. However, the question of whether the Phase III cellulose sulfate microbicides trial met the criteria of scientific rigor, and subsequently reasonable risks is unresolved. Had the already existing scientific data on the stimulatory effect of low concentrations of cellulose been accessed by the investigators and, had the independent ethics review committee raised more safety related questions, the issues of reasonable risks would have been assessed differently.\textsuperscript{298}

Another related question concerns how much the issue of urgency for the development of microbicides, and for that matter the intervention of HIV, weighed on the
minds of the researchers. By 2005, fifty five non-government organizations worked as active campaign partners in the global campaign for microbicides. This number was part of the two hundred non-governmental organizations worldwide that had endorsed the campaign. With a $24 million grant for the phase III cellulose sulfate clinical trial, and a global campaign eager for results, the pressure was on the investigators and research institutions to find the right balance between urgency and rigorous scientific and ethical standards. This was a task which the Global Campaign for Microbicides resolved to take seriously.

Guideline 3 of the Council for International Organizations of Medical Science (CIOMS), concerning externally sponsored research, requires that the investigator submits the research protocol to the sponsoring country and host country for ethical and scientific review. The local ethical review committee reviews the research protocol “to ensure that the means of obtaining informed consent are appropriate to local customs and traditions, as well as to assess the competence of the research team and the suitability of the proposed research site in the host country.” In relation to this guideline Uganda needs to develop mechanisms for effective local ethical and scientific review committees. Particularly, there is a need for building capacity for the effective assessment of reasonable risks, a task that may require networking with external experts.

D. Summary

Policy makers and health providers in Uganda’s HIV/AIDS initiative attest to the stabilization, and a recent slight increase, of the HIV prevalence rate. This development undermines the remarkable success achieved, through the behavioral change approach,
under the acronym of ABC in the 1990s when the HIV prevalence rate dramatically dropped. But, surprisingly, a paradigm shift occurred beginning 2003 when more funds for HIV/AIDS intervention became available, including President George W Bush’s generous PEPFAR initiative.

The grant opened new possibilities for surges in HIV treatment, testing, counseling, and prevention of mother-to-child infection, thereby improving the lives of many people. But at the same time, the PEPFAR initiative generated a divisive and obstructive ABC debate that involved local and global participants in a manner that appears to have endangered the effort to reduce the heterosexual transmission of HIV. Parties strategized to advance policies that favored their exclusive preferences, be it condoms, abstinence, individual rights, or minority rights.

Recent developments that link human rights with public health, and transnational participants can enhance the prospects for provision of better population health while safeguarding individual and human rights. The Mixed Interests Ethics Model (MIEM) is a contribution that innovatively engages the UNESCO’s principles-based approach, suggested in the UDBHR document to effectively manage HIV/AIDS intervention. This chapter applied the illustrative principle of non-discrimination and non-stigmatization, and the principle of the common good to demonstrate an effective way forwards for the improvement of the population health and human rights in Uganda.
6. Chapter Six

Conclusion

(i) The New Era of Public Health, Human Rights, and Biopolitics

Ever since HIV/AIDS epidemics, bioterrorism, and the threat of an influenza pandemic topped the list of public health emergencies at the onset of the 21st Century, the question of how to balance between individual and population interests has been intensely discussed. Conflicting interests range from individual liberty versus societal good, injustice in allocation of resources, and disrespect for individual and human rights. Yet, no single ethical theory such as libertarianism, utilitarianism, or communitarian, solely and sufficiently resolves the conflicts between individual and population interests in influenza pandemic and HIV/AIDS epidemic intervention.

This dissertation has established that influenza pandemic preparedness plans were characterized mostly by concerns for justice in distribution of health goods (resources), and the protection of individual liberties and freedoms. The protection of the individual interests in liberty and freedoms was articulated in the substantive principle of individual autonomy, and strictly guarded in libertarian ethical theory. When population interest in health and safety was the priority, substantive principles such as solidarity and common good, were articulated and strictly guarded in utilitarian, egalitarian, and communitarian ethical traditions.

This dissertation contributes the Mixed Interests Ethics Model (MIEM) as a criterion for negotiating balance between individual and population health interests for the effectively management of pandemics and epidemics. As demonstrated, MIEM entails
engaging related principles and standards. The principles address substantive issues. For instance, the use of the “least restrictive means” ensures respect for autonomous individuals even when those individuals are subordinated to intrusive measures, such as mandatory vaccination, to protect the population’s health and safety. Standards address procedural issues to ensure that moral commitment is retained. For instance, the procedural standard of necessity guarantees that the state police power is not arbitrarily exercised. The public health agent has a moral responsibility to satisfy the justificatory conditions, minimize the infringement of the general moral considerations, and demonstrate transparency.¹

On the issue of HIV/AIDS epidemic intervention, the prevention of the heterosexual transmission of HIV mostly featured conflicts that were related to the distribution of diverse socio-cultural beliefs and values, and how these choices related to civil liberties, individual rights, and human rights. In the experience of Uganda, the application of civil liberties, behavioral change, and human rights (reductionism) to guide policy in the heterosexual transmission of HIV lacked an effective criterion for disambiguating and balancing tension that arises from engaging socio-cultural diversity.

The new field of public health and human rights has dramatically expanded to include biopolitical competencies, as evidenced in transnational civil society advocacy – tasked with the global spread of democracy, human rights and health. Liberal cosmopolitanism features cross-border, post-territorial global communities empowered with “free-floating rights of global advocacy.”² Probably no other global public health ethics issue in recent times has generated so much passion for transnational advocacy and global engagement
in health, human rights and biopolitics than the combination of PEPFAR and Uganda’s HIV/AIDS behavioral change approach.

In the PEPFAR controversy, Uganda’s ABC framework for HIV prevention was perceived as not broad enough to accommodate strategies for addressing the rights of individuals and the legal and human rights of minorities. In another related initiative, the candidate microbicides 6% cellulose sulfate gel clinical trial in Uganda, and other countries, demonstrated the urgency of scaling up global biomedical intervention in HIV, but also exposed the limitation of biopolitical advocacy in driving scientific endeavors.

To effectively manage the heterosexual spread of HIV, Uganda’s strictly guarded behavioral change strategy needed to undergo a paradigm shift so as to engage transnational networked biomedical, biopolitical, and bio-socio-cultural drivers of public health, human rights, and democratic principles. The principles-based approach, as proposed by the UNESCO’s Universal Declaration for Bioethics and Human Rights (UDBHR), and as made practical by the Mixed Interests Ethics Model, offers an effective variable for balancing the individual and population interests in pandemics and epidemics.

(ii) UNESCO’s Bioethics Principles and MIEM

The development of the principles-based approach to mediate conflict in population health has been a gradual process. For instance, a Canadian group of bioethicists proposed substantive and procedural values to negotiate the tension arising from individual and population preferences in the influenza pandemic intervention. These ethicists identified substantive values, such as solidarity and procedural values such as transparence, to aid the process of ethical decision making. But the proposal tended to
slightly favor the overriding goal of population health, and offered little significant
discourse on engaging individual rights and human rights.

At the beginning of the 20th Century, the United States judiciary had implicitly made
a significant contribution toward the later principles-approach discourse when the U.S.
Supreme Court, in Jacobson v. Massachusetts (1905), rejected absolute maxims in public
health intervention. Regarding individual liberty (autonomy), the court ruled that the
Constitution of the United States does not “import an absolute right in each person to be,
at all times and in all circumstances, wholly freed from restraint.”6 Yet again, government
coercive powers were also understood as subject to constitutional restraints “to protect
individual interests in autonomy, privacy, liberty, and property.”7

On the issues of the common good, the United States judiciary understood the state as
possessing broad police power to justify the pursuance of the societal goals of health and
safety. Accordingly, of paramount necessity, the community has a right to self-defense,
against an epidemic disease.8 The court acknowledged the “communal value of health
and safety,” but also established four constitutional standards to limit coercive public
health in the name of ensuring public health. The standards were public health necessity,
reasonable means, proportionality, and harm avoidance.9 The Supreme Court’s ruling
was of significant importance to public health ethics, since it undercut individualism, and
diminished unnecessary paternalism, or arbitrariness.

The practicability and the heuristic aspect of the mid-level biomedical principles to
overlap different ethical theories, and facilitate the delineation and resolving of ethical
dilemmas in individual-oriented clinical medicine and research, has been successfully
argued by Tom Beauchamp and James Childress, in their treatise on biomedical
principles. These scholars adopted Rawls’ reflective equilibrium as a method of choice for negotiating specification and justification of our considered moral judgments.\(^\text{10}\)

Childress and colleagues’ exploration of the use of the principles approach in public health sought to emphasize the notions of specification to delineate the meaning and scope, the justification, and the balancing of competing principles so as to determine their respective weight and strength.\(^\text{11}\) This ethical analysis exercise was considered important for purposes of balancing between conflicting principles, since they were understood to be comprised of areas that increase conflict and those that decrease conflict respectively.\(^\text{12}\)

The global endorsement of bioethics principles occurred when UNESCO’s Universal Declaration on Bioethics and Human Rights (UDBHR) provided a set of foundational bioethics principles as a universal normative standard to guide scientific progress, and to protect human dignity and freedom.\(^\text{13}\) Based on a human rights framework, the International Bioethics Committee identified and acknowledged common values that are accommodative of cultural diversity with pluralistic moral viewpoints, and yet are consistent with the dignity, and fundamental rights and freedoms, of human persons.\(^\text{14}\)

The Committee provided more clarity to the bioethics principles approach when it identified between fundamental principles, derived principles, and procedural principles.\(^\text{15}\) Fundamental principles were defined as “principles that cannot be justified by another principle.”\(^\text{16}\) Derived principles meant those principles that “can only be justified by one or more fundamental principles.”\(^\text{17}\)

The UDBHR document acknowledged and established a requirement for limiting the application of a principle, for instance, for the protection of public health, or the rights and freedom of others. The
interpretation of this requirement was meant to be in accordance with domestic and international law, and in conformity with human rights law.\textsuperscript{18}

The interpretation and practicability of UNESCO’s bioethics principles in population health is considered as a work in progress. As commented by on Ten Have and Jean:

The UNESCO Declaration is the first step: it provides a framework of general principles that is open to various interpretations and applications in the context of human rights and fundamental freedoms, leaving many specific issues and controversies open for further debate.\textsuperscript{19}

But this further debate, as acknowledged by these ethicists, must remain committed to seeking balance, as was guided by the UDHBR, between individualistic and communitarian moral perspectives. For instance, the principle of autonomy and personal responsibility was established along with the principle of solidarity and cooperation.\textsuperscript{20}

The UNESCO’s UDBHR principles framework constitutes a set of universal, minimum normative standards to arbitrate conflicting ethical interests. The Mixed Interests Ethics Model (MIEM) renders the UDBHR principles practical by facilitating the identification of conflicting principles to deal with the related substantive issues, and the procedural standards to address procedures. MIEM requires a normative analysis of the competing substantive principles by way of specification, justification, as well as application of procedural standards to balance between conflicting principles in population health intervention. Subsequently, MIEM contributes to the effective management of pandemics and epidemics, and facilitates UNESCO’s global initiative to ameliorate health and human rights.
The UNESCO bioethics principles approach, and as applied in MIEM, are well suited to the goal of facilitating balance between conflicting principles in Uganda’s prevention of the heterosexual transmission of HIV/AIDS. The major obstacle to the success of the ABC and PEPFAR initiative appears to have been rights-based conceptual frameworks that were either exclusively focused on promoting individual rights, or civil liberties, or minority rights (group rights). The danger with distributing human rights between individual and minority rights is the immoderate focus on one set of interests, rather than a cross pollination between individual and population interests.

In the Uganda context, proponents of individual rights gravitated toward overemphasis on scientific tools for purposes of enhancing individual decisional autonomy, and limiting society’s ability to influence the behavior of individuals.21 The pro-minority rights tended to advocate for legal mechanisms and political instruments, such as granting or withholding foreign aid, as preferred strategies for advancing civil liberties.22 In one approach, a theory of human rights is synonymous with individual rights and, in the other, with collective rights. While each of these rights perspectives accounts for an essential feature of the human rights theory, none provides an overarching, definitive standard for accommodating diversity and reconciling competing individualistic and communitarian interests.

Pandemics and epidemics are better managed by adherence to a criterion that incorporates respect for the dignity of the individual person and furthers the flourishing of the human family. Such a criterion ought to foster, for instance, the principle of solidarity, which constitutes the values of communication, collaboration, cooperation,
and coordination across diversity. Likewise, the societal good of health and safety entails the protection and promotion of autonomy and individual responsibility.

The UNESCO’s bioethics principles approach provides Uganda with an effective strategy for reconciling competing individualistic and communitarian moral dilemmas, so as to combat the heterosexual transmission of HIV. The approach accommodates both individual and communitarian ethical interests, and when applied in MIEM, provides balance. For instance, the bioethics principles approach could provide effective guidance to balancing between societal commitment to distributing socio-cultural roles, and women’s disapproval of gender-based roles that subordinate the individual woman’s interests.

The unjust distribution of gender roles renders women powerless in matters of autonomous sexual choices and enhances the spread of HIV/AIDS. As explained by ethicists, women’s economic dependence and lack of decisional power gives men undue advantage on issues such as property rights, co-habitation, wife inheritance, early girl marriages, dowry, domestic violence, and sex choices. Socio-cultural practices violate human rights when they perpetuate inequality, inequity, and injustice. Moreover such practices often enhance women’s social susceptibility to HIV.

The human rights framework, such as stipulated in the UDBHR document, accommodates diverse cultural values systems and beliefs, in so far as they do not infringe upon human dignity, human rights, and fundamental freedoms. Human rights are regarded as superior to cultural expressions since they are inalienable rights based on the inherent dignity, and equality, of fundamental freedoms and rights of all human beings. Yet, human rights are also understood as guarantors of cultural diversity and
pluralism, for they entail a claim to non-discrimination due to differences such as of race, color, sex, languages, gender, and religion.26

The UNESCO’s human rights-based bioethics principles ought to be differentiated from the reductionist application of the simplified conceptual human rights frameworks, based on legal rights (as in legal positivism), or simple beneficiary theories. Human rights reductionism has emerged as a problem that may attenuate the relation of public health and human rights. Increasingly, as attested to in the Uganda experience, transnational HIV/AIDS advocates get caught up in the “pendulum theory of individual, communal and minority rights.”27

Human rights reductionism in the Uganda debate developed as a slippery slope of linking health to human rights in the global fight against HIV/AIDS. Once the social justice argument was advanced to foster the global HIV/AIDS intervention, transnational, networked civil society and international human rights organizations, such as Human Rights Watch, made the initiative to harmonize civil and political rights with social, economic, and cultural rights. Likewise, humanitarian organizations incorporated rights-based approaches to their strategies of fostering development in poor resource countries, thereby engaging in a debate regarding diversity of beliefs and values.28

While many Western-based transnational advocates are well acquainted with democratic mechanisms, such as the Bill of Rights in United States that enables the exercise of natural rights and accommodates diverse beliefs and values in their countries, the complex pluralistic social-cultural system of sub-Saharan Africa is probably an unfamiliar domain. But a theory of human rights, such as advanced in the UNECSO’s bioethics principles, provides commonality for its accommodation of diversity. As
explained by Peter Jones, a theory of human rights necessarily accommodates, and provides for, diversity by its adherence to a discontinuous strategy with doctrinal disagreement. By being a theory about the equal rights and equal status of the human persons, a theory of human rights positions itself “outside and above the arena of doctrinal disagreement.”

In this sense, the UNESCO’s bioethics principles are a set of universally accepted, minimum normative standards that arbiter doctrinal disagreements. For instance, managing the conflict regarding women’s experience with subordinate gender roles, as well as concerns regarding homosexuality in Uganda’s HIV/AIDS intervention, requires a consideration of the principle of non-discrimination and non-stigmatization as stipulates in article 11 of the UDBHR document. The principle affirms the non-violation of human dignity, human rights, and fundamental freedoms, since all people are born free and equal in dignity and human rights. In the context of the Uganda HIV/AIDS debate, non-discrimination ought to be considered in relation to other principles such as autonomy and individual responsibility, and the principle of respect for cultural diversity and pluralism.

This approach is different, for instance, from a strategy that focuses on the diminution of the marriage institution as a means of enhancing women’s decisional autonomy, and the advancement the freedom of choice regarding sex. The UDBHR principles approach as made practical by MIEM, commits to rigorous scrutiny and analysis of meaning, scope, justification, and balancing of competing principles. Since the balancing between conflicting principles entails limiting the application of these principles in certain
circumstances, the MIEM requires engaging the processes by deploying procedural standards such as reasonableness or necessity.

Taking into account Ugandan’s willingness to embrace the “behavior change initiative” of the 1990s, it not unreasonable to assume that Uganda’s mainly patrilineal society is not indifferent to reforming unjust gender based socio-cultural roles. When President Yoweri Museveni sought to counter the high HIV prevalence with behavior change programs, he took advantage of Uganda’s robust social cohesion. More telling are the people who revealed their HIV positive status to the community, and abstained from sex because they cared deeply about the wellbeing of other human beings. It fact, it could be argued that the community mobilization success proved that respect for the dignity of individuals, the common good, and solidarity are basic features of Uganda’s social cohesion.

(iii) Recommending Bioethics Committees and Education for Uganda

Lessons learned from the Nazi experimentations, eugenics programs, and the Tuskegee syphilis study, among others, helped refocus the trajectory of public health interventions away from coercive and manipulative models towards decisions and practices that enhance human dignity and the wellbeing of the human family. HIV/AIDS policies that are modeled on universally accepted bioethics principles and procedural standards necessarily infer the promotion of a spirit of “professionalism, honesty, integrity and transparency in decision-making.”

The UDBHR document recommends that addressing and reviewing bioethics issues must proceed in a manner that engages professionals and society in dialogue, “for informed pluralistic public debate,” and commits to the “best available scientific
knowledge and methodology.” As applied in the MIEM criteria, dialogue and persuasion require that the influencing agents demonstrate not only substantive justification, but also commitment to a process that is in accordance to procedural standards, such as reasonableness, necessity, and proportionality.

*Article 19* of the UDBHR requires the encouragement of states to establish independent, multidisciplinary, and pluralistic ethics committees which could “foster debate, education and public awareness, and, engagement in bioethics discourse.” In the last four decades, ethics committees have proved to be very effective tools for enhancing dialogue, understanding, and persuasion in clinical medicine and research, as well as in non-academic, health related enterprises. UNESCO advised that bioethics committees could be established at three levels of government, namely, national, regional, and local.

Because of the multi-disciplinary composition and diversity of competencies such as science, law, ethics, political theory, humanities, and social-cultural community representation, ethics committees are appropriate mechanisms for disambiguating Uganda’s HIV/AIDS complex moral dilemmas and fostering the improvement of health and human rights. In the management of the HIV/AIDS moral quandaries, Uganda’s National Bioethics Committee can be significantly enriched by UNESCO’s knowledge, and experience, with different forms and functions of ethics committees.

UNESCO enumerates four forms and functions of ethics committees. The policy-making and/advisory committees (PMAs), on the national level, establish “sound scientific and health policies” for the citizen. Health Professional Association Committees (HPAs) “establishes sound professional practices for patient care
Health care/Hospital Ethics Committees (HECs) “improve patient-centered care (hospitals, out-patient clinics, long-term care institutions, hospices).” Research Ethics Committees (RECs) “protect human research participants while acquiring generalized biological, biomedical, behavioral and epidemiological knowledge (pharmaceuticals, vaccines, devices).”

As envisaged by UNESCO, a national bioethics committee refers to a government body, with usually authoritative power, or a non-governmental body, established for instance, by professional organizations, a policy-advisory body, or NGOs. The National Commission for UNESCO may also steer the creation of a national bioethics committee in certain circumstances. Uganda could also benefit from local bioethics committees that are usually associated with community and religious-affiliated health care institutions.

The purpose of the PMAs is to advise the government, and governmental bodies, “on bioethics problems and issues raised by progress in health care, biology, the biomedical science and biotechnology.” Moreover, PMAs need to “influence policy-making and increase public awareness and participation” through the publication of recommendations on bioethics issues. Additionally, PMAs “provide a forum for discussion at the national level of a plethora of bioethics problems, issues and particular cases,” that attract much public attention through, for instance, extensive press or social media coverage.

PMAs accomplish a number of functions that include formal self-education, fundamental inquiry into scientific innovations and deliberation on appropriate use, and familiarity with regulations regarding protection of participants in human research. Other functions entail the exploration and management of the relation between scientific
innovations and moral, as well as cultural, implications. PMAs are also tasked with facilitating greater understanding, and awareness, of bioethics problems and dilemmas among various health professionals, members of the scientific community, media professionals, and the lay public.\textsuperscript{48}

To underline the importance of policy-making or advisory bioethics committees for Uganda’s population health intervention, one only needs to look, for instance, at the proposed \textit{HIV/AIDS Prevention and Control Bill 2008} that was still shelved in parliament by 2012. The proposed bill “provides for mandatory testing for HIV/AIDS and forced disclosure of HIV status.”\textsuperscript{49} According to Dr. Alex Ario, a Uganda Ministry of Health Official, the “Know Your Status” policy ought to make HIV testing routine when a person seeks treatment or a check-up at a health facility.\textsuperscript{50} In response, the civil society, Center for Health and Human Rights and Development, petitioned the United Nations for intervention against the compulsory measure.

In 2011, the Uganda Law Reform Commission recommended that national legislation should protect the patient’s informed consent in HIV testing, and only make it mandatory for specific cases, and for pregnant mothers to avoid mother-to-child transmission.\textsuperscript{51} A pluralistic policy-making, or advisory bioethics committee, knowledgeable on the UDBHR ethics competencies could be an appropriate platform for handling cases such as Uganda’s “Know Your (HIV) Status” dilemma.

The International Bioethics Committee of UNESCO acknowledged that, in matters of public health, “medical intervention may be justified without consent in specific cases in order to protect individuals.”\textsuperscript{52} But, the consideration has to be weighed carefully against the individual’s right of autonomy as specified in the derived principle of informed consent.
consent, and in relation to the overall societal well being, such as expressed in the principle of solidarity and cooperation. 53

In this case of the proposed compulsory HIV testing policy in Uganda, the task of a bioethics committee, as recommended by UNESCO ought to be the assessment, advice, and formulation of recommendations regarding the relevant ethical, legal, and social problems. 54 By focusing effort on principles, norms, and values, the committee members provide sophisticated ethical scrutiny, and formal oversight, necessary for the improvement of health and human rights. 55

A competent bioethics committee provides informed advice and eliminates the need to petition the United Nations body for intervention, as did the Center for Health and Human Rights for Development. 56 More important, however, is that bioethics advisory committees tend to look beyond the effectiveness of a public health measure to a consideration of the ethical justificatory conditions, and adherence to, procedural standards. The normative ethical analysis involves balancing, for instance in this case, between the conflicting principles of autonomy (and the derived principle of informed consent) and solidarity to advance the population good of health and safety.

One other notable conflict that emerged during the 2012 Ebola outbreak and intervention in Uganda further demonstrates the importance of policy-making, or advisory bioethics committees. Mourners reportedly snatched the body of a suspected Ebola victim from public health officials who had been dispatched to handle the burial. The Muslim mourners, who were “armed with clubs, sticks and stones,” accused the health officials of violating Muslim burial rites by “wrapping the body in a bag.” 57 The
mourners also demanded that they wash the body before burial, in accordance to Muslim practice.

Epidemiologists explain that the Ebola virus spreads from person to person mainly through contact with the bodily fluid of the infected person. But, as evidenced in this case, solely epidemiological factors do not suffice for purposes of containing a public health disaster. Contagious disease outbreaks occur among populations of diverse social, cultural, and religious beliefs and values. For this reason, pluralistic, multidisciplinary, and independent bioethics committees are essential in Uganda for the mobilization and sensitization of the public to create awareness, and to render diversity of belief and value compatible with health goals and human rights.58

The bioethics committee provides a platform for working together on ethical dilemmas from a diversity of competencies, such as epidemiologists, public health officials, health administrators, community representation, and faith-based representation. During the successful years of the behavioral change strategy in Uganda in the 1990s, Muslim leaders and other faith based agents demonstrated a spirit of mutual cooperation, and engagement, in the efforts to prevent the rise of HIV prevalence. Between 1992 and 1997, the Islamic Medical Association of Uganda (IMAU) engaged Muslim leaders in education about HIV/AIDS and mobilized their support in combating the HIV/AIDS epidemic.59

However, while the communitarian approach that informed the behavioral change strategy of the 1990s in Uganda necessarily entails commitment to principles of solidarity and cooperation, the UNESCO’s bioethics principles approach requires cogent and systematic moral inquiry. The exercise of bioethics inquiry presupposes that members of
the bioethics committee have engaged the bioethics self-education. While some of the self-education is formal, such as seminars, workshops, and study of the ethics literature, usually much of the self-education occurs informally through consulting knowledgeable persons, or canvassing existing bioethics literature.

The behavioral change approach of the 1990s aside, much of the bioethics competencies Uganda has mastered, at least in the last ten years or so, appears to be in the purview of human research ethics associated with HIV/AIDS. The Uganda National Council for Science and Technology (UNCST), established by the 1990 Act, Cap 209 of Uganda law, is “mandated to facilitate and coordinate the development of policies and strategies for integrating science and technology into the national development progress.”\textsuperscript{60} UNCST is a government agency under the Ministry of Finance, Planning and Economic Development.

Research ethics oversight in Uganda is carried out on the national level by the National HIV/AIDS Research Committee of the UNCST, and at the institutional level by Institutional Review Committees. Some of the accredited Institutional Review Boards include those of the Uganda Virus Research Institute, the Joint Clinical Research Center, School of Public Health, School of Medicine, and Mengo Hospital.\textsuperscript{61} To aid the process of ethical research oversight, the UNCST issued the \textit{National Guidelines for Research Involving Humans as Research Participants}.\textsuperscript{62}

But, as explained by UNESCO, research ethics committees are only part of the much broader bioethics oversight strategy that includes policy-making and /or advisory committees (PMAs), and health care/hospital ethics committees (HECs). Uganda could expand on the bioethics competencies by adopting UNESCO’s bioethics core curriculum.
developed to introduce university students globally to the Universal Declaration on Bioethics and Human Rights principles. The proposed study materials were based on the principles adopted by UNESCO.\textsuperscript{63}

The curriculum was justified on the basis that it “articulates ethical principles that are shared by scientific experts, policy-makers and health professionals from various countries with different cultural, historical and religious background.”\textsuperscript{64} Subsequently, the UDBHR principles approach enables students to think beyond individualistic approaches to ethics, and reflect as well on the social and community ethical dimensions and human rights considerations of medicine, health care and science.\textsuperscript{65}

A combination of bioethics education and the development of ethics committees will provide Uganda with sound bioethics-principles competencies essential for balancing between individual and population interests to effectively manage pandemics and epidemics, while safeguarding individual and human rights. That engagement will require the deployment of the Mixed Interests Ethics Model (MIEM) to negotiate balance between conflicting substantive principles, and procedural standards to delineate scope.
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