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RESPECTING THE ETHICAL TENSION BETWEEN SURVEILLANCE AND PRIVACY IN
PROMOTING PUBLIC HEALTH AND DISEASE MANAGEMENT

A Dissertation

Submitted to the McNulty College and Graduate School of Liberal Arts

Duquesne University

In partial fulfilment of the requirement for

The degree of Doctor of Philosophy

By

Kamal Althobaiti

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Kamal Althobaiti

2022

RESPECTING THE ETHICAL TENSION BETWEEN SURVEILLANCE AND PRIVACY IN
PROMOTING PUBLIC HEALTH AND DISEASE MANAGEMENT

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ABSTRACT

RESPECTING THE ETHICAL TENSION BETWEEN SURVEILLANCE AND PRIVACY IN PROMOTING PUBLIC HEALTH AND DISEASE MANAGEMENT

By

Kamal Althobaiti

May 2022

Dissertation supervised by Gerard Magill, PhD

The recognition of the need to undertake surveillance and to protect privacy is well established. However, the continually changing circumstances and fast-paced development of healthcare today requires a continuing need to respect this ethical tension between surveillance and privacy. Hence, this dissertation is to respect the ethical tension between surveillance and privacy in promoting public health and disease management. This dissertation investigates the ethics of conducting public health surveillance, including the challenges associated with obtaining consent and protecting data from unauthorized access. The dissertation will focus on the ethical consequences of big data, including issues associated with obtaining informed consent, data ownership, and privacy. As the dissertation concludes, it will provide an ethical justification of observing privacy in public health surveillance.

The analysis is pursued in the dissertation in the following manner. After a brief introduction in Chapter 1, the analysis begins in Chapter 2 by explaining the importance of consent with regard to protecting privacy, including confidentiality in clinical ethics. Chapter 3 moves the discussion to the realm of public health ethics, discussing two examples of population health matters to illustrate the dissertation's focus. Chapter 4 focuses on the complex issue of disease management for which the ethical tension between surveillance and privacy is pivotal. Chapter 5 then discusses the critical need for respecting this ethical tension in research protocols from a global perspective. Chapter 6 moves the discussion to the fast-developing debate of data analysis in healthcare for which respecting the ethical tension between surveillance and privacy will be pivotal for the continuing success in this new arena. Finally, Chapter 7 provides a brief conclusion to the dissertation.

DEDICATION

This dissertation is dedicated to the sake of Allah, my Creator and my Master.

Although they are no longer of this world, I am dedicating this dissertation to my beloved parents, who have meant and continue to mean so much to me. I can't describe how much you brought to my life. I will never forget you.

This work is also dedicated to my wife, Maram, who has been a constant support and encouragement during my graduate studies. Thank you for being there; I am immeasurably grateful for you in my life. You are a great motivator!

To my beloved siblings, Nadia, Jamal, Dr. Fouad, Dr. Waleed, and Ameer, I am truly thankful for having you all in my life.

To my beloved kids, Miral and baby Motaz, "I love you more than I have ever found a way to say to you."

To everyone in my life, I dedicate this dissertation.

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Chapter 1. Introduction

The tension between surveillance and privacy is critical for interventions in promoting public health and disease management. This tension emerges because of the widespread need for surveillance. Public health surveillance is the systematic analysis and collection of purposely data in a timely manner for public health response. In addition, the surveillance of public health depends upon various sources such as health professionals' reports, health records, health surveys, and other data sources. The data sources usually disclose health issues of the public as they arise. For example, the concept of genomic surveillance is a highly precise sequencing process that identifies the accurate pathways of infectious diseases and sources. In other words, surveillance is an epidemiological investigation that has helped researchers and providers to identify disease outbreaks, timely diagnosis, and antibiotic resistance.

Researchers and public health providers need to maintain participants' privacy while conducting disease surveillance. For example, healthcare research is essential to improving the health of populations and the healthcare industry in general. Moreover, protecting individuals participating in research studies is crucial to ethical research. Thus, research ethics requires researchers to protect the privacy of their participants. A balance must be struck between maintaining participants' privacy and ensuring that sufficient data is collected so that health research can benefit communities.

Many common laws support the fundamental rights of individual patients in healthcare. Self-determination and personal autonomy are the patient's basic rights to accept or reject any medical examination or treatment. Individual autonomy requires a sound mind with a capable cognitive capacity unless any legally authorized representative provides informed consent on the patient's behalf for the medical treatment. There are several assessment tools that healthcare

professionals around the globe use to determine the cognitive capacity of a patient towards medical decisions. It is the utmost responsibility of the healthcare professional to adhere to the healthcare profession's rules, allowing the patients to choose the best for their medical condition.

Healthcare interactions regarding privacy and confidentiality depend upon the ethical standard obtained from ethical and specialized professions with their various codes of conduct. Professional codes of conduct provide a secure environment in the healthcare organization, taking an oath to protect the organization's information. These codes emphasize rules and regulations to guide behaviour and being mindful of the consequences of breaching the code, for example, a patient's trust or damage of a professional relationship. Therefore, every staff member, i.e., doctors and nurses, follows a code of conduct.

Consent is crucial in public health surveillance and disease outbreaks. Obtaining consent from individuals is a significant step. However, public health surveillance usually does not obtain explicit patient consent. Furthermore, there is strong support for using name-based reporting for public health surveillance, especially during infectious disease outbreaks. When individual autonomy is overridden, it is typically justified in terms of its benefits towards improving population health and reducing inequalities.

A fast-emerging aspect of health surveillance deals with big data. While big data has introduced significant benefits to public health and the healthcare industry, security and privacy issues emerge as significant threats. Therefore, patients' data must be protected from unauthorized access in the age of big healthcare data. However, the use of personalized medicine in clinical settings has resulted an increase in the availability of health information. The world of the new age is considerably apprehensive towards customized healthcare services. To develop a doctor-patient relationship, personalized medicine and patient-centered care are the two

customized healthcare services provided by healthcare organizations. This, in turn, has raised concerns regarding the safety of patient data. Areas such as pharmacogenomics are also experiencing privacy challenges, especially when protecting a patient's genomic data from being shared without their consent.

This dissertation will highlight public health surveillance and the ethical issues associated with it. It will discuss the main ethical principles applied during public health research and the challenges associated with them. While it is important to uphold privacy and confidentiality during public health surveillance, there are several situations where patient consent is not obtained. Healthcare providers, on the other hand, are expected to respect patient's autonomy. They must also ensure that they use data for the purpose of improving community health and well-being. Therefore, it is essential to create a balance between observing ethical principles and fulfilling their obligations to the community, especially during a disease outbreak. Similarly, it is important to know whether or not there are situations where it is deemed acceptable to forgo an individual's right to privacy, autonomy, and confidentiality for the common good of the community. This dissertation investigates the ethics of conducting public health surveillance, including the challenges associated with obtaining consent and protecting data from unauthorized access. The dissertation will focus on the ethical consequences of big data, including issues associated with obtaining informed consent, data ownership, and privacy. As the dissertation concludes, it will provide an ethical justification of observing privacy in public health surveillance.

This dissertation can be justified by five chapters. The following discussion will be held under five topics of diversified aspects. Furthermore, each chapter consists of two sub-topics under the main heading.

1.1. Consent and Privacy

This chapter explores the concept of the cognitive capacity of an individual patient towards the decision-making process. Secondly, the chapter discusses the concepts of privacy and confidentiality in the field of healthcare and research. The chapter sums up a brief summary of several ethical concerns in healthcare interactions.

1.1.1. Decision-Making and Capacity in Healthcare

1.1.1.a. Informed consent and case consultation

Healthcare providers must ensure that they assess a patient's capacity to consent to any form of medical treatment. However, the process of obtaining informed consent is extremely challenging and often requires the balance between respect for persons and observing the patient's autonomy.¹ When assessing a patient's capacity, there are several factors to consider that affect cognition. These factors include depression, dementia, delirium, and even head injury.² While the law stipulates that all individuals have autonomy and thus, have the right to accept or reject medical intervention, taking care of a patient who cannot make reasonable decisions concerning their health is complicated.³

Informed consent refers to the right of all adult patients to agree or refuse treatment. Currently, standards that measure informed consent place more emphasis on patient's self-determination, education, and autonomy.⁴ Furthermore, all international research ethics codes recognize that informed consent is a crucial ethical requirement and researchers must ensure that those study participants are competent enough to make decisions and provide consent.⁵ Oftentimes, healthcare providers wonder whether a patient has the capacity to refuse medical treatment. While the capacity to make informed decisions concerning one's health can be

determined by a physician, determining a patient's competency is determined by the judicial system.⁶ In the current healthcare industry, lack of health literacy and breakdowns in physician-patient communication are some of the major factors affecting the medical decision-making process. It is, therefore, the responsibility of the clinician to provide all the information needed for patients to make informed decisions about their care.⁷

1.1.1.b. Analysis of a clinical case

Determining capacity usually requires the services of a consultant who is called upon to assess the patient. There are several reasons why clinicians involve consultants. They include situations where determining lack of capacity might negatively affect the relationship between the patient and the hospital, cases where there is a lack of resources to conduct a proper evaluation, in high-stake cases, and lastly, in situations where the patient's mental health is compromised.⁸ However, for these evaluations to be conducted, the patient must provide consent without being coerced.⁹ The assessments also ensure that patients have functional abilities that they can use to survive in society.¹⁰

When approaching a new case, healthcare professionals are taught to first identify the patient, analyze their health history, and conduct a physical examination in addition to laboratory tests and come up with the best course of action.¹¹ However, this framework fails to consider the ethical decision-making process that is associated with a clinical examination. To incorporate ethical decision-making into clinical practice, healthcare professionals can adopt different approaches, the four-topics and CASES approaches for example. The four-topics approach sorts out the facts and values to facilitate the resolution of an ethical issue. The approach also allows healthcare providers to approach a case systematically while also integrating ethical principles into the case.¹² To elaborate more on this, a case will be in depth analyzed using the four-topic

approach. This will help healthcare professionals in improving ethics consultation requests. Healthcare providers and consultants must consider which approach best suits their patients and the ethical dilemma.¹³ From a public health perspective, clinicians may request ethics consultation when the public safety is at risk. For example, patients who are COVID positive with other health conditions and wished to go against medical advice.¹⁴

1.1.1.c. Decision-making process in clinical ethics

Patient decision-making capacity (DMC) is one of the core principles of healthcare consent which deemed to highlight a legal authority for the healthcare practitioners (HCP).¹⁵ Unrepresented patients are individuals who lack decision-making capacity, lack documentation on their preferred care options, and lack a surrogate decision-maker to help them make medical decisions.¹⁶ When handling such a patient, it is recommended that the best interest standard be applied to guide the medical decision-making process. In the case of an ethical dilemmas such as the case of unrepresented patients, consultants or clinical ethics committees are assigned by the court to make the decision for the patient.¹⁷ In addition to encountering unrepresented patients, clinicians encounter patients who refuse treatment or surgery that is essential to sustaining their life.¹⁸ In such a situation, physicians must decide whether to forgo beneficial treatment or to forcefully subject patients to treatment, both of which have grave ethical consequences.¹⁹ However, informed consent ensures that competent patients select the best treatment which is in line with their goals and values. When patients refuse treatment that is expected to improve their life, physicians must first determine if the patients have the capacity to make such a decision.²⁰ Overall, every clinician has an ethical obligation to uphold a patient's informed decision to refuse life-saving treatment and when the patient's capacity to refuse treatment is questioned, clinicians must determine the patient's capacity.

1.1.1.d. The capacity to make decisions and cognitive capacity assessment

When treating patients, providers are faced with the task of determining the circumstances under which individuals have limited capacity. An individual's capacity can be impaired for several reasons. For example, when they have mental health conditions such as dementia and schizophrenia, when they have severe learning disabilities, brain damage, confusion, loss of consciousness, or when they are under the influence of alcohol.²¹ Furthermore, there are several scenarios that should raise an alarm for physicians. For example, if the individual has a condition known as hypoxia that disrupts their mental status, they should be monitored keenly.²² Furthermore, patients with low levels of education, including cultural and language barriers, might lack the capacity to make informed medical decisions. It is, therefore, the responsibility of healthcare providers to assess patients to determine whether these conditions affect their ability to provide informed consent.²³

1.1.2. Ethical debate on Privacy and Confidentiality

1.1.2.a. Privacy and confidentiality

The importance of keeping patient's information confidential is effective and given high priority in a healthcare facility.²⁴ The medical staff and the patient start to form empathy and in no time, there is a noticeable bond between them. Keeping their medical details and diseases confidential, the staff provides them with the utmost respect and fulfills the needs of the patient.²⁵ However, in many countries, problems may arise because of communication barriers or less interaction of patients and sometimes lack of attention or care to the patient. It is considered that for giving proper care to the patients, the healthcare facility should acquire active listening and effective communication conditions.²⁶ Healthcare providers are encouraged to relay health-

related information to their patients in a more sensitive manner.²⁷ The concept of privacy protects patients against the unauthorized access and disclosure of their medical information. Similarly, healthcare providers are required to keep their patients' information confidential during healthcare interactions.²⁸ For physicians, upholding privacy and confidentiality in healthcare interactions is in line with their Oath in most. This code also ensures that they build a trusting relationship with their patients.²⁹ Nurses also have an obligation to uphold the principles of privacy and confidentiality when interacting with their patients. This involves limiting access to patients' electronic information through the use of passwords and usernames.³⁰

1.1.2.b. Technology in healthcare interactions

The use of big data technologies in healthcare is gaining popularity every year. However, big data use raises several ethical issues such as privacy, transparency, and respect for autonomy.³¹ Similarly, the absence of comprehensive regulatory policies has made it almost impossible for ethics review committees (ERCs) to review and give their feedback on studies using big healthcare data.³² Data anonymization is also a major challenge in the use of big data. Furthermore, there is a high probability that data will be re-identified, making it almost impossible for data masking techniques to be effective.³³ Health information technology (HIT) and, more specifically, electronic health records (EHRs) have been successful in improving doctor-patient interactions. However, EHRs face several challenges including security breaches, privacy and confidentiality violations, system implementation, and data inconsistencies.³⁴ Healthcare organizations can limit access to patient information by adopting several security measures, including implementing security policies, data encryption, cloud storage, and password protection interventions.³⁵ However, these technologies also experience privacy and

confidentiality breaches. Researchers also find it difficult to manage the large amounts of data associated with mHealth technologies.³⁶

1.1.2.c. Privacy and confidentiality in healthcare interactions

During clinical interactions, healthcare providers must ensure that they protect their patients' right to privacy and confidentiality.³⁷ By maintaining confidentiality, healthcare providers can further strengthen the physician-patient relationship.³⁸ Similarly, physicians must ensure that they inform their patients in the case where their confidentiality is breached. They must also ensure that they inform their patients of the benefits of limiting access to their personal information.³⁹ In healthcare research, on the other hand, confidentiality involves agreeing to keep the study participants' information private. Furthermore, confidentiality in research highlights how data should be handled while privacy involves allowing individuals to have full access and control over their personal information.⁴⁰ In mHealth, guaranteeing the privacy of users has been a challenge mainly due to a lack of regulations designed to monitor interactions between users. Privacy issues also arise since patients have to provide their personal health information to be able to gain access to mHealth platforms.⁴¹ It is the responsibility of mHealth platforms to provide approaches that will effectively protect users' personal health information.

1.1.2.d. Protecting data privacy

While confidentiality is essential in healthcare, there are several instances where confidentiality breaches are permissible, including; when required by law or when it will benefit the public.⁴² However, in other instances, breaches of confidentiality occur in healthcare settings by healthcare providers. When healthcare professionals engage in careless speech or act maliciously, especially when in public places, they often breach their patients' confidentiality and share private patient information.⁴³ Everyone has the right to privacy and confidentiality and

to have their personal data protected at all times.⁴⁴ There are several interventions that can be adopted to protect an individual's confidentiality. They include data encryption, use of passwords, and general application of physical technical and administrative safeguards to protect patients' health-related data.⁴⁵ An individual's privacy, on the other hand, can be protected by observing data transparency and penalizing individuals who misuse data.⁴⁶

1.2. Promoting Public Health

The chapter contains a comprehensive debate over the concept of human reproduction and health. Secondly, a comparative analysis between Islam and Judaism forms a brief discussion for the COVID-19 pandemic situation around the globe. The chapter holds great relevance in accordance with the promotion of public health and diseases management.

1.2.1. Human Reproduction and Public Health

1.2.1.a. Reproduction and unintended pregnancies

One of the leading causes of maternal death globally is unintended pregnancies. To mitigate the negative impact of unintended pregnancies, women are encouraged to use contraceptives.⁴⁷ However, the morality of contraception has been at the center of many debates, with many physicians struggling with their personal beliefs and ensuring that they respect their patient's decisions. Regardless of their personal and religious beliefs, physicians have an ethical obligation to provide all the information on contraception to allow individuals to make an informed decision on the right course of action.⁴⁸ The introduction of assisted reproduction has also received a lot of attention. The issue of birth control has also received similar attention, especially from religious groups. Professional organizations also offer counseling in addition to

providing emergency contraceptives to reduce the rate of abortions and unintended pregnancies.⁴⁹ However, for some religious hospitals, the use of emergency contraception, even for victims of sexual assault, is still controversial. At the heart of the controversy is whether the use of emergency contraceptives alters the lining of the endometrium, thus preventing fertilization and implantation.⁵⁰ For women who have been sexually assaulted, understanding how hormonal medications result in improved health relies on the mechanisms of drug action. Besides, a majority of these moral judgments are based on outdated assumptions and scientific research.

1.2.1.b. The moral perspective in human reproductive medicine and the impact of contraception on public health

Moral judgments are highly dependent on credible facts. Without accurate information, erroneous judgment is bound to happen. Good facts are, therefore, essential for good ethics. This is true, especially in understanding how emergency contraceptives such as levonorgestrel work. For example, emergency contraceptives do not prevent implantation.⁵¹ Evidence also shows that there is no delay when returning to fertility after emergency contraceptives.⁵² Based on this moral certitude, one might argue that morally and ethically, the use of emergency contraception is the best option, especially for sexually assaulted women. Physicians and pharmacists are also conflicted when it comes to administering emergency contraceptives to teenagers.⁵³ Some choose not to provide emergency contraceptives to teenagers regardless of the condition the teens are in. Others will only provide the drugs if the sexual encounter was non-consensual.⁵⁴ Physicians often have different values when addressing complications of reproductive health in teenagers. Physicians must, therefore, become aware of the impact of their underlying beliefs on their ethical responsibility as medical professionals to provide the best care to patients.

Patient autonomy is one of the main ethical concerns that is associated with access to emergency contraceptives. For some, emergency contraceptives are unethical, while for others, emergency contraceptives violate basic ethical principles.⁵⁵ Since there is evidence that shows that emergency contraceptives do not impede implantation, placing barriers on their use violates patients' ethical principles of respect for autonomy, non-maleficence, and beneficence.⁵⁶ Unplanned pregnancies are one of the main problems affecting resource-poor settings. This is mainly due to limited access to family planning services.⁵⁷ Teen pregnancies also continue to place a significant burden on individuals and the society as a whole. To prevent teen pregnancies, states may consider administering long-acting reversible contraceptives (LARCs) to all teenagers.⁵⁸ However, many might argue that this is not ethical. This could be due to the conflict that exists between the principles of beneficence and autonomy. Furthermore, physicians might struggle with determining the role the adolescent plays in the decision-making process.⁵⁹ Besides, as adolescents continue to grow, they lack consistency in their decisions.⁶⁰ Due to the aforementioned reasons, physicians must examine the teenager's state of mind and the context of their decisions before considering administering contraceptives.

1.2.1.c. A comparative analysis

The main concern for all healthcare providers is the well-being of their patients. Healthcare providers must, therefore, respect the autonomy of their patients while also ensuring that they get the right information and advice regarding the best mode of contraception to use.⁶¹ Healthcare providers are also required to observe the principles of informed consent by providing all the needed information associated with contraceptives. To fulfill this, healthcare providers provide all the information, including potential side-effects and health risks, so that patients can make informed decisions on their most preferred contraceptive.⁶² Sterilization is

another form of contraception that faces a constant ethical dilemma. Ethically speaking, providing sterilization requires careful counseling.⁶³ Additionally, the content presented during counseling should contain up-to-date information regarding the sterilization procedure and other forms of contraceptives available.

1.2.1.d. Theoretical analysis of contraception

While it is evident that the use of contraceptives should be aligned to the woman's health status, a woman's decision to use contraceptives is highly dependent on their cultural practices. Furthermore, poverty, illiteracy, and religiosity have created an environment of misinformation.⁶⁴ Additionally, for women with intellectual disabilities, the ethical justification of forced sterilization has been highly debated over the years.⁶⁵ This systemic injustice violates the women's right to bodily integrity and to make decisions regarding their reproductive health.⁶⁶ In addition to the forceful sterilization of women with mental disabilities, the sterilization of incarcerated women also raises several ethical issues. Care should be taken to ensure that incarcerated women give consent to be sterilized and that they are not coerced into providing consent.⁶⁷ Moreover, in many parts of the world, forceful sterilization, especially of marginalized women, is viewed as a human rights violation. Similarly, these parts of the world frown upon obtaining consent while the individual is under duress or when they are provided limited information regarding the procedure or medical intervention.⁶⁸ Regardless of the situation, forced sterilization violates the woman's right to autonomy and to provide informed consent.

1.2.2. The Ethical Obligation to Minimize COVID-19 Deaths as an end-of-life Mandate from Islamic Perspective

Public health and global health have been greatly affected by the ongoing pandemic of COVID-19. The global pandemic has been a resulting factor of increasing cases and mortalities, as stated by the World Health Organization (WHO).⁶⁹ In terms of the seriousness of the disease, many countries have built their very own crises management systems to ensure economic stability and public health.⁷⁰ In addition, the global pandemic has heavily impacted the aspect of religion around the world. For instance, in the Islamic religion, the religious activity of Pilgrimage – *Hajj* has been disregarded in the years of the pandemic. Furthermore, Islamic laws are pertaining towards any of the covid patients for burial process in case of death. Islamic traditions emphasize the collective duty of funeral of any deceased Muslim individual.⁷¹

1.2.2.a. The Nature of Bioethics in Islam

The COVID-19 pandemic has introduced several challenges to public health and to the global economy.⁷² For Muslims who are affected by the pandemic, they can rely on the teachings provided in the Qur'an, the Sunnah, and the Ijtihad.⁷³ Furthermore, Muslims can rely on the interpretations of the learned or the *Ulema* to address ethical dilemmas in healthcare.⁷⁴ Consensus groups are also called upon for rulings that are associated with medicine. Islamic legal and ethical traditions are used as guiding factors when dealing with emerging issues in bioethics.⁷⁵ The *faqih*, who are qualified scholars in matters of Islamic laws, also play a crucial role as the guiding force in all schools of thought in Islam. However, currently, there are no Muslim jurists who specialize in handling bioethical issues. To fill this gap, Muslim jurists are applying the primary sources of Islamic law: the Qur'an and the Sunna in addition their own legal reasoning.⁷⁶

Islamic bioethics believes in the four main principles of bioethics: autonomy, beneficence, non-maleficence, and justice.⁷⁷ According to the Quran, respect for autonomy is demonstrated in allowing individuals to accept or reject Islam. The Islamic autonomy also extends to decisions on life and death, with more emphasis placed on preserving life.⁷⁸ The principle of beneficence, according to the Hadiths of Prophet Muhammad and the Quran, encourages Muslims to do good and avoid engaging in harmful practices. The principle of justice is also highlighted in Islam.⁷⁹ According to the Quran, God has raised prophets whose main role is to establish justice and to enforce it in all spheres of life. As such, God commands justice.⁸⁰ The Quran also calls on all believers to stand firmly and avoid being swayed by others who do not value justice.

1.2.2.b. Value of life in Islam

Due to recent advancements in biotechnology, several bioethical issues have emerged. End-of-life issues are among the major healthcare challenges that the public faces. These issues include physician-assisted suicide, euthanasia, withdrawal of treatment, do not resuscitate orders (DNR) and consent.⁸¹ Muslims across the world oppose euthanasia because human life is sacred and it is only Allah who can determine how long an individual will live on earth.⁸² However, DNRs is permitted in some situations. Other issues such as determining when an individual is brain dead are also a major issue in the Islamic community.⁸³ Furthermore, determining when it is ethically justifiable to withhold treatment is also a challenge.⁸⁴

1.2.2.c. End of Life Issues

While life is considered sacred in Islam, death is an inevitable and irreversible experience.⁸⁵ When illness occurs, other believers are encouraged to take care of the sick, pray for them and seek forgiveness.⁸⁶ Islam also encourages believers to seek treatment when they fall

sick.⁸⁷ This is also encouraged in Prophet Muhammad's Hadiths and the belief that God would never send a disease that he has not already provided a cure. Based on this, treatment is highly encouraged and even considered mandatory.⁸⁸ However, when it is highly unlikely that the medical intervention will bring any benefits, Muslims are encouraged to abstain from it.⁸⁹ In all these, the ultimate goal or purpose of life is to worship God alone. Therefore, Muslims should view illness as an opportunity to get even closer to God.

1.2.2.d. Covid-19 Deaths in Islam and Judaism

Statistics from respected international organizations show that Muslims are affected more by COVID-19 compared to individuals who lack a religion.⁹⁰ Evidence also shows that the coronavirus is causing mayhem in the Jewish community.⁹¹ To reduce the spread of the virus, Muslim and Jewish religious leaders are encouraging the adoption of public distance strategies or (PDS). The practice of religious rites has significantly changed with gravesite gatherings or even prayer sessions have also significantly changed. However, to fully prevent the transmission of COVID-19 in the community, a whole society approach should be adopted.⁹²

1.3. Disease Management

This chapter discusses the professional challenges faced by healthcare organizations towards the process of disease management and public health ethics. A brief discussion of genomic surveillance and sequencing formulates a formal debate towards disease outbreaks and their surveillance.

1.3.1. Surveillance and Outbreak Response

1.3.1.a. Ethical challenges

Research involving infectious disease management has several ethical challenges. These challenges arise, especially when it is conducted in developing countries by researchers from resource-rich countries. Due to their low social and economic status, a majority of these resource-poor countries are exploited.⁹³ Furthermore, the emergence of new infectious diseases has created a new set of public health problems for scientists. When conducting research on infectious diseases, scientists struggle with upholding traditional public health ethics.⁹⁴ The aim of public health ethics is to prevent harm and promote health. Furthermore, public health ethics and policies protect individuals against harm while also improving their overall public health benefits.⁹⁵ The main role of public health ethics is to provide the right conditions required to promote health. However, this role is increasingly being threatened by emerging infections and decreasing vaccination rates.⁹⁶ Taking a different approach result in the violation of respect for autonomy and freedom of choice for individuals participating in public health research.⁹⁷ However, this is necessary if progress is to be made in infectious disease research.

1.3.1.b. Public health ethics

The Ebola virus outbreak witnessed in West Africa introduced multiple ethical concerns on how health officials respond to disease outbreaks. For some countries affected by the virus, the struggle was in maintaining ethics during the treatment process. In addition, the quarantine conditions imposed on areas affected by the virus were questioned.⁹⁸ In addition to the standards set by public health ethics, public health officials should ensure that they are aware of the principles of ethical considerations associated with human research participants. Public health officials are also expected to demonstrate principled leadership that integrates ethics into

practice.⁹⁹ Public health has a mandate to ensure that public health is moral. To fulfill this mandate, several ethics governing the use of human test subjects have been developed. These ethics guide healthcare providers on the most appropriate interventions to use in the field.¹⁰⁰ Moreover, these ethics guide humanitarian crises that have ethical dilemmas. During emergency situations such as during emergency vaccinations, there is a need for ethical guidance on how the vaccines are administered. Furthermore, issues associated with vaccine allocation, balancing harms, and benefits and lastly, obtaining informed consent are considered when conducting mass vaccinations during emergencies.¹⁰¹ Overall, healthcare providers must uphold ethical principles during emergency vaccinations.

1.3.1.c. Surveillance and outbreak response

Disease surveillance refers to the process of collecting, analyzing, and interpreting large volumes of data collected from several sources. The information obtained afterwards is then used to investigate the effectiveness of the control and preventive measures.¹⁰² Public health surveillance is usually done without informing patients or asking for their consent. Rather, public health surveillance is used to quantify the rate at which health problems are affecting the public and to describe the natural history of diseases and outbreaks.¹⁰³ Furthermore, public health surveillance is a legal requirement that is dependent on the reports provided by healthcare providers regarding the conditions affecting the community. Public health surveillance may don't require the consent or knowledge of individuals.¹⁰⁴ The ethical justification of conducting public health surveillance without obtaining patients' consent has several challenges. More specifically, the principles of public health ethics. On one side, healthcare providers are required to observe the principle of respect for patients' autonomy and obtaining consent. On the other hand, healthcare officials are responsible for using data to improve the overall health and well-being of

the community.¹⁰⁵ Besides, biomedical ethics mainly operates on the principles of autonomy, nonmaleficence, beneficence, and justice while public health ethics focuses on the entire population and the well-being of the community rather than focusing on a single patient.¹⁰⁶ To fulfill the requirements of biomedical ethics, healthcare providers must identify the relevant principles and weigh them against concerns and also justifying their decisions and recommendations.

1.3.1.d. Future work: policies and plans

Healthcare workers should be professional and accountable in their practice. To achieve this, and to be able to deal with ethical challenges, they must receive clinical ethics support. This method is used to give advice and support to healthcare providers on ethical matters that arise during their clinical practice.¹⁰⁷ Ethics education also provides a critical foundation for highlighting ethical problems that might arise in practice. These problems often focus on concerns surrounding informed consent, upholding truth, and protecting participants' rights and the rights of their families.¹⁰⁸ To solve these problems, interventions such as task shifting have been employed.¹⁰⁹ With the increasing need for healthcare providers to maintain ethics, there is an even urgent need to incorporate ethics in public health education in learning institutions.¹¹⁰

1.3.2. Genomic Surveillance

1.3.2.a. Genomic surveillance and genome analysis

The increasing progress that has been made in nucleic acid sequencing technology has made it possible for genomic surveillance to be used in the investigation of infectious diseases transmission and determinants of antimicrobial resistance.¹¹¹ Genome analysis has the potential to transform public health management of infectious diseases and pathogens.¹¹² The field of

public health has grown over the years and emerged as a way of protecting the health of individuals and communities.¹¹³ Genomic knowledge is now being incorporated into public health and offers new ways of differentiating sub-groups with the larger groups of individuals. Whole-genome sequencing is increasingly being used to transform the field of public health microbiology. Genome sequencing is used to diagnose infections, identify outbreaks, and predict antibiotic resistance.¹¹⁴ Furthermore, whole-genome sequencing is an essential tool used in the surveillance of infectious diseases. Next-generation sequencing (NGS) has an even higher accuracy used in the tracing and identification of sources of infections.¹¹⁵ Furthermore, technological advancements have made genome sequencing to be more efficient and cost-competitive. Overall, whole-genome sequencing of pathogens provides an unlimited examination of the genetic content of pathogen isolates thus allowing laboratories to benefit from analyzing the entire genetic content.¹¹⁶

1.3.2.b. Technology for genomic surveillance

Despite the benefits associated with genetic sequencing, several privacy concerns arise. An individual's genetic information is extremely private since every genome is unique and different. However, in every person's genome, there are specific variations that are similar to biological relatives, therefore, making this private genomic information helpful to the public.¹¹⁷ Advanced communication technologies have made it possible for individuals to share personal details even without the consent of the concerned individual.¹¹⁸ One of the ways that genetic privacy is breached is through the introduction of identity attacks. To reduce these breaches, differential privacy and regulation laws have been proposed with the goal of enhancing the protection of private information. Another technique that is used to ensure genetic privacy is implementing controlled access, which allows specific individuals to download data only after

they are approved and under certain conditions.¹¹⁹ The trust-but-verify approach is also another approach whereby users are prevented from downloading any form of data but are allowed to execute queries that are based on their privileges and audits.¹²⁰ Through these audits, it is possible to detect adverse events and prevent malicious users from accessing sensitive information. However, privacy protection using controlled access mainly focuses on data control and, therefore, requires extensive auditing and data verification.

1.3.2.c. Privacy regulations

The use of genetic information in healthcare also raises several issues, including the type of information that can be disclosed as per the requirements of the law, whether consent is needed and the individuals who can access the information.¹²¹ Laws and regulations have been documented to play a crucial role in clinical practice. Furthermore, the protection of genomic anonymity is increasingly becoming more challenging, especially since researchers have been known to combine patient data obtained from genealogy databases with the information they get from social media posts.¹²² The law also places a lot of value on privacy which might conflict with the public health framework. Genetic privacy legislation has also been enacted in all states with various laws already implemented to govern and limit disclosure of genetic information.¹²³ One such law is the Genetic Information Nondiscrimination Act (GINA) that addresses undocumented discrimination associated with health information disclosure. GINA also has provisions that prohibit any form of discrimination by preventing employers from accessing their employees' genetic information.¹²⁴ HIPAA also covers some aspects of healthcare disclosure. As highlighted above, an individual's genetic information is private.¹²⁵ However, while the law protects individuals' genetic information, these protections are more of an illusion. This is because, in cases of public health emergency in infectious disease, genetic privacy would not be

ensured, and the patient's data might end up being shared to assist in vaccine development and in the containment of the spread of the disease.¹²⁶

1.3.2.d. Ethical considerations in genomic surveillance and infectious diseases

At the core of bioethics and health ethics are the principles of beneficence, maleficence, justice, and autonomy. They are also considered as the duties of healthcare providers and patients.¹²⁷ However, while the duty to reduce harm is applicable in research, the duty of justice and autonomy are complex in their application since research is not mainly aimed at benefiting the research scientists.¹²⁸ Genome sequencing also reduces harm to patients by reducing occurrence of ineffective treatments that might result in adverse side effects.¹²⁹ Similar to other forms of medical tests, genome sequencing requires that healthcare providers obtain informed consent to guarantee that the decisions they make are informed. Patients might decide not to undergo through the procedures or take the tests. Providing informed consent should take place through a series of several conversations between the participant and the healthcare provider. This should also apply in genome sequencing research.¹³⁰ In genome sequencing, confidentiality and privacy are unique and are governed by unique guidelines that are appropriate within this field.

1.4. Research Protocols

The chapter explores the global research on infectious diseases. As a growing risk in most of the developing countries, there are certain ethical issues connected with the process of research. In addition, public health surveillance and privacy in global research are also discussed in the chapter.

1.4.1. HIV Research in Developing Nations

1.4.1.a. HIV Research in developing countries

Ethical standards are designed to protect the vulnerable in society. The ethics of HIV/AIDS research conducted in developing countries has been under question for many years.¹³¹ Developing countries are known to provide easy access to study participants, less strict regulations, and reduced costs of operation. Double standards are, therefore, created for research that is considered ethically unacceptable in developed countries but is conducted in developing countries.¹³² Developing countries often struggle to provide HIV therapies. For instance, South Africa, has initiated campaigns for national testing, prevention, and cure. It has mainly strengthened its HIV testing camps to fight with this growing threat. Yet, convenient admittance to proper HIV treatment remains the foremost concern in Africa, due to multiple of challenges.¹³³ Additionally, standards of care during research in developing countries have been questioned and more specifically issues to do with informed consent. Since HIV research on human subjects has both economic and social benefits, balancing ethical laws should be of the utmost importance.¹³⁴ Furthermore, studies should ensure that they adhere to globally accepted standards used to govern clinical research.

1.4.1.b. Reasons why developed countries conduct research in developing countries

There are several reasons why developed countries prefer conducting research in developing countries. Furthermore, there are several elements that make developing countries more attractive for researchers. These elements include relevancy of the research to the issue under investigation, sensitivity to local culture and lastly, the actions taken once the research is completed.¹³⁵ The rules that govern international research are usually impacted by the ethics principles of beneficence, respect for autonomy, doing no harm and justice. Additionally,

potential research participants are encouraged to participate freely in research without being coerced by either rewards or compensation.¹³⁶ Determining the custody of bio-specimens is also a major ethical issue in developing countries.¹³⁷ In developing countries, the low levels of investment in healthcare systems coupled with high poverty rates ease the selection and performance of clinical trials. However, questions arise on whether the interventions administered in developing countries are the standard of care globally.¹³⁸ It is, therefore, essential that the highest ethical standards should be observed to protect human subjects in developing countries.

1.4.1.c. Human subjects in research in developing countries

The protection of human subjects requires that no private information be released to external sources who are not part of the research study. This need-to-know principle stipulates that all members of the research team should know the names of research participants only if it is necessary.¹³⁹ Research participants must be protected with positive benefits maximized and potential harms minimized. The rapid increase in HIV research has also resulted in the development of strict standards that are applied to protect human participants.¹⁴⁰ As a result, the ethical review process is becoming longer. Currently, when conducting research involving human participants, researchers are required to give study participants adequate time to consult with other individuals before consenting to the research.¹⁴¹ Lastly, study participants are encouraged to leverage the use of new technologies in participant tracking, especially in study retention.¹⁴² Best practices and existing standards should be aligned with research guidelines to ensure that human subjects are always protected.

1.4.1.d. Critical analysis of existing research framework models in low-income countries

One of the main challenges affecting research conducted in developing countries is the lack of ethical standards that can be used to guide human research.¹⁴³ Since a majority of individuals affected by HIV/AIDS are teenagers, biomedical HIV research is increasingly focusing on this group. However, research involving adolescents in other parts of the world is considered highly sensitive.¹⁴⁴ Adhering to legal and ethical requirements of clinical trials requires the adoption of specific principles and benchmarks. Researchers must also be aware of contradictory ethical and legal requirements in different countries.¹⁴⁵ Relevant regulations have also been developed to prevent the occurrence of ethical violations. Regulations such as the Nuremberg Code have been developed to protect human participants in research settings.¹⁴⁶ With the main purpose of avoiding exploitation, ethical principles are used to provide a comprehensive framework used to guide ethical clinical research.

1.4.2. Surveillance & Privacy in Global Research Ethics

1.4.2.a. Introduction

Public health surveillance is the systemic collection and analysis of data for the timely dissemination of information used to inform public health response. Public health surveillance also faces several challenges, including issues associated with informed consent. Public health surveillance raises several issues on privacy and civil liberties.¹⁴⁷ Healthcare providers might get exposed to infections when they take care of patients.¹⁴⁸ Furthermore, concern has been raised on how surveillance data is going to be protected. In response to this, the WHO has designed guidelines on how surveillance data can be protected.¹⁴⁹ Additionally, the Universal Declaration on Bioethics and Human Rights (UDBHR), published by UNESCO stipulates the need to

consider the political and social aspects in addition to life sciences. One of the main achievements of the declaration is that it protects individuals who lack the capacity to provide consent.¹⁵⁰

1.4.2.b. Bioethics and UDBHR

Bioethics field has grown to be one of the most significant influences in the modern-day world to control global ongoing changes. The ethical issues in the field of bioethics include biotechnology, healthcare, medicine, and environment.¹⁵¹ Moving towards the ethical principles in global bioethics and *Universal Declaration on Bioethics and Human Rights* (UDBHR), it can be stated that surveillance in public health raises several issues regarding civil and privacy liberties which in turn develops stigmatization. There are various diseases such as HIV/AIDS for which public health surveillance is counterproductive. Throughout the year, the bioethics field has evolved to adopt resolutions and norms. The field of bioethics is accredited in UDBHR which is published by UNESCO. In current times, this advanced field of bioethics is the only present text of bioethical considerations to which world has committed to itself.¹⁵²

1.4.2.c. Privacy and confidentiality issues in public health research

Public health ethics is a discipline that believes that individuals should be made part of major decisions affecting their well-being. However, the individuals who are not capable of making decisions on their own such as children, the state should guarantee their protection and their long-term interests promoted.¹⁵³ Surveillance acts as the foundation of public health. With the increase in clinical trials, opportunities have arisen to address major questions associated with the advantages and disadvantages of interventions. Furthermore, a large gap exists between the use of informed consent and how healthcare providers obtain it. A balance must, therefore, be met between improving evidence and promoting privacy.¹⁵⁴ Bioethics is also confronted with

several issues such as abortion, euthanasia, and genetic testing.¹⁵⁵ Furthermore, privacy violations constitute a high risk that have the potential of resulting in a threat to security. Additionally, privacy violations run the risk of diluting security further showing a level of disrespect to the law and violating universally-accepted ethical principles.¹⁵⁶ Data privacy must, therefore, be assured. In efforts to improve data privacy, the International Health Regulations (IHR) were signed. The IHR were designed to address issues in global health security among other concerns involved in the protection of global health.¹⁵⁷

1.4.2.d. Principles of public health ethics, community health, and individual's autonomy

While organizations such as the IHR and HIPAA were designed to improve security and privacy of patients and study participants, too much regulation could be doing more harm than good. Restrictions and policies intended to protect patients often hinder researchers from accessing crucial information and population data which in turn, negatively affects public health research.¹⁵⁸ Evidence generation is extremely important to public health. Therefore, restrictions that prevent data collection and evidence generation hinder the public health process.¹⁵⁹ Another major issue that researchers struggle with is whether consent is important in global health research. There is strong support from the scientific and legal field to use name-based reporting for infectious diseases.¹⁶⁰ Furthermore, by applying principles of public health ethics, researchers are able to override individual's autonomy. This can be justified from the point of view that the act will improve overall population's health or even reduce healthcare inequalities.¹⁶¹ Lastly, while health informatics community continues to create new approaches to ensure the intelligent analysis and use of healthcare data, the transfer and use of these technologies in real world clinical environments encounters several unique challenges.¹⁶²

1.5. Data Analysis in Healthcare

The chapter puts forward a detailed discussion about the technological advancements in the field of healthcare. The use of big data analytics has been a primary topic of discussion, which formulates the prospective profile of healthcare technology and surveillance mechanisms.

1.5.1. Ethical Justification of Big Data Privacy in Age of Surveillance Technology

1.5.1.a. Big data

Big Data is increasingly fueling the data driven 21st century. Currently, big data is being used in society to promote computerized intelligence-based solutions that are aimed at reducing the cognitive burden of processing large volumes of data.¹⁶³ However, with the increasing use of big data society must agree on the common values associated with protecting data and ensuring privacy. Furthermore, finding a middle ground in this conflict between the commercial interests of companies and the protection of individual liberties is extremely complicated.¹⁶⁴ To mitigate this, it is recommended that ethics be used to measure and judge what is right and what is wrong. Furthermore, there needs to be joint collaboration of states and supervisory regulation that will monitor all big data activities.¹⁶⁵

1.5.1.b. Big data analytics

Currently, big data analytics is incorporated in daily practices, especially for organizations that are purposing to use big data to obtain valuable information. Many organizations deploy big data analytics to improve the efficiency of their operations. Furthermore, big data is used in the decision-making process.¹⁶⁶ In addition, big data has several advantages, including contributing to effective cost reduction practices, improving the decision-making process, improving organization's products and lastly, detecting any fraud.¹⁶⁷ While

there are several advantages associated with big data, privacy concerns have also emerged. With the rapid increase in large volumes of data, privacy of data must be guaranteed. There are several mechanisms that can be adopted to improve data privacy. For example, during the data generation stage, access should be restricted. Encryption techniques can also be adopted.¹⁶⁸

1.5.1.c. Privacy in the age of surveillance technology

Privacy can be understood to be the privilege individuals have in controlling how their private information is obtained and shared. Furthermore, data privacy is the ability of individuals or groups of individuals to have to protect their personal information from being shared. One of the main privacy concerns associated with big data is the identification of personal information, especially during transfer. Security on the other hand, can be understood to highlight the process of using technology to defend information.¹⁶⁹ Training has also been shown to reduce unauthorized access, disclosure, and modification of data, thus, improving security.¹⁷⁰ Big data analytics are also not fully accurate. The data files that are used for big data analysis are known to contain inaccurate data and to use data models that are usually not accurate. This further increases the risk that additional inaccurate data will be added to data sets, therefore, affecting the entire decision-making process.¹⁷¹ Many people are also concerned that big data could make it even harder to obtain patents since organizations will be overwhelmed with the amount of data analysis that will be required to identify uniqueness in submitted patents.¹⁷²

While it is crucial to ensure privacy in the digital age, both the normative and descriptive dimensions should be analyzed. The analysis should also emphasize on the fact that privacy is not neutral and the fact that an invasion of privacy significantly results in the violation of things that are vulnerable and that should be protected.¹⁷³ Often times, privacy is viewed as the right accorded to all individuals

1.5.1.d. Ethical issues in big data and surveillance technology

As technology has advanced, there came some ethical issues with it. Companies that have been observed to use surveillance technology or big data have been certainly observed to use unethical means to collect customer data such as through facial recognition. Moreover, there has also been observed certain disadvantages in supply chain in case of big data. Big data has also been used as a weapon, as Google has used its app region-specific which limits the use of its app in one region to another in certain functionalities.¹⁷⁴ In order to enforce global ethical principles to protect big data and privacy of any individual or company, there are certain rules or regulations that have been set at governmental scale such as U.S. Federal Trade Commission's Fair Information Practices, Asian regulations, and international benchmarks, including the Organization for Economic Cooperation and Development. These includes authority of an individual as well as legal right to know which data or personal information is being monitored.¹⁷⁵

1.5.2. Surveillance & Privacy in Next-generation Personalized Healthcare

1.5.2.a. Review and background of personalized healthcare and big data analytics

Patients are increasingly being drawn towards personalized healthcare and care customization in general. Personalized healthcare involves two main concepts: patient-centered care and personalized medicine. Patient-centered care refers to the organization of patient management to take care of all the patient's needs. On the other hand, personalized medicine customizes care and treatment plans to suit all the biological and genetic needs of the patient.¹⁷⁶ Advancements in technology have created a shift in healthcare where care is more personalized and individualized. Technologies such as Data as a Service (DaaS), cloud computing, and

wearable technologies have introduced real time monitoring of patients and consequent communication with healthcare providers.¹⁷⁷ However, while personalized healthcare has been resulted in a shift in disease treatment, it has introduced several ethical issues. Some of these issues include risks associated with the use of internet-enabled devices and health-related data sensitivity.¹⁷⁸ Healthcare-Internet of Things (H-IoT) has been shown to have immense capability. However, individuals who use H-IoT are oblivious of the manner in which their personal data can be accessed by outside unauthorized sources.¹⁷⁹ In addition, the incorporation of genomic data in Electronic Health Records (EHRs) results in unique ethical issues, including data security and patient access.¹⁸⁰ Furthermore, the use of big data in healthcare often encounters compromised privacy, lack of transparency and respect for personal autonomy.¹⁸¹ Despite the enactment of regulations that define identifiable data and acknowledge how multifaceted and unique big data is, the likelihood of privacy violations is still high.¹⁸²

1.5.2.b. Next-generation technologies in personalized healthcare

Next-generation sequencing (NGS) presents unique challenges to healthcare providers due to the large volumes of data it generates. Furthermore, NGS raises issues associated with informed consent and observing data privacy. NGS has also been shown to lack appropriate measures to interpret the genetic information it generates after profiling an individual's entire genetic profile.¹⁸³ The adoption of big data technologies in many healthcare facilities has significantly improved patient outcomes. However, many healthcare facilities cannot guarantee that patient's data will be secure. Similarly, the inflow of extremely large amounts of data from multiple sources overburdens the facilities' storage and processing platforms.¹⁸⁴ In addition to NGS and big data, public health surveillance encounters several ethical challenges. For example,

a majority of surveillance data is usually obtained without the consent of the affected individuals. Likewise, there are numerous privacy violations and lack of respect for autonomy.¹⁸⁵

1.5.2.c. Surveillance and privacy of healthcare data and other ethical concerns

The use of big healthcare data has introduced key areas of concern, including; data ownership, privacy, informed consent objectivity, and an increase in the divide that exists between those who have resources to analyze big data and those who lack similar resources.¹⁸⁶ Similarly, there are other issues associated with the use of big data in healthcare, including; intellectual property ownership challenges, allowing access to individuals without resources and errors associated with medication administration.¹⁸⁷ In public health surveillance, the main challenge experienced is provision of informed consent. It is very crucial that informed consent is obtained from affected individuals before their data is used in public health surveillance. Moreover, participants must be protected from any harm through the provision of informed consent.¹⁸⁸ However, some might argue that the provision of informed consent is not necessary, especially in public health surveillance since in most instances, individual interests are disregarded for the general good of the public.¹⁸⁹ While there are multiple conditions under which obtaining informed consent is not necessary, regulations must be implemented to ensure that the principles of public and clinical health ethics do not intersect.¹⁹⁰ Public health surveillance has been shown to use name-based reporting and as such, triggers concern on participants' privacy and high risk of stigmatization and discrimination. Guidelines must, therefore, be designed to ensure ethics is observed in public health surveillance.¹⁹¹

1.5.2.d. Protecting patient privacy in next-generation healthcare

The technologies of next-generation such as IoT, 3D printing, AI, and robotics are the foremost components leading towards a safe and secure future of healthcare industry. However,

the abovementioned technologies are subjected to some ethical issues as well. For example, when it comes of AI and Robotics, it is much probable that it may neglect the basic autonomy of an individual and even ethical decisions. Meanwhile, the technology is much proficient towards the medical dilemmas as they could ensure patient's safety on a relatively good level. It could also contribute towards the security and privacy and may improve the facilitation of customized healthcare which could definitely eradicate any ethical challenge on its way.¹⁹²

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CHAPTER 2. Consent and Privacy

2.1. Decision-Making and Capacity in Healthcare

It is often paramount for healthcare professionals to assess a patient's capacity to provide informed consent to medical treatment. However, this process is challenging and requires a unique balance between respect for persons and recognizing the ethical duty to view the patient as an autonomous agent capable of deciding what happens to their bodies.¹ Assessing a patient's capacity to consent to treatment is especially necessary for mental health professionals. That is, they cannot continue with treatment unless the patient or a legally authorized representative provides valid informed consent.² Capacity to make decisions is fundamental to one's autonomy. One of the main determinants of impaired capacity is cognition and conditions that affect cognition have the potential of affecting capacity. Some of the conditions that affect cognition include depression, dementia, head injury or delirium.³ When assessing a patient's capacity to make treatment decisions, clinicians should be aware of applicable standards in their jurisdiction. Additionally, when using compound standards, independent evaluation of each standard's performance ability should be conducted. Lastly, before characterizing an individual as incompetent, the policies used must be fashioned with extreme caution.⁴

Common law dictates that individuals have autonomy and self-determination. Therefore, they have the right to accept or refuse medical treatment.⁵ Managing a patient's medical condition can be complicated especially when the patient's ability to make reasonable decisions regarding their care is called into question.⁶ Using a case adopted from the literature, this chapter will review ethics and case consultations and reasons why such consultations are requested. For example, patients who are COVID positive with other health conditions and wished to go against

medical advice. In addition, the chapter seeks to assess the patient's cognitive capacity in the decision-making process utilizing the case provided.

2.1.1. Informed consent and case consultation

In line with the ethical principle of respect for autonomy, healthcare providers have an ethical obligation and legal mandate to provide all the necessary information concerning the care patients are receiving. Thus, to ensure that they participate in the decision-making process. At a minimum, respect for autonomy acknowledges that patients have an opinion and are capable of making choices on their own.⁷ Additionally, informed consent enhances autonomy. However, there are several circumstances where informed consent has no significant impact on the care provided. Patients might have the option of providing consent but might lack resources to access the care being provided. Secondly, the settings in which the patient is in might impede autonomy and thus invalidate the need for consent. For example, patients in nursing homes often have their autonomy and ability to provide informed consent taken away. Residents in these homes and other 'total institutions' are denied the freedom to make decisions regarding their care. However, through intentional and tailor-made interventions, residents in the aforementioned settings can be granted autonomy.⁸ Regardless of the physical or mental state of the patient, the medical care provided should be provided in a collaborative manner between the patient and the healthcare provider.

2.1.1.a. Background and overview

Informed consent is the right of adult patients to decide whether to agree or consent to treatment. Organizations such as the American Medical Association and the American Psychiatric Association have stipulated multiple ethical codes associated with informed consent.

The guidelines provide ethical standards that must be followed when informing patients of their treatment options and possible side effects before obtaining consent. Additionally, guidelines for obtaining informed consent have evolved over the years from a previous belief that a patient automatically provided consent if they did not explicitly dissent. Currently, standards for informed consent emphasize on the patient's education, self-determination, mutual respect and autonomy.⁹ In biomedical research, obtaining informed consent constitutes a crucial ethical requirement essential to all international research ethics codes. Obtaining valid informed consent requires the researcher to make sure that consent is provided voluntarily, and the patient is competent enough to make the decision.¹⁰ Overall, informed consent should be provided before treatment is provided or research is conducted.

One of the most important questions that healthcare providers ask is; does the patient have capacity to refuse treatment? Competency is “the degree of mental soundness required to make decisions about a specific issue or carry out a specific task.” Capacity on the other hand, is an individual's ability to make an informed decision.¹¹ Determining a patient's competency is a matter left to the judiciary system. However, a physician can determine a patient's capacity to make informed decision about their care. In the case where a patient lacks capacity to make informed decisions about their care or provide consent, the physician must refer the patient for a competency hearing or appoint a guardian to make decisions for them. Psychiatrists are often called upon to assess a patient's mental status and gauge its potential for interfering with certain areas of functioning. However, in most cases, the physician determines a patient's capacity. The components of capacity evaluation include free choice, comprehension, and reliability. Comprehension involves the patient's understanding of the facts of their medical condition including the risks and benefits of treatment. To determine if the patient has complete

understanding of their treatment, the primary care physician must be familiar with the patient's medical condition. In addition, free choice refers to the patient's decision to either accept or reject proposed treatment. This process should be voluntary and without coercion. In assessing free choice and capacity, the physician should determine any underlying fears, treatment expectations, and impaired mental processes that might impair their choice.¹² Lastly, reliability refers to the patient's consistency to provide a choice. Therefore, a patient who is inconsistent is incapable of making decisions about their care.

Breakdowns in the physician-patient communication coupled with inadequate health literacy are associated with reduced quality of medical decision-making and poor patient outcomes. Health literacy is a combination of skills such as the ability to perform basic reading and numerical tasks needed to function in the healthcare environment. In the current medical environment, health literacy level is the degree to which individuals contain the ability to acquire, analyze, and understand basic information about their health and the essential services required to make appropriate health decisions.¹³ Additionally, literacy deficits can prevent a patient from following prescription instructions and making informed decisions about their care and treatment. In addition to medical literacy, physician-patient communication greatly affects capacity to make informed consent. The physician-patient communication involves the process where information is exchanged between a patient and their physician through symbols, signs or behaviors. Research shows that effective communication between healthcare providers and their patients significantly improves overall health outcomes. Moreover, low levels of health literacy combined with poor patient-physician communication affects the patient's decision-making abilities. Patients with chronic conditions such as cancer, are often surrounded by complex treatment interventions that require.¹⁴ When the patient fully understands their treatment plan

and is able to communicate effectively with their clinicians, they are then able to make informed decisions about their treatment plan.

2.1.1.b. Reasons why consultations are requested

When determining capacity to provide consent, clinicians often call a consultant to assess the patient. Cases in which clinicians find reasonable to involve a consultant include; cases where a determination of lack of capacity could negatively impact the relationship between the patient and the hospital, cases where the healthcare facility lacks resources to properly evaluate the patient, high-stakes cases such as the ones that involve legal proceedings and lastly, cases in which the patient's mental health is affected. However, for patients whose capacity is questioned, a potential surrogate decision-maker should be engaging early enough for the purposes of obtaining treatment history and discussing the patient's preferred treatment route. When a patient is determined to lack capacity to make informed decisions, resources should be utilized to make them make treatment decision.¹⁵ In the rare case where a clinician is unable to reach a consensus about the patient's capacity, an ethics consultation should be done.

One of the main reasons why psychiatric consultations are done is to help healthcare providers decide whether a patient has the clarity of mind to make decisions about treatment. During the process of obtaining informed consent, competency is a key issue in determining whether an individual has the ability to accept or reject a procedure.¹⁶ If a person is deemed incompetent to make medical decisions by a judge, then a substitute decision maker is appointed to make the decision on behalf of the patient. Capacity on the other hand, is a clinical assessment that is made by a psychiatrist or by a primary care physician. Capacity is the clinical determination of a patient's ability to conduct basic tasks. In certain situations, psychiatrists are called upon to assess a person's capacity to make medical decisions. If a patient is found to lack

capacity, a decision may then be made by a judge. However, if the judge agrees with the capacity assessment conducted but finds the patient incompetent to make medical decisions about their care, a substituted decision maker is then appointed.¹⁷ Of importance to note is that capacity assessments cannot be performed for past or future situations.

Psychological evaluation is the process of assessing a patient's memory, attention span, reasoning, interpretation, and ability to communicate. However, for a psychiatric or a psychological evaluation to be conducted, a patient must provide consent and cannot be coerced to submit to the evaluation. If a physician believes that their patient lacks capacity to make medical decisions regarding their treatment, a consulting psychiatrist is usually called upon to assess the patient's cognition.¹⁸ In other situations, if the psychiatrist has reasonable doubt about a patient's cognitive abilities to provide informed consent, the information is sufficient to legally show the patient is not competent and cannot refuse further treatment. Therefore, the physician must collaborate with the patient's family, next of kin or a surrogate decision-maker to come up with an effective treatment plan for the patient. There is no rule to determine whether physicians must first assess the patient's capacity or test for previous medical conditions that might affect capacity. Often determining capacity is a matter of situational severity, lack of comprehension, irrationality, or other observed cognitive impairments. Furthermore, physicians must follow available standards when assessing a patient's decision-making capacity.¹⁹ Usually, the process of determining whether a patient has capacity is left to the primary care physician, however, a psychiatric consultation might be relied upon when doubt arises.

Psychiatrists are usually consulted to determine whether a patient has capacity to make decisions about their treatment. In addition, psychiatrists are called upon to determine capacity to participate in discharge planning. For a patient to be discharged, they must demonstrate

discharge planning. They must have the capacity to self-care, ability to cope with illness and access to medical care once they have left the hospital. Often, during discharge planning, psychiatrists are called upon when patients refuse advice and guidelines for a safe discharge. Dispositional capacity is distinct from the capacity to give informed consent either to accept or refuse a medical procedure. Although all assessments and determinations of decisional capacity require consideration of the ethical, legal, medical, and psychosocial dimensions of medical care, most decisional capacity determinants focus on a single decision that acts as a threshold to determine if the patient can provide or withhold consent. Dispositional capacity determinations require assessments of a patient's functional capacity, their future behavior, and ability to manage their health after hospitalization.²⁰ Additionally, after a patient is discharged from hospital, they must have the ability to make decisions that will facilitate their recovery.

The decisional capacity assessments performed by clinicians help protect vulnerable patients from exploitation. Likewise, decisional capacity assessments preserve the patient's autonomy and facilitate the communication between clinicians and administrators thus addressing complex bioethical dilemmas. Medical decision-making involves choices that require additional thought processes which are more complex and require sophisticated domains of capacity such as understanding and communicating the choice. Dispositional capacity requires the patient to make current and future decisions that promote good health. Additionally, it requires patients to possess functional abilities that will help them survive in society. While neurocognitive disorders are the main causes of impaired decisional capacity, other psychiatric conditions may also impact decision making.²¹ In line with this, the psychiatrist should make a biopsychosocial assessment that is inclusive of all elements that affect capacity.

2.1.2. Analysis of a clinical case

2.1.2.a. Mr. J Case

“Mr. J, a 73-year-old with sepsis caused by a gangrenous foot, was admitted to the hospital. His medical history includes diabetes mellitus, peripheral vascular disease, and experiencing a stroke approximately 2 years before this admission. He says that he does not want to undergo surgery. When asked if he understands that he will likely die without surgery, he says that he “doesn’t want to give up hope” and that he would just like to return to the long-term care facility where he lives. His closest potential surrogate decision-maker is a nephew who lives in another state. The nephew believes that his uncle should undergo surgery and that his uncle does not seem himself (ie, depressed). The nephew, however, says that they were never close and he feels awkward trying to make this kind of decision for his uncle. It is also unclear where his uncle could be appropriately and safely placed if he does not receive surgery. Discharge to the nursing facility would likely result in readmission to the hospital in a short time because of recurrent sepsis or pain management issues as the gangrene progresses.”²²

Mr. J is a 73-year old patient with sepsis resulting from a gangrenous foot. What is unique about the patient is the fact that he is denying treatment despite being told by his healthcare provider that it would lead to death. His closest potential surrogate decision-maker is his nephew who does not feel comfortable making medical decisions for his uncle and believes that his uncle is suffering from depression. The case presents a dilemma for healthcare providers. Competence to consent for patients with impaired cognitive functioning is central to the process of informed consent in clinical care. During care, clinicians bear the responsibility of protecting the right of competent patients to make decisions about their medical care and the right of incompetent patients to be protected from resulting harm associated with their decisions.²³

Medical literature has presented several abilities as being relevant to determine capacity for informed consent. They include ability to understand information relevant to making decisions about their treatment, appreciation of the personal significance of information concerning the patient's illness and the consequences of treatment, reasoning with the right information to weigh treatment options, and lastly expressing a choice based on the information acquired. The aforementioned elements are also part of the MacArthur Competence Assessment Tool (MacCAT) used for competence assessment.²⁴

Healthcare providers are taught to approach a case in a systematic manner regardless of the complexities associated with it. They first identify the patient, and then progress towards identifying the health history of the patient, conduct a physical assessment, and laboratory tests to come up with a diagnosis. Based on the diagnosis, a treatment plan is developed and implemented and a follow-up schedule developed.²⁵ However, the aforementioned framework fails to acknowledge the ethical decision-making process. The four topics approach sorts out facts, values and facilitates a discussion and resolution of the ethical issue. The four topics include medical indications, patient preferences, quality of life, and contextual features. The four topics approach allows healthcare providers to approach a clinical case in a systemic manner integrating ethical principles and the clinical case.²⁶

2.1.2.b. The four-topics approach

There are several frameworks that have been developed to help healthcare providers manage ethical challenges that might arise during care. Jonsen, Siegler, and Winslade have presented an approach to guide caregivers during the clinical ethical case analysis process. The four topics approach provides a more clinically aimed approach to ethical challenges in clinical settings. Moreover, each of the four topics “(medical indications, patient preferences, quality of

life, and contextual features)” is approached through a set of unique questions. The main purpose of these question is to help in identifying circumstances surrounding a specific case, thus linking them to their primary ethical principle. The medical indications quadrant involves diagnosis, prognosis, evaluation, treatment, and expected outcomes. For all clinical cases, it is advisable that healthcare providers start describing known facts about the case. In the context of Mr. J, the 73 year-old man with sepsis in the selected case study, this might include the severity of the sepsis, planned interventions to control the sepsis, and expected outcomes. When establishing the treatment goals, the principles of non-maleficence and beneficence should be observed.²⁷

Therefore, any decision about Mr.J’s treatment should weigh both clinical and ethical benefits and potential risks. Issues associated with decision-making capacity arise in cases where the patient is in too much pain and cannot make decisions accurately. Lastly, it is important that the patient understands how certain management decisions might impact their care. For Mr. J, this includes the appropriate time to operate on his foot, nutrition optimization to prevent re-occurrence of diabetes, wound management, and rehabilitation. If the foot will be amputated, the primary physician should discuss this with the patient and his family member, his nephew.

Patient preferences are essential from both a medical and an ethical standpoint. If the patient is able to make informed decisions, their preferences should be respected. However, if the patient lacks decision-making capacity, a surrogate should convey the patient’s presumed wishes and best interests. Determining decision-making capacity is challenging in patients with injuries such as Mr. J. When addressing questions presented in this quadrant, it is crucial to discern whether the patient has the capacity to make decisions and whether the competent patient has all the information needed to make an informed decision. Likewise, care providers should determine whether consent is given voluntarily. Mr. J is highly unlikely to make informed decisions during

the early stages of sepsis. Therefore, the healthcare providers should make emergent decisions in addition to educating the patient and his nephew regarding Mr. J's clinical situation. Based on the results of the previous clinical evaluation conducted in the first quadrant including the decision-making capacity assessment, the physician should include the patient in the decision-making process. Lastly, the patient-physician relationship plays an important role in improving patient outcomes. Studies show that when the decision-making process is shared between patients and physicians, it results in improved patient care.²⁸ Mr. J preferences include not having surgery and being placed back to the long term care facility he has been living in. He claims to understand that refusing surgery would result in death.

Illness or injury negatively affects an individual's quality of life. During the treatment discussion process, healthcare providers should discuss the consequences of the proposed treatment on the patient's quality of life. In addition to discussing the impact of treatment on quality of life, healthcare providers should consider the principles of beneficence, respect for autonomy, and non-maleficence. Furthermore, healthcare providers should aim to determine whether therapeutic interventions will have a positive or negative impact on the patient's quality of life. This can be determined with the help of valid measurement tools and clinical judgment. The main ethical challenges associated with Mr.J's case include medical futility and the impact of withdrawing and withholding care. Ethically speaking, any interventions that are unlikely to improve patients' outcomes should not be provided. For severely injured patients, further medical or surgical interventions might reduce their quality of life and should therefore not be provided. In line with this, healthcare providers should assess the severity of Mr. J, the gangrenous foot and whether administering surgery would negatively affect Mr. J's quality of life.

Contextual features that have an impact on decision-making include finances, religious beliefs, family dynamics, “legal ramifications of care and personal bias” of individuals involved in the care.²⁹ The aforementioned factors can affect patient care and should therefore be considered. An analysis of Mr. J’s case reveals several contextual features that might play a role in his decision to refuse treatment. They include religious beliefs evidenced by his reference to losing hope and lack of familial support evidenced by the fact that his potential surrogate decision-maker does not have a close relationship with him. Research shows that cases that involve decisions on whether healthcare providers should proceed with the care, are usually affected by contextual features. Overall, the four-topics approach allows for complete analysis of a clinical case and equips healthcare providers with the necessary tools to systematically address complex issues.

The Four-topic approach is considered the best approach to use for Mr. J case for the following reasons. Within this approach, all ethical problems are analyzed based on four key topics: “medical indications, patient preferences, quality of life and contextual features.” This approach observes the principles of beneficence and non-maleficence when setting care goals. As such, decisions made regarding treatment weigh both clinical and ethical benefits. In addition, the model requires healthcare providers to establish the patient’s decision-making capacity prior to addressing ethical concerns. When using this model, healthcare providers assessing Mr. J’s case must first determine his decision-making capacity before providing treatment. Additionally, the model respects the patient’s preferences and contextual features including religious beliefs and family relations. Thus respects their autonomy.³⁰ The steps are easy to follow and any qualified physician can follow them. However, another approach can be used such as the CASES approach. This approach was developed by “the National Center for Ethics in Healthcare” to

regulate the process of ethics consultation. It involves five key steps; “Clarify the consultation request (C), assemble relevant information (A), synthesize the information (S), explain the synthesis (E) and support the consultation process (S).” The steps in the CASES approach were developed to provide guidance to ethics consultants to allow them to respond effectively to ethics consultation requests.³¹

2.1.3. Decision-making process in clinical ethics

Clinicians often use the term unrepresented to refer to individuals who lack decision-making capacity. Additionally, unrepresented patients lack clear documentation of their preferences and lack a surrogate decision-maker to make medical decisions for them. In such situations, clinical ethics recommends substituted judgment or a best interest standard to guide the medical decision-making process. However, the recommended procedure for medical decision-making is dependent on the state in which the hospital is located in, reasons why the patient is unrepresented, hospital policies, and the type of decision being made.³²

2.1.3.a. What is the decision-making process in clinical ethics consultation?

In practice, the decisions for an unrepresented patient are made by the treating physician. However, commentators argue that it is inappropriate for a physician to make medical decisions on behalf of their patients. Instead, a court-designated guardian or a multidisciplinary ethics committee should act as surrogate decision-makers for the unrepresented.³³ Clinical ethics consultation (CEC) is usually done by clinical ethics committees or consultants. Ethics consultation can be classified as either being “soft” or “hard”. When an ethics consultation is classified as being soft, it means that the ethics consultant acts as a facilitator, facilitating the discussion between involved parties. Additionally, the consultant clarifies their moral positions,

explores options, and mediates resulting conflict to reach to a conclusion. The second classification implies that the ethics consultant is a clinical professional with specific expertise to make recommendations on the ethically preferred course of treatment.³⁴ Overall, the difference between “soft” and “hard” models is the provision of a recommendation.

For ethically troublesome cases, the ethics consultant might be required to be more active and play a substantial role to help resolve conflicts. Likewise, for cases that lack clear ethical or professional standards of resolution, the consultant is encouraged to play a bigger role than the role of a neutral mediator. Of importance to note is that effective ethics consultation should be applied in a flexible manner and in a person-oriented form. On the other hand, other settings require the consultant to apply a systematic framework to structure the process of moral reasoning and process evaluating. The operating logic in ethics consultations should highlight the interests of everyone involved including the patient, family members, physicians, and therapists.³⁵ Additionally, the consultation should include an analysis of the patient-physician relationship, the relevant social context, and related issues affecting the patient’s decision-making process. Likewise, the societal and legal circumstances associated with the treatment should be highlighted. Acknowledging the universal ethical principles provides consultants a general ethical orientation. A set of rules should be made available during the ethics consultation. Ultimately, ethics consultation should highlight cases with limited chances of therapeutic success. Also, ethics consultation should be conducted in an atmosphere that allows for constructive reflection and mutual trust and respect.³⁶

The process of resolving ethical dilemmas involves several key steps. First, the ethical dilemma is identified. After the dilemma is identified, a resolution is attempted at the institution and if the dilemma is not resolved at the institution, it should be referred to a clinical ethics

committee to facilitate the resolution. Once the case has been referred, the clinical ethics committee facilitates the resolution process. In addition, the clinical ethics committee conducts an ethical analysis and provides recommendations to help resolve the ethical dilemma. The resolution is then documented and recorded appropriately to include the resolution, implementation of the plan to resolve it, plan evaluation, who is accountable and what results are expected. An ethical decision making framework is a process that assists staff members make decisions regarding ethical dilemmas that occur. The ethical decision making framework includes the explore stage, discussion stage, and the act stage.³⁷ Overall, ethics consultations must observe the patient's quality of life, their dignity, consent, and confidentiality.

2.1.3.b. Decision making process regarding the case

When a patient rejects medical intervention, the law requires that their wishes be respected unless they are found to be legally incompetent. In Mr. J's case, an ethics consultation should begin by asking the patient if they understand the situation. It is also important to help the patient gather all the information about treatment options. Since Mr. J is living in a nursing facility, a palliative care or hospice consultation would assist the patient better understand their medical situation and thus come up with an appropriate course of action. This referral might help Mr. J better understand different ways to manage the pain and appreciate what it means to die of a gangrenous foot. In such consultations, the consultant's role is to facilitate the decision-making process rather than determining consent. This process therefore enhances the patient's decision-making capacity. Lastly, if the patient's cognitive ability appears to be impaired, a psychiatrist should be consulted to determine capacity.³⁸ However, consultations should only be done if there is clinical indication of psychiatric distress or depression.

One of the greatest dilemmas for healthcare providers is when patients refuse treatment procedures or surgery that is essential to sustain life. When this occurs, the physician must choose between forgoing beneficial treatment and forcefully subjecting the patient to treatment which both have ethical and legal consequences. In Mr. J case, sepsis resulting from the gangrenous foot has the potential of resulting in death. However, death can be avoided if surgery is conducted, but Mr. J is refusing this life-saving treatment. Based on the aforementioned facts, it is crucial to determine whether he understands the consequences of refusing treatment and the suggested intervention.³⁹ Decision-making capacity refers to the ability of patients to make decisions at specific times. Medical decision making capacity on the other hand, involves a patient's ability to understand information regarding their medical condition and its consequences and use the information to make a choice in line with their goals, communicate the choice to their caregiver and maintain this choice over a long period of time.⁴⁰ Legally, competent, non-terminally ill patients have the right to refuse life-saving treatment.

Informed consent and refusal give competent patients the option to select the most preferred treatment in line with their goals, values, and future aspirations. Sometimes patients refuse treatment that will improve their life, in this case, physicians should ascertain whether a patient has the decision-making capacity to refuse treatment. In line with this, the physicians handling Mr. J must first determine whether he has the decision-making capacity to refuse being operated on. There are several frameworks that the physicians can utilize to evaluate decision-making capacity. The MacArthur Competence Assessment Tool for example, takes on an interview format tailored to the patient's needs. Other models encourage physicians assess absence of cognition, lack of patient judgment, understanding or ability choose between presented options. The sliding scale model compares the risks and consequences of medical

decisions and notes that patients need to demonstrate higher levels of decision-making capacity compared to when they are faced with low levels of decision-making. To use this model, physicians must ensure that they respect patient autonomy as well as protecting them against the consequences of their bad choices.⁴¹ Overall, when a patient with decision-making capacity refuses life-saving treatment, their refusal must be accepted and upheld.

2.1.4. The capacity to make decisions and cognitive capacity assessment

Depressed individuals are usually asked to participate in clinical research studies. These study participants are usually assumed to be mentally competent to take part in research since depression has limited impact on a patient's cognitive abilities. Studies have shown that severely depressed individuals may lack the competency to consent since they are not accountable for their own actions.⁴² Additionally, it is argued that some depressed individuals lack the appropriate minimal degree of concern for their health and wellbeing. Competency assessments must therefore account for emotional factors affecting depressed individuals. Likewise, if patients are found to be severely depressed, they should be labeled incompetent to provide consent.⁴³ Advocates have also expressed fears that incompetent individuals may be recruited into research projects without them fully comprehending their choices. However, others argue that the stringent standards and procedures used to recruit patients into research might affect the quest to find solutions to psychiatric disorders.⁴⁴ What is clear though, is that major depression impacts the cognitive functioning of individuals rendering them incapable of making informed decisions. Furthermore, impairments exist in concentration, information processing, and in reasoning. The decreased motivation to protect one's interests and wellbeing might alter their choices and treatment decisions. This has been backed up by several studies that show that

roughly, 25% of hospitalized depressed patients show problems in the decision-making process associated with treatment.⁴⁵ Overall, evidence shows that severe depression compromises a patient's capacity to consent to research.

2.1.4.a. In what circumstances do patients have limited capacity?

An individual lacks capacity if their mind is impaired in some way. There are several ways as to how a person's brain can be impaired such as mental health conditions like schizophrenia and dementia. Additionally, an individual's capacity is impaired by severe learning disabilities, brain damage as a result of a stroke or intoxication caused by alcohol and other drugs. Individuals might also suffer from physical or mental conditions that result in confusion, drowsiness or loss of consciousness. Individuals with any of the aforementioned conditions are believed to lack the ability to make decisions. Furthermore, if patients cannot fully understand information, remember information, use it to make decisions and communicate their decisions to relevant personnel either through talking or using sign language.⁴⁶

For a large proportion of individuals, the capacity to make decisions regarding their health is affected either temporarily or permanently. An individual with a learning disability may lack the capacity to make important decisions that have a major impact on their lives. In addition, a person who struggles with their mental health might struggle to make decisions about their health. Lack of mental capacity is often associated with a stroke or a brain injury, dementia or a mental health problem among other causes. However, when a patient refuses recommended treatment or medical procedure without providing a reason for the refusal, they should be assessed keenly. Lastly, patients with cultural or language barriers, low levels of education, and a recognized fear of healthcare settings might lack capacity to make medical decisions.⁴⁷

Therefore, healthcare providers must carefully assess patients with the aforementioned conditions to determine decision-making capacity.

2.1.4.b. Evaluating cognitive capacity for Mr.J

Mr. J's refusal to undergo surgery might result in his death. The physicians handling his case have explained to him that surgery is essential since it will eliminate the pain caused by the gangrenous foot and ultimately save his life. Regardless, Mr. J refuses treatment and is hopeful that the problem will resolve itself. In line with this realization, Mr. J requires a more careful assessment of his capacity. Physicians can either use a directed clinical interview or a formal capacity assessment tool. One example of a directed clinical interview is ancillary tests that may be required depending on the patient's unique therapists, their history obtained from their therapists or from other caregivers. In addition, a physical assessment might be conducted and a laboratory evaluation done. These tests might help physicians to diagnose the patient's current level of functioning and capacity and tell if they change or improve in the future. The interview also outlines specific patient abilities that are to be investigated and suggests questions to assess the patient's abilities. After the assessment is conducted successfully, the patient's mental status should be examined to determine whether there are any psychopathologic factors impairing the patient's judgment.⁴⁸ A psychopathologic assessment is essential since it will help the physician determine whether the patient has the ability to make specific decisions regarding their health. However, it is important to note that lack of one ability does not necessarily mean that the patient lacks the ability to make overall decisions about their health.

In addition to the direct clinical interview, a structured assessment can be used to evaluate Mr. J's cognitive capacity. The MacArthur Competence Assessment Tool (MacCAT) discussed earlier is one such tool that uses standardized questions and a scoring system to assess

more aspects of cognition than a clinical interview does. The Aid to Capacity Evaluation (ACE) is another structured assessment tool that achieves the same goals as the MacCAT. The ACE is short, simple and it is clinically oriented. Physicians are encouraged to address barriers to communication, discuss treatment interventions, and address patient's concerns and questions. Regardless of which tool is used to determine cognitive capacity, proper documentation must be made and the final judgment regarding patient's capacity recorded. If the physician chooses to use an interview, a brief summary of the interview should be documented. On the hand, if the physician uses a formal assessment tool (MacCAT or the ACE), they should include in the patient's clinical record.⁴⁹ In general, physicians have the responsibility of assessing the decision-making capacity of their patients. If they encounter patients who require further assessments, they should easily identify their cognitive capacity using standardized evaluation tools such as the MacCAT and the ACE.

The main role of clinical ethicists is to offer guidance to patients, their families and healthcare providers on ethical issues and concerns associated with their health and wellbeing. For Mr. J's case, it is recommended that a psychiatrist be called in to help the primary physician make the determination. In addition, it is recommended that the psychiatrist's conclusions are taken to a court to determine Mr. J's legal competency. This step is specifically important since Mr. J's nephew is not comfortable making medical decisions on his behalf. In other cases, similar to Mr. J where the patient's mental capacity to make decisions is put in question, a psychiatrist is usually called to determine cognitive capacity. The psychiatrist's conclusions may be taken to court to determine legal competency. However, other cases are not necessarily referred to a judge. The determination of capacity should involve two components: the ethical component and the clinical component. When the psychiatrist determines mental capacity, they

must not only determine what the patient is capable of doing but what they should be capable of doing when placed in a situation that requires them to make a critical decision.⁵⁰ However, of importance to note is that despite a psychiatrist's clinical gifts, they often struggle to make an unbiased clinical observation. Therefore, the moral view of the psychiatrist doing the evaluation may determine if the patient has the ability to choose or refuse life-altering treatment. In line with this, determination of capacity may be different from one psychiatrist to the next. The outcome of a cognitive capacity assessment and determination should not solely rely on the moral view of the psychiatrist in charge of the evaluation.⁵¹ Overall, when determining a patient's mental capacity, the psychiatrist should try and avoid imposing their own moral values on the patient's evaluation.

There are several criteria that the psychiatrist may use to assess a patient's mental capacity. Some of them include understanding alternatives, appreciating the relevance of the alternatives to them, understanding the reasons regarding the alternatives and expressing choice. Other psychiatrists propose that patient choices be consistent with what they would select in their past lives. However, the criteria that a psychiatrist uses may be influenced by the applicable law of the region. Furthermore, even when psychiatrists use specific criteria, they must determine how the criteria is to be applied. To facilitate this, it is recommended that the psychiatrist handling Mr. J's case uses the MacCAT tool. The tool includes a semi-structured interview that will assist the clinician acquire information regarding their specific condition and treatment options available. Additionally, the MacCAT tool prompts clinicians to assess the patient's comprehension and understanding in regard to the decisions they are expected to make. To further enhance the validity of their conclusions, psychiatrists might use other forms of criteria such as observing how a patient lives in their home. In this case, how Mr. J. lives in the nursing

facility. This approach may also include providing patients with information through electronic media such as videos. During the course of treatment, a psychiatrist will face ethical challenges when determining a patient's cognitive capacity.⁵² However, they should put aside their beliefs and personal opinions to provide an accurate determination of a patient's cognitive capacity.

2.2. Ethical Debate on Privacy and Confidentiality

Over the past few years, the adoption of a more humanistic approach to healthcare has brought forth the issue of empathy as one of the critical components of clinical practice. Healthcare providers are encouraged to not only provide quality care to patients, but also relay the information in a sensitive manner.⁵³ Furthermore, the concept of privacy stipulates that patients be protected against the unauthorized disclosure of their medical information. Privacy also allows individuals to make their own decisions regarding their medical information. For doctors, nurses, and other healthcare professionals, privacy is imperative to the relationship they have with their patients.⁵⁴ However, the increasing diffusion of new information into healthcare has created several challenges especially in the way information is managed. Moreover, since information access in healthcare is highly dependent on interactions across several professions, the diffusion of information and technology might hinder information control resulting in additional disruptions. As such, medical professionals are forced to depend on their own assessment of what ethical IT use entails.⁵⁵ In clinical interactions, patient information should always be kept confidential. However, in reality, the complete adherence to confidentiality is not always possible resulting in a breach of trust between healthcare professionals and their patients.⁵⁶ How then can healthcare providers ensure that they uphold privacy when handling patient's medical information? Additionally, how can confidentiality be used to improve privacy

in healthcare interaction? The aim of this section is to highlight ethical issues that arise during healthcare interactions with an emphasis on privacy and to propose interventions such as maintaining confidentiality, that will help uphold privacy in all healthcare interactions at the clinical, professional, and organizational level.

2.2.1. Privacy and confidentiality

The interaction between patients and healthcare providers is crucial to effective and high quality healthcare. To determine the effectiveness of this interaction, patient experience is usually analyzed. Furthermore, by looking at the different aspects of patient experiences, caregivers can assess the extent to which the care they are providing is respectful and responsive to the patient needs.⁵⁷ In other scenarios, challenging situations arise during patient-physician interactions that affect the entire care process. These challenging interactions may occur due to several factors including poor communication between the patient and the healthcare professional or differences in expectations between patients and their caregivers. In addition, factors such as overworking and overstretching of healthcare personnel to meet the growing demand, often results in insufficient time allocated to interactions with patients, which ultimately affects the quality of care provided.⁵⁸ However, to improve patient-physician interactions, optimal conditions must be created that allow for active listening and effective communication.

In this age of big healthcare data, protecting a patient's privacy is becoming challenging. Maintaining and transmitting large amounts of data to support the provision of quality healthcare faces the challenge of lack of proper security. Healthcare interactions continue to be among the most susceptible to data breaches.⁵⁹ This unauthorized access of protected health information (PHI) has significant consequences on both the patient and the healthcare organization. Not only

are such breaches extremely expensive to manage, but also result in the disclosure of a patient's confidential health records. Moreover, the inappropriate disclosure of PHI may occur during the care process resulting in privacy breaches.⁶⁰ Implementing security measures should, therefore, be a top priority for all healthcare organizations.

2.2.1.a. Healthcare Interactions

The quality of the doctor-patient interaction during the consultation is essential to the success of the healthcare delivery process. Moreover, patient satisfaction after a doctor-patient interaction is a good indication of the doctor's level of competence. The doctor-patient interaction significantly influences healthcare outcomes including patient satisfaction and adherence to treatment.⁶¹ At the center of any doctor-patient interaction is effective communication. Poor communication between doctors and patients could negatively affect the consultation process. Many patients have reported not receiving sufficient information during a consultation. As a result, they have been reluctant to follow the doctor's recommendations. Furthermore, poor communication during doctor-patient interactions may result in high levels of anxiety, dissatisfaction with the treatment, and lower quality of life.⁶² Evidence shows that patients who are not satisfied are more likely to discontinue treatment.⁶³ To improve on this, doctors must maintain good technical skills, demonstrate professionalism, and practice ethical practice that meets the expectations of their patients.

At the professional level, doctors interact with other healthcare professionals in interprofessional teams. Evidence shows that teamwork results in improved patient safety and fosters better work environments.⁶⁴ However, the conceptions that members of these teams have about their team significantly impacts their performance. Problems also occur when team members from different professions interpret the purpose of the team differently. Furthermore,

insufficient knowledge regarding other team members' professions negatively affects collaboration.⁶⁵ For any collaboration to be successful, every team member should execute their own unique roles. By doing so, they are able to create a collective synergy ensuring that patient needs are effectively met. Team members should also be comfortable when their skills overlap ensuring that they put the patient's best interest first. Additionally, trust is one of the most important elements of successful interprofessional teams. To achieve this, researchers suggest the implementation of interprofessional education (IPE) in healthcare curriculums.⁶⁶ Overall, collaboration between healthcare providers significantly improves patient outcomes and increases team members' abilities to perform tasks.

Healthcare organizations are increasingly encountering patients from diverse cultures. Culturally diverse patients access healthcare facilities less than local communities and once they do, they encounter several challenges including language barriers and differences in treatment beliefs.⁶⁷ To improve healthcare interactions at the organizational level, healthcare facilities must promote and implement cultural competence at all levels of care. By doing so, healthcare providers ensure that they increase their accessibility and the quality of services they provide to minorities and the disadvantaged in the community.⁶⁸ At the national level, diversity responsiveness is ensured through legislation. For example, in the U.S. diversity responsiveness has been made possible through the implementation of "Standards for Culturally and Linguistically Appropriate Services or CLAS." In Europe, diversity responsiveness has been promoted through several publications including intercultural competence and migrant-friendliness.⁶⁹ These cultural competence frameworks have the potential to significantly improve patient interactions in healthcare organizations.

The use of information and communication technologies (ICTs) in healthcare has benefited healthcare organizations, patients, and the ICT industry in general. As the population continues to age, the number of individuals seeking medical care is expected to increase. Using ICT interventions has been shown to be effective in helping healthcare providers improve patient interactions and the entire treatment process.⁷⁰ Electronic health or eHealth refers to the use of information technology to reinforce healthcare. eHealth is also associated with other concepts such as telemedicine, telecare, and telehealth that when used, result in a concept referred to as blended care. eHealth has been shown to increase opportunities for self-care and patient participation. Additionally, eHealth increases the range of disease prevention while also improving patient education regarding the entire care process.⁷¹ However, due to the multiple domains involved in sharing of medical information, eHealth has become extremely difficult to manage. To improve on this, cloud-based eHealth models are usually employed. They include private, public, and hybrid models. In addition to applying the abovementioned cloud-based models, security and privacy in eHealth is extremely important.⁷² Frameworks and policies such as HIPAA have been implemented to protect patient data.

Social media and mobile technologies are increasingly being incorporated into daily healthcare interactions. The increased ability to obtain information has made social media and internet technologies attractive for patients. By using these platforms, patients are able to exchange information thus becoming more involved with their own care. For individuals with chronic diseases, using social media allows them to exchange information and improve their human experience. Furthermore, social media has created a platform for patients and their family members to receive emotional support and ask for guidance from other healthcare professionals.⁷³ Social media also provides healthcare professionals with the necessary tools to

share information, advocate for healthcare policies, engage with the public and interact with patients and their family members. Similarly, healthcare providers can leverage social media to improve health outcomes and develop professional networks.⁷⁴ Ultimately, when used prudently, social media has the potential to improve healthcare interactions. However, when used without caution, social media can result in medical data misuse.

2.2.1.b. Privacy and Confidentiality in Healthcare Interactions

Privacy and confidentiality in clinical interactions are mainly based on professional ethical standards obtained from several health professions. Throughout their practice, all physicians abide by their code of ethics of protecting patient privacy and confidentiality. This code of ethics has instilled a relationship of trust between physicians and patients ultimately improving their welfare.⁷⁵ The code also advises physicians to be mindful of the consequences of breaching patient's trust and damaging the professional relationship. However, upholding confidentiality in clinical interactions is not always absolute. There are several occasions such as when the law requires the information or when the breach is done with the patient's consent.⁷⁶ Nurses also abide by their own code of ethics that requires them to observe confidentiality in their practice.⁷⁷ Through the Nightingale pledge and other nursing codes published by the American Nurses Association, nurses ensure that they safeguard every patient's right to privacy and confidentiality. In addition to the nursing codes of ethics, legislations such as "the Health Insurance Portability and Accountability Act (HIPPA)", have been created to protect the health insurance privacy of patients and to limit individuals who have access to a patient's health.⁷⁸ Ultimately, for doctors and nurses, upholding the principles of privacy and confidentiality is an obligation that is governed by their codes of ethics and set legislations.

Any information shared in a clinical interaction is considered confidential and should therefore, be protected. This information can be in the form of diagnoses, lab results, and even progress results and can be stored in several platforms such as paper and electronic files.⁷⁹ Preserving the confidentiality of this information involves ensuring that only authorized individuals have access. One way of limiting access is through the use of usernames and passwords. Healthcare organizations can also ensure that employees adhere to the HIPAA privacy and security rules.⁸⁰ Protecting patient information is especially important in this age of electronic health information systems. While these systems offer several benefits to healthcare organizations, they suffer from security and privacy breaches. The unauthorized disclosure of personal health information could result in discrimination, psychological, and economic harm on the affected. Furthermore, if patients lose confidence in the way their information is used, they may refrain from providing critical information during their clinical visit.⁸¹ The use of social media in healthcare also raises several privacy and confidentiality issues. In many healthcare settings, the use of social media raises several issues associated with integrity and accountability among other professional boundaries. There have also been reports of healthcare providers disclosing their patients' private information and medical students providing denigrating descriptions of their patients.⁸² Despite this high risk, it is crucial for physicians to have access to their patients' information for them to deliver quality care.

Sharing of patient healthcare information is crucial to the success of the interdisciplinary collaboration between physicians and other relevant medical personnel. Collaboration in healthcare involves the capacity of all healthcare professionals to take up key roles within the team ensuring that they work cooperatively, sharing all the responsibilities for problem-solving. Evidence shows that interprofessional collaboration between healthcare providers including

nurses and physicians, improves the quality of care provided to patients and the overall decision-making process.⁸³ However, many patients are oblivious of how important these interactions are and why sharing their medical information improves the care process. This concern can be attributed to the fact that maintaining information privacy and confidentiality faces many challenges.⁸⁴ Patients are also not sure about what entails medical data sharing especially between doctors or even between medical centers. On one hand, patients ultimately want their data secure and protected from unlawful access. On the other hand, they want their data to be made available for others to use to deliver a comprehensive diagnosis. While ensuring data privacy is challenging, HIPAA restrictions allow patients to decide on how their data will be used. This has been affected in several areas including in research albeit presence of resistance from researchers.⁸⁵ Regardless, sharing of patient medical information must be accompanied by strict restrictions and protections to ensure data privacy and confidentiality.

Informed consent, privacy ,and confidentiality are some of the fundamental concepts of medical ethics. In the past, informed consent focused on the simple rights of all patients to approval of their treatment. Currently, upon further development, the term informed consent acknowledges both the patient's autonomy in making medical decisions and also acknowledges their right to complete information.⁸⁶ Moreover, the current process of obtaining informed consent requires the healthcare provider to explain in detail the treatment process for the patient to make expert decisions concerning their care.⁸⁷ However, doctors and other healthcare providers face the challenge of obtaining informed consent from certain groups of patients such as those who have undergone trauma. For emergency physicians, understanding patients' preferences and values is extremely difficult. In such situations, physicians must ensure that they secure the patient's informed consent as a way of respecting their autonomy.⁸⁸ In other

situations, the information that patients must comprehend is overwhelming and the patient cannot attain the understanding needed to make informed decisions. An example of such a situation is seen in research focusing on whole genome sequencing and the identification of an individual's entire genome. In such situations, obtaining informed consent may not be possible.⁸⁹ The concept of consent emphasizes the patient's autonomy and the duty of all physicians to provide the patient with all the necessary information to help them make optimal decisions.

2.2.2. Technology in healthcare interactions

Healthcare information technology (HIT) refers to the application of information processing hardware and software to facilitate information storage and sharing, thus facilitating the decision-making process. The use of HIT in healthcare presents several opportunities for improving service delivery, reducing human errors, improving practice efficiencies, and keeping track of patients' medical data over an extended period of time.⁹⁰ Similarly, HIT has been used to prevent quality and safety events from taking place. For example, automated reminders and alerts are used to provide key information that facilitates the decision-making process. Likewise, HIT is used to identify quality and safety events before they occur. HIT is used to locate the electronic health records of patients who might be associated with lower reimbursement rates. By doing so, healthcare providers are able to improve quality of care and reduce unintended readmissions thus increasing reimbursement rates.⁹¹ HIT solutions such as dashboards are also used to ensure that significant patient data is placed in a primary viewing position while other non-essential data is placed in a secondary viewing position. Healthcare organizations can therefore, leverage HIT to improve operations and the overall quality of patient care.

While health IT has been shown to transform the way care is delivered, it's inappropriate use could result in unintended adverse consequences. One of the main adverse consequences includes implementation failures. Implementation failures are failures to deliver programs as they are intended thus resulting in failures to achieve intended interventions.⁹² Furthermore, ensuring the safety of HIT is a major challenge in healthcare settings. Moving forward, HIT must support user goals and the technology used must be implemented correctly by healthcare organizations who must ensure that the technology is used for its intended purpose which is, to improve quality and safety of care.⁹³

2.2.2.a. Big Data in Healthcare Interactions

The healthcare industry constantly generates large amounts of data referred to as big data. Big data holds the promise of improving a wide range of healthcare functions including disease surveillance and providing support to population health management. Furthermore, big data in healthcare involves large electronic health data sets that are too difficult to manage using traditional means of data management.⁹⁴ Big data in healthcare interactions include both clinical data and other support system data such as physicians' notes, laboratory results, and insurance and administration data. Additionally, big data is obtained from electronic patient records, social media posts, and less-patient-specific information such as medical journals and news feeds. This high proliferation of big data requires deeper understanding of patterns and trends through what is known as big data analytics.⁹⁵ Through big data analytics, patterns and trends in healthcare are analyzed allowing healthcare providers to develop better diagnoses and treatment interventions.

The demand for big data technologies in healthcare is growing. Many healthcare organizations are struggling with escalating healthcare costs, different reimbursement trends, and an overall need to improve quality of care. Furthermore, the healthcare industry is generating

large volumes of healthcare data.⁹⁶ This is mainly associated with technological advancements and the digitization of medical records. Advancements in technology such as the introduction of sensor systems and smartphones have become a significant source of healthcare data.

Additionally, health-related data sources such as electronic health records, mobile health, robotics, medical internet of things, and screening tests; are being used in high-speed analysis. New sources of data are introduced on a regular basis making it extremely difficult to analyze the data using traditional database management tools. To improve on this, the use of healthcare big data analytics is currently being adopted in numerous healthcare disciplines.⁹⁷ Regardless, the incorporation of big data in healthcare has introduced several ethical challenges.

Despite their far-reaching impacts, big data approaches in healthcare raise several ethical challenges. Ethical issues such as privacy, personal autonomy, transparency, and fairness have been associated with big data use in healthcare.⁹⁸ Moreover, data protection, data heterogeneity, and appropriate data storage infrastructure are some of the major challenges of healthcare big data. For ethics review committees (ERCs), the ethical implications of health-related big data raise several challenges. For example, ERCs are often asked to evaluate studies involving big data which is often difficult to assess.⁹⁹ Additionally, the absence of comprehensive regulatory policies has made it near impossible for ERCs to review health-related big data studies. In fact, evidence shows that traditional conceptual tools such as informed consent and fair subject selection are not efficiently equipped to facilitate the evaluation of big data projects. Similarly, the nature of big data studies involving publicly available data is viewed to be outside the scope of ERCs. In addition to the aforementioned factors, researchers have shown that de-identified and de-anonymized data can be used to re-identify study participants thus creating doubt in the effectiveness of data anonymisation.¹⁰⁰ The lack of guidelines and regulatory policies to guide

the review of healthcare big data has made it difficult for ERCs to address ethical challenges that arise during the care process. More should be done to protect the privacy of patient data.

A few years after the completion of the human genome project, there have been a variety of policies to address privacy risks associated with the increase in genetic data research. As concern increases on the privacy of such data, many countries are adopting legislation that prohibiting the misuse of such data. Countries such as Canada have prohibited the use of genetic data by life insurers. The Council of Europe has also recommended that insurers should not require applicants to undergo genetic tests. The U.S. on the other hand, has implemented the Genetic Information Nondiscrimination Act (GINA) to protect citizens from being discriminated by health and employment insurers.¹⁰¹ In addition, issues of consent in genetic data have also been experienced especially after the emergence of bioresources that have created databases for research. Concern mainly revolves around the legality of broad consent in biobanking. Regardless, many organizations such as the American College of Medical Genetics and Genomics (ACCMG), stipulate that data sharing is a crucial component of improving genetic healthcare.¹⁰² However, to mitigate the risks associated with data sharing, responsible sharing should be practiced at all times.

An ethics framework for big data is needed to address complex issues that arise in the use and sharing of big data. One of the major issues in the use of big data is the issue of data anonymisation. The multifaceted nature of big data has increased the probability of privacy threats occurring to data sets that are otherwise believed to be protected. There is also the increased risk that the data will be re-identified thus weakening any security provided by data masking techniques.¹⁰³ Furthermore, researchers face the challenge of finding ways to utilize big data for the common good while also ensuring that individual rights are respected and protected.

Legitimacy concerns also arise over the extent to which digital disease detection (DDD) is ethically justifiable. While some might argue that DDD is ethically justifiable in the sense that it provides an early warning sign when there is a disease outbreak, others argue that DDD must build its legitimacy over time.¹⁰⁴

2.2.2.b. Health Information Technology Integration into Healthcare Interactions

The growth of health information technology has transformed the healthcare industry making it possible for everyone to access care from any location. Furthermore, delivering patient-centered care is essential for ensuring active patient participation that results in positive patient outcomes. Physician-patient interactions have also been shown to affect patient outcomes. Positive physician-patient interactions increase patient satisfaction and reduce the likelihood of medical malpractice lawsuits.¹⁰⁵ Health information technology (HIT) provides patients, healthcare providers and organizations access to a wide range of information thus facilitating the decision-making process.¹⁰⁶ HIT comprises of several technologies that support advanced decision making and can also be integrated with other technologies. Some of these technologies include electronic health records, electronic physician orders, smart pumps, automated medication dispensing cabinets, and telemedicine. HIT also plays a significant role in reducing medical errors, improving patient outcomes, facilitating the care process, and keeping track of data over an extended period of time.¹⁰⁷

Electronic health records have been shown to have a positive effect on doctor-patient interactions. For physicians to be successful in their practice, they require good sources of information. Electronic medical records (EMRs), and its associated information technology, have been used as a reliable source of information. By using EMRs, physicians report experiencing improved patient care and overall quality of care.¹⁰⁸ Physicians have also reported that by using

electronic health records, healthcare services have been more efficient. Additionally, physicians report that EHRs have reduced their workload and medical errors.¹⁰⁹ During the clinical interaction, EHRs have given physicians the opportunity to document their diagnostic investigations, facilitate communication with patients and other healthcare professionals, and lastly, facilitate clinical decision making. However, EHRs have resulted in an increase in the time clinicians spend documenting their interactions. Additionally, EHRs has increased non-clinical workload such as quality measures and coding.¹¹⁰ Poor EHR system design has also been associated with errors that affect the integrity of information that could eventually endanger patient safety. Other healthcare providers also note that EHRs result in a lack of focus on the patient since the physician spends a majority of the time during the interaction, on a computer.¹¹¹ Given the significant benefits associated with EHRs, it is vital that the ethical challenges of EHRs be highlighted.

There are four major challenges associated with EHRs. They include privacy and confidentiality, breaches in security, inaccurate data, and system implementation.¹¹² Any information that a patient gives during a healthcare interaction should only be released to others only if the patient allows it or the law stipulated it. However, when a patient is incapacitated and lacks the ability to give consent, their legal representative or guardian should decide on whether to share the information. All the information that is shared in a clinical interaction is confidential and must therefore, be protected. Preserving privacy in EHRs involves limiting access to patient information by only allowing authorized individuals the access. Furthermore, healthcare organizations can implement additional security measures such as designing security policies.¹¹³ Security breaches on the other hand, threaten the privacy and confidentiality of a patient's health information. One of way of protecting patients' data from security breaches is data encryption.

Data encryption ensures that only authorized individuals can understand the encrypted data and is usually done by the use of data encryption keys. In addition to data encryption, healthcare organizations can implement cloud storage and password protection interventions especially when using portable EHRs. Lastly, healthcare organizations can also implement security measures such as firewalls and intrusion detection software.¹¹⁴

Privacy in healthcare is specifically important to patients and is often threatened when technology is used. Confidentiality is also very critical to healthcare interactions since patients might find it difficult to share sensitive information with their healthcare providers if they are in doubt that their data will be kept confidential. Privacy and confidentiality are therefore crucial for all healthcare interactions. One of the areas that privacy and confidentiality must be ensured is in mHealth technologies.¹¹⁵ Mobile Health or mHealth technologies are designed with the intention of motivating and persuading behavioral changes in individuals. mHealth technologies use smartphone applications to transmit electronic medical records, monitor patients remotely, and implement interventions to improve patient outcomes.¹¹⁶ Many people rely on mHealth technologies to manage their weight, stress and to deal with chronic conditions. However, despite its promise, mHealth faces several issues revolving around privacy and security. For research involving mHealth technologies, researchers struggle with ensuring protection of sensitive data. Additionally, researchers struggle with the large amounts of data collected using mHealth technologies.¹¹⁷ To effectively address confidentiality and privacy challenges in mHealth, healthcare organizations must implement cost-effective solutions.

There is an increasing amount of personal healthcare data being collected through multiple electronic channels. However, ensuring the privacy and confidentiality of this information is challenging for many organizations.¹¹⁸ The collection of personal health data is

necessary for the monitoring and evaluation of health services in a facility. However, if patients are not assured of the security of their personal information, they might be reluctant to provide it. To ensure that the benefits of HIT continue to be enjoyed by both patients and healthcare professionals, the privacy, confidentiality and security of personal health information must be ensured.

2.2.3. Privacy and confidentiality in healthcare interactions

Privacy and confidentiality are some of the major components of patient care. Clinicians and other healthcare providers have an ethical obligation to protect the privacy and confidentiality of their patients' information at all times. Furthermore, the patient's rights to privacy and confidentiality should be respected during healthcare interactions.¹¹⁹ However, during Health Information exchange, patients might be concerned about the ability to control access to their healthcare data. This concern might also affect the level of openness that the patient has during the patient-provider interaction. Besides the lack of trust that breaches in health information cause, patients experience increased financial burden that threatens their healthcare outcomes. In addition, data breaches affect the quality of care, incorrect information can find its way into a patient's medical records. This in turn, might result in the patient missing out on necessary medication and other treatment interventions.¹²⁰ Healthcare organizations must ensure that they better protect patients' privacy by adopting several preventive measures including implementing user authentication and training healthcare professionals on data protections and safety.

Respect for confidentiality is essential towards the safeguarding of patients' well-being. Moreover, healthcare providers have a duty to ensure confidentiality when interacting with

patients. This duty ensures that a level of trust is developed between patients and their healthcare providers. Confidentiality can be defined as the moral right to protect the privacy of patients' healthcare information.¹²¹ Similarly, the right to confidentiality is highly dependent on the basic rights to privacy and to personal data protection. However, confidentiality comprises of additional data protection rights that transcend privacy. For example, for confidentiality to be triggered, privacy must have been disclosed. However, researchers and other healthcare providers struggle to ascertain the duty of confidentiality and when it can be violated.¹²² Ultimately, both privacy and confidentiality must be present to guarantee effective data protection.

2.2.3.a. Principles of Data Privacy and Confidentiality in Healthcare

The principle of confidentiality is highly integrated in the four key pillars of medical ethics: autonomy, justice, beneficence, and nonmaleficence. Respect for autonomy ensures that an individual's right to choose is upheld. Additionally, respect for autonomy implies that individuals are free from coercion and their information must be protected. The same principles apply to privacy and confidentiality of health-related data. For healthcare professionals, maintaining confidentiality further strengthens the physician-patient relationship and ensures that patients' information is protected.¹²³ Informed consent is another aspect that mirrors the ethical principle of autonomy. Informed consent provides patients with the power to make health-related choices based on their true desires. While healthcare professionals are required to obtain informed consent from patients before administering treatment, healthcare providers have no legal obligation to notify patients of the limits of confidentiality. In most occasions, it is the ethical duty of the physician to do so. Physicians also ensure that they inform their patients about the situations in which their confidentiality might be breached before treatment begins.¹²⁴ Based

on the ethical principle of beneficence, individuals should avoid doing harm. Breaches of confidentiality may result in harm and therefore, should be prevented. Lastly, based on the ethical principle of respect for persons, healthcare providers must prudently explain to patients the reasons why limiting access to their information is beneficial.¹²⁵

Confidentiality in healthcare interactions is a tool used to protect the privacy of patients' healthcare information. However, in order to fully protect privacy, refraining from disclosing patient information is not enough.¹²⁶ To fully guarantee privacy, the use of sensitive information should be reduced. This is significant especially in this age where data breaches are a common occurrence in medical settings. Data minimization in healthcare settings is a necessity putting into consideration the sensitive nature of medical data. Furthermore, when patients are interacting with their physicians, they are at their most vulnerable state. In such a state, it is the duty of healthcare professionals to protect the patient by minimizing privacy losses.¹²⁷ Besides, for their self-respect, it is prudent that patient remove any doubt they might have about healthcare professionals. Patients must also hold the highest responsibility so that they can feel confident during healthcare interactions. The overall safety of patients' information requires united efforts from both patients and healthcare providers.

In the context of research, confidentiality refers to the agreement that a study subject's information will be kept private. Confidentiality in research exists either as a promise that a researcher makes to their test subject or as a legal requirement stipulated by HIPAA or other legal agencies. Confidentiality in research is different from privacy. Confidentiality focuses on the agreements made on how data is to be handled while privacy focuses on individuals and their own desires to control access to their personal information.¹²⁸ In research confidentiality of personal information implies that researchers must respect study participants and make

appropriate choices when it comes to information that should be reported or even publicly disclosed. Researchers must also ensure that data obtained throughout the course of the study is stored in a safe and secure location that cannot be accessed by unauthorized individuals.¹²⁹ However, for the strategies to work, the researcher must begin by acknowledging the value of confidentiality. Moreover, the researcher must act on behalf of the participant and ensure that they champion their own research above others.

Privacy is the right of individuals to keep their information from being disclosed to others. Additionally, privacy involves the right of individuals to be left alone and to be free from surveillance or any other form of interference from other individuals or organizations.¹³⁰ In mHealth, the privacy of user health data has been a recurrent issue in addition to issues associated with regulation that monitors access to user interactions. Furthermore, less experienced users of smart devices are often exploited by targeted marketing thus making them more prone to privacy and security breaches. Naïve users are often misled to download apps that contain malware. Additionally, these users are lured into using medical apps that are not compliant with set standards and regulations.¹³¹ When it comes to treatments via the internet, privacy concerns arise especially since patients provide PHI for them to access treatment. Privacy concerns also arise when individuals are recruited for clinical trials via the internet. For this types of recruitments, determining eligibility is a challenge. Researchers have provided technology-based approaches to protect users' PHI. For example, software that creates random identifiers has been developed to conceal the identity of individuals.¹³² Individuals also rely on media sharing platforms such as Instagram to seek a diagnosis or advice to manage their medical conditions.

While it is believed that individuals who share their personal information via these platforms have consented for their information to be shared, loss of privacy still remains a concern. To mitigate these risks, practical guidelines have been developed to guide on how images can be shared via social media while reducing the risk of privacy breaches. Lastly, crowdsourcing, the practice of obtaining information from large groups of individuals to create ideas to complete projects. Crowdsourcing faces several privacy issues associated with data de-identification.¹³³ However, many social media platforms protect their users by restricting access to content.

2.2.3.b. Ethical Explanation to protect Privacy and Confidentiality

Confidentiality is essential to the preservation of trust between patients and physicians. For years, doctors have upheld confidentiality as a major component of their practice. However, there are other circumstances that allow for confidentiality breaches to occur. These circumstances include; when the law requires it, consent is provided and when it is in the public interest.¹³⁴ One of the major ways that confidentiality can be broken is when the patient or owner of the information gives their consent. On the other hand, if the information is needed by a court of law, then confidentiality can be broken. A court order must be obtained for this to take place. Thirdly, confidentiality can be breached if the information being protected is required by the public. However, the court might be called upon to decide if the information will benefit the public once released.¹³⁵ Ultimately, respecting confidentiality is important since it protects the well-being of patients and increases confidence and trust in the doctor-patient relationship.

Breaches of confidentiality in healthcare settings are usually made careless healthcare professionals. Healthcare professionals may at times, engage in careless speech or even act maliciously jeopardizing the doctor-patient relationship. Careless behavior involves instances

where healthcare professionals speak about their patients in cafeterias and in other public places.¹³⁶ The improper disclosure of patient information could result in significant harm to the patient including loss of opportunities, personal humiliation among other financial consequences. To avoid the abovementioned consequences, patients should be made aware of the number of individuals who will have access to their medical information. This large group of healthcare professionals should also undergo appropriate training on how to observe confidentiality.¹³⁷

In the physician-patient relationship, confidentiality is used as a tool to foster trust. Furthermore, regulations such as HIPAA specify the need to protect identifiable health information. Any individual who has access to patients' medical information has an obligation to protect it.¹³⁸ The law gives patients the right to privacy and confidentiality. Additionally, individuals are given the right to know how their data will be used and disseminated. Confidentiality represents one of the core principles of research ethics. For researchers, breaching confidentiality may expose study participants to harm, reduce trust especially when dealing with vulnerable participants. In spite of the consequences associated with a breach of confidentiality, there are instances where the law obligates researchers to disclose information about study participants. For example, when dealing with vulnerable communities such as children and people living with disabilities, researchers are legally bound to report any form of abuse. In many cases, researchers avoid acquiring knowledge of non-convicted offenses to free themselves from the dilemma of reporting the offense and ultimately breaching confidentiality.¹³⁹

While the parameters of confidentiality vary from one clinical setting to the next, there are five key exceptions that healthcare professionals must be familiar with. In addition to consent and court orders, physicians can release a patient's confidential information to facilitate the

continued treatment of the patient. Similarly, the clinician may reveal a patient's confidential information to comply with specific statutes or law enforcement investigations. Lastly, a physician can breach confidentiality if the patient is a risk to others.¹⁴⁰ Before breaching confidentiality, clinicians must ascertain whether they have a duty to maintain confidentiality, is there an exception? Can they receive advice from a colleague? And are they familiar with the law and additional confidentiality policies of their affiliate organizations? Overall, to keep a patient's medical data confidential, it is crucial that healthcare professionals first analyze the scope of the problem.¹⁴¹

The right to privacy and confidentiality is usually associated with the right for individuals to protect their personal data. However, the right to personal data protection is not always absolute. In the current world, personal medical data is stored in different systems such as the cloud. As a result, information technology systems designed to protect data confidentiality must target all areas of data storage to effectively avoid data breaches.¹⁴² At its core, confidentiality involves restricting information to individuals who are authorized to access the data. To protect confidentiality, several interventions can be implemented including data encryption and adoption of passwords. Additionally, confidentiality can be achieved by targeting the moral disposition of healthcare providers. With the adoption of HIPAA, healthcare organizations have been able to apply administrative, physical and technical safeguards to protect patients' medical data.¹⁴³ Administrative safeguards comprise of several techniques such as regular performance audits and developing contingency plans. Physical safeguards on the other hand, focus on physically protecting patient information from being accessed by unauthorized individuals. Lastly, technical safeguards focus on protecting the entire information system located in the organization's network.¹⁴⁴

Healthcare professionals have an ethical duty to uphold patient confidentiality. Providing patients with the ability to decide how their information will be disclosed is a crucial part of the principle of autonomy. Confidentiality is rarely challenged by healthcare providers and patients and is accepted as a tool to build trust during healthcare interactions. While there are regulations designed to protect patient privacy such as HIPAA, more needs to be done to improve data protection. Is confidentiality enough to guarantee privacy or should there be more advanced interventions? The following section will attempt to answer this question.

2.2.4 Protecting data privacy

The concept of privacy focuses on limiting access to patient's personal information. Once personal information has been shared, it cannot be acquired back. Privacy is an individual's ability to control the manner in which their data is collected, used, disclosed, and retained. However, this control tends to overlook several important aspects of protecting information privacy especially when it is shared widely. To mitigate this, several interventions have been proposed: obfuscation, observing data transparency, and penalizing data misuse. Obfuscation implies that unauthorized individuals can access private information, but they cannot derive any meaning from it. Penalizing data misuse ensures that if data has been acquired without the consent of the owner, the unlawful individual pays the consequences. Lastly, data transparency implies that everyone can monitor data to determine if it is being misused.¹⁴⁵ Prioritizing these strategies will ensure that health data is widely shared for the betterment of healthcare in general.

Many researchers argue that legislative efforts designed to protect the privacy of patient data have significantly reduced the flow of data use in research and increased costs and delays. This in turn has affected the quality of research analysis. One of the major challenges in research

is balancing between the risk of data re-identification with data analysis utilities. Unfortunately, increasing access to data results in an increase in the risk of data re-identification.¹⁴⁶ How then can researchers ensure that they avoid the risk of data re-identification while also ensuring that they avoid incurring high costs due to delays? Researchers have recommended the use of best standards and practices associated with data protection.¹⁴⁷ Furthermore, conservational and analytical methods can be adopted to protect patients' medical records during clinical interactions.

2.2.4.a. Data Protection Techniques, HIPAA and Confidentiality

When HIPAA first became law, many believed that it was too complex and cumbersome to fully protect patient's medical information. Over time, HIPAA has proved to be effective in implementing privacy and security rules that protect patient's information. Furthermore, HIPAA has accomplished its main objectives which involve; ensuring that patients feel safe when giving out their private information to physicians and also improving information flow for research, treatment, and public health interventions.¹⁴⁸ HIPAA also covers a wide range of areas including electronic medical records, websites, and also medical imaging. Through its administrative safeguards, HIPAA has ensured that healthcare professionals have the right skills to handle PHI, those who violate HIPAA laws are disciplined and that information access policies provide appropriate access to health records. Additionally, the administrative safeguards ensure that adequate preparation policies are implemented and procedures put in place in the case of emergency data breaches. HIPAA's technical safeguards provide the right software and equipment to protect PHI. This further involves the adoption of encryption and decryption technologies when transmitting patient data. Lastly, physical safeguards protect the devices that healthcare organizations use when protecting patient information. This involves physically

monitoring who is accessing the facility and employing privacy officers.¹⁴⁹ HIPAA has thrust all healthcare providers into new roles of being information gatekeeper, information access arbiters, and data specialist. To become proficient in their new roles, healthcare providers must undergo HIPAA compliance training.

Privacy in big data involves having the ability to protect personal medical information. Furthermore, protecting privacy involves” making policies and establishing requirements that ensure that information is collected and distributed” appropriately. To ensure data privacy, several technologies are used.¹⁵⁰ Authentication technologies are mainly used to protect patient data from man-in-the-middle attacks. For example, transport layer security and secure sockets layer are used to protect communications over the internet.¹⁵¹ Data encryption on the other hand, protects patient data external breaches and theft of storage devices. Before adopting this intervention, organizations must ensure that they select suitable encryption algorithms that meet the needs of their patients. Data masking is another technique that involves replacing sensitive information such as a patient’s name and their social security number, with an unidentifiable value. Data masking is one of the most preferred technique due to its low cost.¹⁵² Access control policies involve granting practitioners the privilege of accessing patient’s private information. Security monitoring involves investigating events to identify areas of intrusions. This involves maintaining a log of every access to patient data. While this technology is difficult to implement, organizations can adopt security monitoring architecture.¹⁵³

When considering the adoption of electronic health records, privacy of patients’ medical information is crucial. Many organizations have implemented the use of firewalls to protect their information technology systems.¹⁵⁴ The most preferred type of firewall utilized by many organizations is the packet filtering firewall that filters internal electronic feeds while also

blocking external feeds. Cryptography has also been used to ensure the security of patients' information. Encryption as a form of cryptography, enhances the security of electronic health records. Encryption and decryption methods also ensure security of PHI uploaded through mobile agents. In the same light, usernames and passwords can be used to protect patient information against security breaches. Other security techniques include installing antivirus software, cloud computing, risk assessment software and adoption of a chief information security officer.¹⁵⁵

Confidentiality is essential to the preservation of trust during clinical interactions between doctors and patients. The duty to uphold confidentiality arises when one individual discloses information to another. However, the increased use of technology in the form of EMRs has increased the risk of data breaches. Additionally, healthcare professionals might mistakenly breach patient information to their colleagues. To prevent this kind of data breach, data encryption e-mail programs can be adopted. In the clinical setting, confidential patient charts and files should be shredded and other information such as digital recordings kept under strict security.¹⁵⁶ Breaches in confidentiality due to carelessness on the physician side, jeopardize the doctor-patient relationship and compromise the care process. As such, healthcare organizations should implement policies that address confidentiality issues. These policies should focus on the technological environment and employee interactions that could result in breaches in confidentiality. Furthermore, the organization should provide training opportunities for employees to ensure that they conversant with privacy policies and regulations.¹⁵⁷

The increasing use of technology in healthcare has created new challenges for healthcare providers. Protecting patient's privacy and confidentiality is increasingly becoming difficult. However, there are several ways that healthcare providers can prevent privacy breaches and

improve confidentiality. For example, healthcare facilities can create wide-ranging confidentiality agreements and policies ensuring that all employees are aware of what is expected of them.¹⁵⁸ Similarly, healthcare organizations can provide regular training opportunities for staff members to help reinforce the benefits of confidentiality in practice. Lastly, the organization should also ensure that it correctly stores patient information in protected areas that are easy to access for authorized individuals.

2.2.4.b. Future Work

The ongoing COVID-19 pandemic has paved the way for a shift in data privacy in healthcare. While HIPAA was adopted several years ago to protect patient privacy, healthcare technology has experienced widespread transformations. Currently, many healthcare organizations are transitioning from using paper records to EHRs. The future is also full of opportunities to protect patient information. For example, de-identified data may be used more in research to replace identifiable patient information. Big data mining is also expected to continue and the use of social media to predict health outcomes will increase. Individuals may also gain control over how their data will be used. This includes participating in health surveillance programs or deciding how their social media information was going to be used.¹⁵⁹

The COVID-19 pandemic has forced many governments around the world to track data-driven tools to be able to monitor and control the spread of the virus. This invasion of privacy is highly unlikely especially during times of normalcy. However, in the case of disease outbreaks and pandemics, the use of location data obtained from technology companies is a viable option for many governments.¹⁶⁰ Furthermore, despite the presence of legal regulations to protect individuals, privacy violations still occur. Private organizations are also developing apps that allow individuals to share their social contacts and whereabouts. Regardless of the potential

benefits of such ventures, it is crucial to note that they have negative consequences on data protection and privacy. While COVID-19 has required governments to create a balance between security and individual freedoms, it has come at the cost of privacy and security. Other areas of concern include use of big data for unethical purposes, overreliance on biased data, and lastly erosion of humanitarian principles.¹⁶¹ There is also concern that governments could exploit the pandemic sing it as an opportunity to normalize domestic surveillance. There may also be disproportionate privacy invasions especially on the less privileged in society. Law enforcement agencies might also transfer individual information from telecommunication companies.¹⁶² It is, therefore, important to adopt best practices to ensure that individual data is protected amidst the pandemic.

Data privacy in the age of big data and artificial intelligence is a growing concern. AI is a branch of computer science that incorporates computer algorithms in performing cognitive tasks. The combination of Big Data and AI offers several benefits for healthcare organizations including reduction in medical errors, increased productivity and decreased operational costs. However, the use of AI presents several ethical challenges especially during the consolidation of data from several sources.¹⁶³ If the consolidation is executed poorly, it may increase occurrence of data breaches. Furthermore, there are gaps that exist in laws and regulations governing the use of big data and AI. While HIPAA helped close some of these gaps, more needs to be done. To address these gaps, emerging approaches are targeting the technology used. For example, differential privacy is among the strategies that is used to guarantee privacy in AI and big data. Differential privacy focuses on describing patterns of groups rather than focusing on individuals. In addition, federal learning and distributed models are used to train algorithms found in multiple server through the use of separate data samples.¹⁶⁴ The abovementioned tools that are designed

to protect data privacy must adopt quickly to the changing nature of AI. Moreover, these tools cannot be used in isolation. They require additional ethical and legal frameworks among other safeguards for them to be effective.

The 3R interdependent privacy protection framework is an additional framework proposed to protect data privacy. The 3Rs include realizing, recognizing, and respect. The first step towards protecting patient data is realizing that the data is about to be transferred. Failure to realize that information is being transferred is usually associated with information collection using technology. Individuals fail to realize that their data is being shared when they give permission to apps and other devices to access their data. The second R focuses on recognizing that others have rights to their data. Individuals who recognize this right recognize they are infringing on it before they share data that belongs to someone else. The last R involves respecting the rights of other individuals. Respecting other peoples' information can be done by refraining from carrying out the transfer, obtaining consent from the owner of the information and lastly, anonymizing data before transferring it.¹⁶⁵

The Internet of Things (IoT) is another area in healthcare that faces several challenges associated with protecting patient privacy. Due to the large number of devices connected, the IoT has unique security and protection challenges.¹⁶⁶ In healthcare, IoT involves the use of remote sensors to collect patient information. The data is then sent to the healthcare facility where it can be stored and shared. Future IoT organization systems will have the capacity to report security breaches and unapproved information sharing. Furthermore, IoT technology should advance and become more self-dependent in recognizing external attacks and responding to them appropriately.¹⁶⁷ Overall, the internet of things (IoT) provides several advantages to the

healthcare industry. However, to provide reliable IoT services, organizations must ensure that they comply with data protection and privacy regulations.

The right to data protection is usually closely associated with the right to privacy. However, despite the similarities, the right to data protection has unique elements that should be addressed separately. As such, data protection should be made into a distinct right with both normative and practical significance.¹⁶⁸ Besides, data protection encompasses several key factors including privacy, autonomy, transparency, and non-discrimination.

2.3. Conclusion

Common law provides individuals who possess autonomy and self-determinations the right to either accept or reject medical treatment. Management of a patient's treatment plan can be overly complicated especially when the patient's ability to make reasonable decisions is questioned. Furthermore, it is expected that when patients freely accept or refuse medical treatment, they are competent enough to do so and must therefore, become accountable for their choices. However, concern rises when a patient is found to be incompetent and thus is unable to provide informed consent. To protect the patient from the consequences of their decisions, physicians must determine whether they have cognitive capacity to make informed decisions. A patient might be found incompetent by the court but determining cognitive capacity is left to the clinical team. Patients often refuse life-saving treatment for various reasons. Determining whether the patients are competent enough and have capacity to make medical decisions is of the utmost importance. Physicians have relied on several assessment tools to determine capacity. However, the most preferred tool is the MacCAT tool that takes on an interview format and allows physicians to acquire patient information that will help them determine capacity.

Consultations are also critical to this process. Physicians are encouraged to consult the services of psychologists before proceeding with the patient's requests. After assessing the patient, the psychiatrist's conclusions can be submitted to a judge who uses them to determine competency. Generally, for Mr. J and other patients who refuse medical treatment, their right to refuse treatment should be respected unless their capacity is placed under question.

Healthcare providers have an ethical obligation to protect patients' information during healthcare interactions. The right to privacy provides individuals with the freedom to control their information including minimizing access by unauthorized third party individuals. Data privacy breaches disturb trust and ultimately affect the security of patients whose data has been violated. Protecting data privacy is necessary especially in the current technology-driven environment. While several legislations such as HIPAA, have been developed to protect data privacy, more needs to be done at the organization and individual level to improve data protection practices. Furthermore, protecting data privacy should be the responsibility of both healthcare providers and patients during any healthcare interaction. At the organization level, data protection interventions such as data encryption and adoption of passwords, have been proven to be effective in protecting data privacy. At the professional levels, healthcare providers must ensure that they are well versed with set data protection policies and guidelines. Additionally, healthcare providers should undergo data protection training to avoid breaching patient confidentiality during clinical interactions.

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CHAPTER 3. PROMOTING PUBLIC HEALTH

3.1. Human Reproduction and Public Health

One of the main causes of maternal death globally is unintended pregnancies. In addition to increased maternal morbidity and mortality, unintended pregnancies have an economic and social impact on individuals and their families. Women should therefore be encouraged and empowered to achieve their ideal family. One of the major ways of achieving a desired family size is using contraceptives.¹ The morality of contraception has been at the center of debates. For Catholics, theologians, and priests, the teaching that contraception is a grave evil has not always been clear. According to Pope John Paul VI, contraception is a sin and if it was looked on as a moral issue, then the human person would be devalued. Likewise, Catholic physicians and the entire Catholic medical community are affected by similar beliefs regarding contraceptives. Despite their beliefs, Catholic physicians still prescribe contraceptives and sterilization.² Over the years, the use of contraceptives has incited mixed reactions from the church and the medical community.

For a couple, fertility is the ability of a man and a woman to get pregnant and for the woman to sustain the pregnancy. Debates on contraception being inherently wrong observe that contraception is unnatural and carries health risks. However, for women around the world, using contraception improves their health and offers them financial stability. Statistics also shows that women in less developed regions shy away from contraceptives due to myths surrounding its use. Other studies show that Catholic women are embracing contraception and spacing their births contrary to popular belief. Regardless of their religious views, healthcare providers have an ethical duty to provide all the information concerning contraception to allow patients to

provide informed consent. Additionally, they should respect the patient's decision and provide the best form of care that upholds the patient's wishes.

3.1.1. Reproduction and unintended pregnancies

The human response regarding developments in birth is largely shaped by religious beliefs. The logic of *Humanae vitae* offers a religious vision of human sexuality and conjugal love. It has also played a critical role in catalyzing the field of natural family planning, also referred to as “the fertility awareness-based methods (FABMs).” Additionally, the *Humanae vitae* has inspired the development of “morally acceptable techniques” including the Billings ovulation method, the symptothermal method, and the Creighton Model system.³ FABMs strive to introduce new perspectives to the church's prohibition on the use of family planning before, during and, after sexual intercourse. In line with this vision, FABMs finds rationale in the church's belief that contraceptive intercourse is inconsistent with conjugal love.

According to the church, conjugal love is self-giving and open to love while contraceptive intercourse is a muted form of love and does not represent interior truth.⁴ Christians who are against the use of contraceptives usually appeal to two arguments. First, the unifying moral tradition that all religions agree on which is against contraception. This moral tradition regards sex outside marriage as being morally wrong and that people should abstain from having sex and using birth control. Furthermore, more conservative churches preach that using contraceptives before marriage is not desirable and that married women should naturally regulate and space their families.⁵ Second, natural arguments that are against contraception believe that the main purpose of having sexual intercourse is to procreate.⁶

3.1.1.a. Assisted reproduction and birth control

The introduction of assisted reproduction into the medical practice received a lot of criticism from some religious groups and praise from others. Currently, assisted reproduction is accepted in Judaism, Buddhism, and Hinduism. However, the Roman Catholic Church accepts some form of assisted reproduction such as IVF and encourages infertile couples to either adopt or turn to science for a solution.⁷ While Anglicans and Protestants accept some of its forms. The Islamic Republic of Iran accepts gamete donation, which is a Shia-dominant country, while the rest of Islamic countries rejects the principles of gamete donation, especially the Sunni Islam.⁸ The Chinese culture strongly accepts all forms of assisted reproduction that do not rely on third parties.⁹ Other communities believe in the religion of the majority in that community. Overall, the debate will continue as long as there are new developments in the field of assisted reproduction.

The issue of birth control has been a constant source of argument between the Catholic Church and the medical world. The *Humanae Vitae* that strict prohibition against artificial contraceptives was issued by Pope Paul VI after the development of the birth control pill. Ever since, the declaration was made, some traditional Catholics praise the move while others find fault in it. According to historical texts, Egyptians, Hebrews, Greeks, and Romans knew about contraception. They practiced simple contraceptive methods including the withdrawal method and “the use of crocodile dung and honey to kill semen.” Although Judeo-Christian scripture allows followers to procreate, it does not explicitly prohibit contraception. When the first Christian theologians condemned the use of contraceptives, they did so based on social pressures and the culture of the land. Before the 20th century, theologians believed that individuals who took contraceptives were fornicators and if a couple tried to prevent conception, they were

immoral and were self-indulging.¹⁰ By the end of the 19th century, contraceptive technologies improved and Christians from Catholic regions in the world began using contraceptives.¹¹ Over the years the fight against the use of contraceptives by the church has seen its ups and downs. While the prohibition of birth control continues, many church leaders discuss the benefits of using artificial contraceptives to allow couples make the right decisions.¹²

3.1.1.b. Impact of contraception on public health

Since its introduction, emergency contraception (EC) has proven to be effective and well received globally. Professional organizations offer counseling and advance provision of emergency contraception to reduce unintended pregnancies and abortions.¹³ However, despite available clinical trials, the benefits of emergency contraception on public health in terms of unintended pregnancies has not yet been proven. Currently, there are different types of EC that exist. The Yuzpe regimen is often used with “72 hours of unprotected intercourse and repeated 12 hours later.” However, due to the high content of levonorgestrel and estrogen in the drug, there is an increased risk of venous thromboembolism. In addition, Ulipristal acetate (UPA) which is “a selective progesterone receptor modulator” and is used as a single dose of 30 mg in Europe and in the USA. Mifepristone is used in China, Vietnam, and Russia.¹⁴ The copper intrauterine device (IUD) is an effective short and long-term contraception. However, despite their prevalence, there is no placebo-controlled trial to determine the efficacy of EC. Currently, efficacy is estimated by analyzing the cases of pregnancies that occur among women who have used EC and the number of pregnancies that would have occurred if EC was not used.¹⁵ Very few studies demonstrate any reduction in unintended pregnancy or abortion among women.

3.1.2. The moral perspective in human reproductive medicine and the impact of contraception on public health

There is still controversy over the use of emergency contraception in Catholic hospitals especially for victims of sexual assault. At the heart of the controversy is whether the medications used prevent fertilization and implantation by altering the lining of the endometrium. Based on the belief that EC inhibit implantation of a fertilized egg, some Catholic hospitals prohibit their use.¹⁶ However, for women who have been sexually assaulted, a lot relies on understanding how hormonal medications improve health. In many instances, the moral judgments are based on assumptions concerning the mechanisms of drug action, manufacturer labeling, outdated scientific research, and mere assumptions.

The standard EC used when dealing with a sexually assaulted woman is levonorgestrel 0.75 mg given within 120 hours of the sexual assault. This is then repeated 12 hours after first administration. In other cases, a dose of 1.5 mg is given in a single dose. The drug works primarily to prevent ovulation.¹⁷ One of the main ethical truisms is that good moral judgments depend on “good facts”. Without precise information, there is an increased occurrence of incorrect analysis and “erroneous judgment”. Furthermore, the moral judgment might be viewed to lack credibility either due to an unclear basis or on the basis of reputable data.¹⁸ Good facts are therefore necessary for good ethics. According to recent studies, levonorgestrel has minimal effects on events that occur post-fertilization.¹⁹ The Catholic moral tradition requires an individual to make a moral judgment and stand by it regardless of the consequences.

Additionally, one must have the moral certitude to exclude all reasonable possibility of error. How does moral certitude affect the use of emergency contraception? The first consideration assesses the mechanism of action of EC. Additionally, how do the results of

scientific research on EC rise to the level of moral certitude should be considered? As the evidence suggests, EC does not prevent implantation. Therefore, there is moral certitude regarding the mechanism of action. One might argue that theoretically, all the studies conducted could be mistaken. However, this is highly unlikely.²⁰ Thus, if the scientific research is correct, then morally and ethically, emergency contraception should be used in sexually assaulted women.

3.1.2.a. The moral debate on the use of emergency contraception in adolescents

There are several ethical issues associated with the distribution of emergency contraception to pediatric patients. While most healthcare providers support adolescent contraception, others raise a concern about a society becoming more accepting of teenage pregnancy. Some of the reasons and barriers to emergency contraception for adolescents include fear, knowledge deficit, embarrassment, and privacy issues.²¹ Statistics show that the United States has the highest teen birth rates compared to other industrialized nations. The use of EC has been documented to reduce the risk of unwanted pregnancies. Individuals younger than 17 years must obtain a prescription from a clinician to be able to access EC.²²

The efficacy of combined use of progestin-only EC is highly dependent on the timing of use. One of the most effective progestin-only methods is Plan B. This method has been effective in preventing pregnancy compared to a combination of hormone methods. Despite available evidence showing that hormonal EC does not disrupt established pregnancies, the personal values of healthcare providers such as physicians and pharmacists, remain to affect the access of EC, specifically for adolescents. Some physicians choose not to provide EC to teenagers regardless of the condition and situation the teenager is in. Others will only provide EC only if the penetration was nonconsensual. Often, physicians have conflicting beliefs and values when

approaching issues of reproductive health with teenagers. Therefore, pediatricians should strive to be informed about the impact of the beliefs they bring to their clinical practice, especially when dealing with a population such as teenagers.²³

Patient autonomy and parental rights are the main ethical concerns associated with access to emergency contraception. There are those who believe that using EC is unethical while others believe that restricting the use of EC violates basic ethical principles. For those who are against the use of EC, their argument centers on the mechanism of action where EC prevents implantation thus putting the fertilized egg considered as an unborn child in danger.²⁴ Therefore, preventing implantation is similar to abortion.

Additionally, the argument against EC for adolescents is also based on the belief that having easy access to EC encourages promiscuity. However, these ethical objections to the use of EC are invalid since they are based on misinformation that EC prevents implantation. In addition, there is sufficient evidence that shows that levonorgestrel does not impede implantation.²⁵ Since emergency contraception is an effective tool for the prevention of unwanted pregnancies, placing barriers to its use violates the ethical principles of respect for autonomy, non-maleficence, and beneficence.

3.1.2.b. Impact of long-acting reversible contraception on public health

Long-acting reversible contraceptives (LARCs) are “safe and effective”. The use of intrauterine devices (IUDs) and “the subdermal contraceptive implant” is highly effective since they are not user dependent. When placed, the risk associated with user error or gaps found in contraceptive coverage is significantly reduced. As a result of the increased effectiveness of LARCs, the Centers for Disease Control and Prevention (CDC) recommends its use as a first-line contraceptive method. One of the barriers associated with the use of LARCs is the cost.

Additionally, women also note that the requirement for two clinic visits is both costly and time-consuming. When these barriers are reduced, women become more inclined to choose a LARC method and thus reduce the occurrence of unintended pregnancies.²⁶ Unplanned pregnancies remain a common problem in several resource-limited settings, mainly due to limited access to family planning services. In such settings, the use of the more effective LARC methods remains low compared to other short-acting methods like condoms and hormonal pills.²⁷

Pregnancy among teen places significant burdens on the individual and society as a whole. They include costs to the state in the form of support to the teen mother and child. Additionally, opportunity costs are resulting from missed school and future earnings. Moreover, the children of teen pregnancies are more likely to be incarcerated, become poor, or experience teen pregnancies. Therefore, some researchers believe that proposals to provide LARCS to all young people by the state should be considered.²⁸ Is it ethical and moral to provide LARCS and EC to teenagers? Ethical problems revolve around the conflicts of the principles of beneficence, and autonomy. Adolescents often struggle with the principle of autonomy.²⁹ Physicians are further confronted with the dilemma of sorting out the role that the adolescent plays in decision making.

Additionally, as the adolescent grows and develops their moral code, they lack consistency in their decisions. Birth control pills also reduce heavy periods, acne, endometriosis, and amenorrhea.³⁰ Therefore, before prescribing contraceptives to teenagers, physicians and providers must examine the total context of their decisions and the state of mind of the teenager.

3.1.3. A comparative analysis

For many Catholics, the morality of contraception has always been clear as they hold the most conservative view against any means of it.³¹ Since the introduction of the *Humanae Vitae* by Pope Paul VI, the Catholic Church has received numerous controversies from theologians. The condemnation of contraception in the United States healthcare system has entered public discourse mainly due to the proposed federal mandate that “requiring healthcare providers to pay for contraception regardless of their beliefs towards contraception.”³² Besides emphasizing that contraception was a sin, Pope Paul VI in the *Veritatis Splendor* observed that if contraception was viewed as being moral, the human person will be devalued. This devaluation of the person in marriage has resulted in even greater moral issues including abortion on demand, devaluation of women, child abuse, and destruction of the family moral values. With this devaluation, one is left to wonder, what is the moral good of marriage? According to traditional Catholic teachings, marriage relates to the nature of God, the world and the married couple. Furthermore, Catholic teachings believe that marriage should be between two consenting adults of the opposite sex who are united by God. This union must be monogamous and indissoluble since it results in the formation of children.³³

The formation of children is not a purely biological one but a lifelong commitment that involves the Creator himself directly causing every human soul to exist. Therefore, the conjugal act that results in the creation of the human soul must be respected. When utilitarianism is introduced into the marriage, the married couple are dehumanized. According to John Paul II, the use of contraception naturally introduces utilitarianism into marriage and removes children from the union. While the church permits couples to space births, it forbids the use of contraception and encourages natural family planning.³⁴

3.1.3.a. Natural family planning versus the use of contraception

There is a constant debate regarding natural family planning versus the use of contraception, especially for religious reasons. There are several reasons why natural family planning is morally different from contraception, based on the Church's preference. Natural family planning (NFP) recognizes that sex is person-oriented and requires one to give themselves to others. Contraception, on the other hand, is pleasure-oriented.³⁵ It is used as a means of ensuring maximum pleasure to the maximum number of individuals thus separating the act of procreation from its intended meaning. Moreover, NFP conforms to the natural order of the woman's cycle while contraception respects the selfish desires of the individual. NFP encourages the virtue of chastity and self-control while contraception is method that is simply designed to block conception and thus has no demands on human self-control. In addition, NFP is more spiritual since "the couple goes beyond the physical expression of love to a more spiritual connection."³⁶

Conversely, according to the American pregnancy association, NFP can be at 25% failure rate. There are several reasons NFP can be less effective and more challenging even if it is 100% safe and free of cost. The NFP benefit, therefore, can be limited with women who have irregular menstrual cycles or breastfeeding. Also, NFP requires "abstinence" which means that no sex for almost third of the month. Although NFP meets certain religious guidelines, women may require having contraceptive as a backup when using NFP.³⁷ Thus, they must be careful, otherwise, NFP will be not a successful method.

Healthcare professionals

Before giving contraceptive advice, doctors and other medical professionals face the conflict of giving the best care to their patients and their ethical or religious views regarding

contraception. The primary concern of all healthcare professionals is the welfare of their patients. In addition, doctors must respect the autonomy of their patients by allowing them to make their own decisions.³⁸ Therefore, the doctor should ensure that the patient gets the right information and advice regarding their preferred mode of contraception. Furthermore, healthcare professionals are required to observe the principle of informed consent and provide all the information regarding contraceptives. For every contraceptive, the doctor should ensure that the patient is aware of the method reliability, ease to use, potential side-effects, and health risks.³⁹ In addition to providing continuing support for their patients, healthcare professionals should provide continuing support, outline emergency contraception methods, and ensure that they are aware that methods such as sterilization are not reversible.⁴⁰

When the healthcare professional has strong ethical or religious views against contraceptives, they are faced with a dilemma. Should they make the patient aware of their views against the use of contraception or should they disregard their own religious and provide unbiased medical advice. It is considered unethical for a healthcare professional to provide medical advice that is influenced by their own personal beliefs.⁴¹ This creates a problem for doctors who disapprove of contraception and for those who are not willing to provide it to patients who are unmarried. Doctors have an ethical obligation to maintain patient confidentiality.⁴² A dilemma then arises when a teenage patient seeks help with contraception but requests the doctor not to tell their parents.⁴³

According to a 2003 British Medical Association report, children under the age of 16 should be entitled to privacy during a consultation in connection with contraception or pregnancy.⁴⁴ Additionally, in the case of a departure from this directive, doctors should be held liable to justify this departure.⁴⁵ Overall, whether a doctor has ethical or religious beliefs against

contraception, they have an ethical obligation to their patient to ensure informed consent, respect their decision and uphold the principle of confidentiality.⁴⁶

Sterilization

Sterilization is a method of contraception and the most common form that married couples use worldwide. For most women, “sterilization is a route to reproductive autonomy.” In other times, sterilization has resulted in reproductive injustice as seen in the United States when key populations such as low-income and women of color were forcefully sterilized as part of a state-funded program.⁴⁷ According to the same source, the American College of Obstetricians and Gynecologists, an ethical approach that ensures sterilization is accessible to women who wish to use it as a method of sterilization must be designed. The ethical provision of sterilization requires careful counseling. During counseling, there are three key areas of consideration; the information presented to the patient, the process through which the information is conveyed and the obstetrician’s self-reflection. The content presented to patients must contain up-to-date information about the sterilization procedure and other alternative forms of contraception available.⁴⁸ Physicians and care providers should ensure that the counselling process is nonjudgmental and patient needs are put into consideration. Finally, the clinician must avoid introducing conscious and unconscious biases into the clinical encounter.⁴⁹

For religiously affiliated healthcare facilities, sterilization may be prohibited based upon teachings from religious doctrine. This affects access by many women who might require contraceptive services in these facilities. Additionally, a majority of women are not aware of these restrictions on reproductive health. Some physicians have developed ways to work around this policy. For example, some designate one room in the hospital that does not observe strict religious views. Historically, clinicians would offer hysterectomies for medical reasons with an

underlying motivation of sterilization. Some reports show that cesarean deliveries were done with the same underlying motive. If providers or institutions will not provide sterilization services due to religious beliefs or other reasons, patients must be informed early enough and provided alternative forms of contraception.⁵⁰ Likewise, if postpartum sterilization cannot be provided due to an unstable work environment, the patient should be informed.

3.1.3.b. Religious beliefs in using contraceptives and woman's health

According to a new report by Guttmacher Institute, both Catholics and Evangelicals use contraceptives. The findings, therefore, show that regardless of religious beliefs, women in the United States are using contraceptives. Furthermore, the report shows that a majority of sexually active women who do not want to get pregnant are using contraception.⁵¹ Despite the Catholic Church's opposition to contraception, the report shows that many Catholic women are not shying away from contraception. This is also true for Evangelicals and Mainline Protestants. The report, which is based on a nationally representative U.S. government survey, counters the myth that shows that Catholics and other socially conservative organizations are opposed to contraception. Women from diverse religious backgrounds have discovered that contraceptive use prevents unintended pregnancies and improves the social and economic wellbeing of families.⁵²

The Church considers the moral nature of contraception to be completely different from the nature of man. Natural family planning (NFP) often referred to as fertility awareness uses several models such as the symptom-thermal method (STM) that cross-checks the woman's temperature, mucus, and changes in the cervix. NFP methods are natural and they are 99% effective especially when they are used properly.⁵³ Additionally, NFP methods combine the procreative and unitive aspects of marriage. They are inexpensive, readily available, and lack

chemicals. Contraception on the other hand, “is against life and wills that life does not exist. It further destroys the union of love and the very essence of man’s existence.”⁵⁴

Conversely, access to appropriate contraception for women improves their wellbeing and overall quality of life. According to the WHO “an estimated 225 million women are deprived of access to essential modern contraception”.⁵⁵ However, there are several ethical issues that arise in the use of contraception including respect for the autonomy of the woman and the issue of justice.⁵⁶ To uphold the principle of autonomy, the woman’s personal choice must always be respected. Likewise, the individual is entitled to beneficence, non-maleficence, and justice when accessing contraception.

Woman’s health

It is undeniable that contraceptive use should be dictated according to the woman’s health status. However, in low-income countries, cultural practices play a critical role in the woman’s decision to use contraception. Despite the research and evidence highlighting the benefits of contraception to the woman, myths about contraceptive are still prominent in such area. These myths further lower general health, uncontrolled fertility rates thus creating obstacles for the effective adoption of family planning programs. Poverty, illiteracy, and religiosity have resulted in an environment of misinformation.⁵⁷ For example, an earlier study done in Egypt showed that approximately 57% and 52% of urban and rural Egyptians respectively believe that using oral contraceptives negatively affected their health. Additionally, over 86% believe that “contraceptive pills cause severe headache, anemia, sterility, breast cancer and birth defects.”⁵⁸

The women who believe these myths opt for traditional methods of contraception. Research also shows that pregnancies that occur within a year of the mother’s preceding birth are at a higher risk of mortality compares to pregnancies acquired later.⁵⁹ Medical guidance,

therefore, recommends uptake of postpartum family planning a few weeks after birth. However, the success of postpartum family planning programs in low-income regions is highly limited by poor access to healthcare facilities and lack of skilled personnel to deliver family planning services. Traditional birth-spacing has also significantly declined in developing countries. However, there is limited research on why African women prefer traditional family planning practices than modern forms of contraception.⁶⁰

Classic utilitarianism

The moral theory of classic utilitarianism has insightful views regarding the moral nature of contraception. In the case of population change, a government might consider “whether to provide free contraceptives” to control the rise in population. Without providing free contraceptives, the population rise and overcrowding will introduce hunger, diseases, and pain leaving people worse-off than they were. Still, every new person will have enough goods resulting in an increase in the total net utility. Classic utilitarianism focuses mainly on total utility. Therefore, based on this, the government should not provide free contraceptives.⁶¹ For many utilitarians, this idea is morally wrong only if the consequences have more pain than the alternatives. This negative utilitarianism implies that the government should avail contraceptives to its citizens since by doing so, it reduces pain even though it decreases its total net profit. However, “average utilitarianism”, which stipulates that the best consequences are the ones that have the highest average utility, is the most preferred response and in such, the contraception program will achieve higher average utility.⁶² Generally, all maximizing consequentialists must agree on whether moral rightness depends on increasing total good or maximizing the average good.

For the Catholic Church and any other denomination, have a right to speak against it. Also, the Catholic Church believes in and teaches the Primacy of Conscience. However, they should respect the fact that contraception is a personal choice and help having healthy families and ensure responsible parenthood. The Episcopal Church, since the 1930s, has approved contraception to be used for the purpose of family planning. The church organizes programs and projects where “it provides information to both men and women on a full range of safe and affordable reproductive health services.” For the United Methodist Church, the right to control conception lies with the family. Other Churches such as the Presbyterian Church USA have taken “a public stand supporting contraception as a basic part of healthcare.” Even more traditional conservative churches believe that contraception is a moral decision for a woman and her family.⁶³

3.1.4. Theoretical Analysis of Contraception

The ethical debate on the sterilization of young women with intellectual disabilities is gaining momentum. Are there situations where it is justifiable for a parent to sterilize their mentally challenged daughter? Furthermore, the role of the state in monitoring and authorizing such decisions is also under discussion.⁶⁴ In many parts of the world, most women have access to a wide range of contraceptives including voluntary sterilization. However, in other occasions, sterilization is not a choice. Forced sterilization occurs when an individual is forcefully sterilized without their knowledge or consent. Women with disabilities are at an even higher risk of being forcefully sterilized. This is mainly due to systemic prejudices and widespread denial that they have rights to have sexual relationships.⁶⁵ Every woman has a right to bodily integrity and to

make their own reproductive choices. However, many women who live with disabilities across the world are denied access to these rights.

3.1.4.a. Sterilization and public health

Forced sterilization is an act of violence and inserts profound physical and psychological torture on the victim. This practice is part of an even broader pattern of denial of reproductive rights of disabled women and girls.⁶⁶ Moreover, the difficulty that most women with disabilities have in expressing this injustice further increases their vulnerability. Arguments that support forceful sterilization base their arguments on the fact that they are avoiding inconveniencing caregivers, protecting these women against sexual assault. However, improving the reproductive health of disabled women can be achieved without forceful sterilization.⁶⁷ Measures such as training in self-defense and assertiveness in conjunction with sexual education should be implemented to equip disabled women with the necessary tools and sources to make informed decisions.

The sterilization of incarcerated women also raises several key concerns. The prison environment is designed to restrict the liberty of prisoners. In addition, the concept of autonomy is diminished since all the prisoner's choices and behaviors are closely monitored and punished. While these women are not fully denied the freedom to make medical care decisions and still in prison, in such a setting that is known for occasionally violating the rights of women, permanent procedures such as sterilization should not be performed.⁶⁸ However, it is important to note that some incarcerated women may have previously requested sterilization outside of the prison system. Therefore, designing a policy that prohibits sterilization in prison infringes on the rights and desires of those who willingly request sterilization.⁶⁹ Generally, special procedural

safeguards are required when sterilizing incarcerated women because of the increased likelihood of coercion that impedes true consent.

Many legal systems across the world view the forceful sterilization of marginalized women as a violation of their human rights. However, the courts fail to acknowledge that forceful sterilization is primarily a violation of the prohibition of discrimination and completely undermines efforts to eradicate the practice altogether. According to the principles of human rights, marginalized populations should be highlighted to determine vulnerability to discrimination in healthcare settings. Additionally, the rights of the medical providers providing medical services should be maintained and the state should address any and all systemic human rights violations against its citizens.⁷⁰ Therefore, finding violations of the prohibition of discrimination in forced sterilization cases is crucial in addressing the injustices of the practice. Often, forced coercion occurs when consent is obtained under duress, the patient is provided limited information regarding the procedure thus invalidating their consent or consent is not obtained at all.⁷¹

Medical personnel have justified forced sterilization as necessary for public health. In the early 20th century, medical personnel believed that forced sterilization was essential to address genetic and hereditary defects. Later on in the 20th century, forced sterilization was used as a means of controlling the growing population. In Peru, many women were coerced to agree on sterilization as part of a discriminatory public health program.⁷² The sterilization of Roma women has been justified by healthcare providers as a necessary tool to improve the women's health. Regardless, forced sterilization is a violation of women's rights and any violations should be examined intensively by legal systems.

In an attempt to reduce the spread of mother-to-child HIV transmission rates, some countries around the world are turning to forced sterilizations of women. According to International human rights bodies, forced sterilization violates the individual's right to autonomy and to informed consent. Forceful sterilization of women living with HIV further marginalizes the women who are facing stigma due to their HIV positive status.⁷³ South Africa is one of the countries that has received increased the most attention for forcefully sterilizing women living with HIV. The irony in this is the fact that the country boasts of its highly progressive laws that support women's sexual and reproductive rights and prohibit sterilization. In Chile, the involuntary sterilization of women living with HIV is gaining momentum. In a 2004 study, "12.9% of sterilized women living with HIV had been sterilized without their consent" at all. Additionally, 29% of those sterilized stated that they consented under coercion.⁷⁴ Physicians who perform forced sterilization are violating their patient's human rights and their duties as medical professionals.

3.1.4. b. Decision making

According to internationally recognized codes of ethics, patients should make their own determination regarding their course of treatment. The ability to make decisions regarding their health is diminished when they are coerced to accept certain medical procedures. The World Medical Association's (WMA) International Code of Medical Ethics provides a list of several duties and responsibilities that physicians are expected to uphold. They include; respect for a patient's right to treatment, not allowing personal judgments and beliefs to influence the care they offer, acting in the patient's best interest, respecting their rights, and providing complete patient care while all the resources available to them. Therefore, coercing women living with HIV to undergo sterilization conflicts with the aforementioned duties and responsibilities.

Many women who are forcefully sterilized are “threatened with halting of antiretroviral medication if they refuse to sign a consent form.” This process also violates the ethical principle of beneficence that requires that all treatments must be beneficial to the patient. The medical rationale that sterilization of women living with HIV reduces the risk of mother-to-child HIV transmission is unsound. There is evidence that shows that consistent antiretroviral use significantly reduces the spread of HIV from mother to child.⁷⁵ With this evidence, there is therefore, no need for forced sterilization. Ultimately, the duty and loyalty of the patient should be upheld at all times.

Religion

For the Catholics, contraception is wrong. According to the Catholic Church, contraception has little moral relevance outside the institution of marriage. Catholics are not consequentialists, nor do they determine the morality of any act by foreseeing its potential consequences.⁷⁶ However, they determine the prudence of any act by assessing the potential consequences of the act. Furthermore, even morally neutral acts can either have good or bad consequences and should therefore be selected or discarded accordingly.

For many moralists, contraception use is morally neutral and should therefore be considered outside the confines of marriage. However, contraception is intended to suppress the natural outcome of intercourse and as such, it has immediate consequences. First, contraception introduces a casual attitude toward sexual intercourse. Therefore, the intimate and mutual commitment a couple applies to their relationship is overshadowed by the fact that the basic meaning of the act has been eliminated. As a result, many couples end up having casual sex. Casual sex negatively affects a couple’s psychological and emotional well-being. Secondly, contraception shifts the main meaning of intimacy from procreation to pleasure.⁷⁷

3.2. The Ethical Obligation to Minimize COVID-19 Deaths as an end-of-life Mandate from Islamic Perspective

The COVID-19 pandemic presents several challenges to public health and the global economy. Due to the rapid spread and the increased number of cases and deaths, COVID-19 has been declared a pandemic by the World Health Organization.⁷⁸ Given the seriousness of the disease, countries across the world have intensified their control and preventive measures in addition to implementing strategies to manage the economic, health, and social consequences of the pandemic. For some countries, implementing crisis management interventions act as turning point from enduring unstable economies.⁷⁹ In addition to affecting economies, health, and social factors, COVID-19 has had a significant impact on the world's religions. Since the virus is transmitted through contact, mass gatherings like the Hajj for Muslims, are highly discouraged. Furthermore, religious leaders are required to expand their teachings to include COVID-19 prevention measures such as regular hand washing among others.⁸⁰ However, in the unfortunate case where a Muslim has succumbed to COVID-19, Islamic burial laws exist to guide the process. According to Islamic traditions, the burial of a deceased individual is a collective obligation for the entire community.

Furthermore, current crisis management theories mainly focus on models that highlight the steps for crisis management such as “identifying the crisis, collecting data on the crisis, setting alternatives, implementing solutions, and evaluating the results.” However, these crisis management theories ignore major aspects of crisis management as described in Islam. Islam has laid down the scientific foundations for crisis management that are based on the directives of the Holy Qur'an and the Hadiths. These foundations include preparing for the crisis, verifying

information, developing a strategic plan, working together to face the crisis and lastly implementing strategies to face the crisis.⁸¹

The COVID-19 pandemic has introduced several ethical challenges for religions in the world. To further provide clarity on this issue, this section will highlight the nature of bioethics in Islam and the resulting end-of-life issues that arise during care. The section will also highlight end-of-life contemporary issues in Islam such as foregoing treatment. Lastly, the section will compare what Islam and Judaism say about forgoing end-of-life treatment, especially during the COVID-19 pandemic. The two religions are being compared because they have similar practices and beliefs such as forgoing treatment if it is considered futile. Additionally, Islam and Judaism have been disproportionately affected by the COVID-19 pandemic in different parts of the world.

3.2.1. The Nature of Bioethics in Islam

Islamic bioethics is the Islamic guidance on issues related to human life.⁸² In Islam, bioethics is believed to belong to a specific subfield of Islamic legal reasoning known as *fiqh*. The field of bioethics developed following the introduction of new technologies in medicine and end-of-life care.⁸³ However, when the principles used to guide Islam's ethical framework are applied to real-life clinical experiences, they are not sufficiently understood by healthcare providers. As a result, they act as a hindrance to the delivery of culturally sensitive healthcare.⁸⁴ For the last couple of years, the concepts of bioethics have been developed in life sciences and health. However, as the field of bioethics continues to grow, so does the realization that while some interventions exist and can be given to patients, it does not necessarily mean that they should.

3.2.1.a. Islamic Sources and Bioethics

Muslim jurists, scholars, and healthcare professionals, over the years, have been addressing issues associated with modern biotechnology.⁸⁵ Islam medical ethics obtains its teachings from the Qur'an (The Holy text believed to be the direct word of God), the Sunnah (Prophet Mohammed's traditions, including; His sayings, actions, and approvals) and the Ijtihad (the law of deductive logic).⁸⁶ Furthermore, since Islam does not admit clergies, the learned or the *Ulema*, are charged with the responsibility of interpreting religious texts for other Muslims. The views of the *Ulema* with regards to the ethical dilemmas in healthcare is that, in situations where specialist knowledge is required, the concept of a consensus edict can be used. On the other hand, for rulings associated with medicine, the consensus groups often include the *Ulema* and other specialist from other disciplines. The decision-making process is also transparent with relevant individuals allowed to choose the best decision or judgment they are comfortable with. This process of deductive reasoning is what is referred to as *Ijtihad*.⁸⁷

In Islamic societies across the world, the teachings of Islam play a crucial role in shaping Muslim's attitudes towards health and life in general. Islamic legal and ethical traditions are the main guiding factors when dealing with emerging issues in bioethics. Furthermore, both Islamic legal and ethical traditions cover major aspects in both research and clinical related decision-making. However, due to lack of a central authority guiding different believes in Islam, a majority of the decision-making is left to the *faqih* (learned scholars of Islamic laws). Moreover, when bioethical questions arise in Islamic jurisprudence and there is no textual source or base that is offering complete guidance, decisions are left to the *ijtihad*. This further shows that in Islamic bioethics, decisions are always shaped by several factors. Besides, in practice, Islamic jurists and scientists always come together to provide guidance in the case of any dilemma. The

fatwa or the Islamic judicial ruling, also facilitates the decision-making process when it comes to matters bioethics.⁸⁸

A common concept in Islamic bioethics is the *Maqasid-al-Shariah* which, as the name suggests, uses major concepts of the *Shariah* to analyze and assess bioethical issues. According to this concept, major bioethical issues are examined from three aspects: intention of the issue, method, and final goal. Afterwards, an evaluation is done on the issue from, the hierarchy of human interest, inclusivity, and the degree of certainty. This new approach to bioethics can be used effectively to overcome complex and complicated bioethical issues in society.⁸⁹ *Maqasid Al-Shariah* refers to the higher objectives of Islamic law. Additionally, the concept reflects the true purpose of the Lawgiver, which is to command, prohibit, or propose an action. It also represents an understanding of human interests and the intent of lawgivers to protect it. In this sense, the *Maqasid* acts as an axiology of the interests of humans which are legitimized by the Divine Lawgiver.⁹⁰ *Maqasid al-Shariah*-based Islamic bioethics can be understood to be an Islamic morality system that is based on two key knowledge disciplines; biological science and knowledge related to human value systems. Furthermore, *Maqasid* acts as a standard providing guidance in the case of a bioethics discourse and when there is a need to decide the hierarchy of value and other humankind needs that are consistent with the Islamic perspective.⁹¹ Overall, *Maqasid al-Shariah* protects mankind's interests based on the Islamic framework and not on human desires and wishes.

3.2.1.b. The Role of Muslim Jurists in Bioethics and the Four Principles of Biomedical Ethic

There are two major sects in Islam. They include; Sunni and the Shiite. However, a majority of Muslims are Sunnis (85%) while the remaining 15% belong to the Shiite.⁹² The name “Sunni” owes its origin from the phrase “Ahl al-Sunnah” which means “the people of the

tradition” or people who live their lives based in the teachings and actions of Prophet Muhammad. Sunnah guides all Muslims.⁹³ When addressing matters concerning bioethics, Sunni Muslims prefer incorporating *Ijmaa* (consensus) and *Giyas* (analogy) in addition to the Quran, the Sunnah and reason or *alaql*.⁹⁴ Furthermore, due to the connectedness of Islamic law and ethics, Islamic bioethics must incorporate Islamic law or *Sharia* in addition to other moral considerations. As a result, all decisions must be double checked against both the legal and moral standards.⁹⁵

Currently, there are less Muslim jurists who only specialize in tackling bioethical issues. Many Muslim jurists are graduates of Sharia Faculties and have received training that addresses a wide range of issues in the social, political, financial, and bioethical fields. One of the main shortcomings of having Muslim jurists who have not specialized on bioethics is that there is lack of interpretive techniques that are only unique to Islamic bioethics.⁹⁶ Some Islamic jurists, in other occasions, have faced difficult decisions to find answers and interpret the language of the Quran and the Sunnah in a way that would help in understanding some of contemporary issues in the field of bioethics. In these occasions, legal reasoning or *ijtihad*, is applied. Muslim Jurists have also developed a corpus of several linguistic rules that attempt to help in understanding the scripture. The main reason for the notion of *ijtihad* is that the jurist can establish a unique legal norm for every case they confront. In addition to the *ijtihad*, Muslim jurists can also rely on *ijmaa* or consensus. *Ijmaa* also refers to the agreement of jurists, who after being subjected to different legal opinions and are living in a particular age, come to an agreement. This consensus is founded on the Quran or the Sunnah.⁹⁷ Furthermore, under the same realm of legal reasoning as *ijtihad* and *ijmaa*, is *qiyas*, or analogy. *Qiyas* is not viewed as a legal source, rather, jurists can use it as a legal source that can provide content to help them make a legal decision.⁹⁸ Overall,

Muslim jurists are tasked with the role of applying the two primary sources of Islamic law; the Quran and the Sunnah either by applying the definitive legal rulings or by using Ijma' (consensus) or Qiyas (analogy) depending on the situation at hand.

The relationship that Islam has to medicine is extremely intimate. Islam, as a religion, has over the years encouraged the use of medicine and science to solve human suffering. Furthermore, Islamic medical ethics believes and practices the four main principles of biomedical ethics of autonomy, beneficence, non-maleficence, and justice.⁹⁹

Respect for autonomy involves clarifying the distinction between an individual's capacity to rule themselves and another individual's reaction to the capacity.¹⁰⁰ According to the Quran, religion does not have compulsion. Therefore, everyone has the will to accept Islam or reject it. The Quran is also full of scripture that encourage freedom of faith. In Islamic teaching, the man is entrusted with his body. As such, he is only permitted to act in a manner that is in line with God's wished. Based on this, the health provider should encourage patients to avoid a risky lifestyle that could harm their health.¹⁰¹ This Islamic autonomy also extends to decisions about life and death with the preservation of life among the top five purposes of a sacred life. Furthermore, one is forbidden from committing suicide. A physician has therefore, no authority to terminate any life under their care. While there might be significant suffering towards the end of any disease, Muslims are encouraged to persevere since they will be rewarded by God.¹⁰² However, of importance to note is that administering pain killers is permissible if the pain is to the extreme.

Beneficence is referred to as the aspect of human nature that compels everyone to act in line with the best interest of others.¹⁰³ The Quran and the Hadiths of Prophet Muhammad (pbuh) contain scripture of the prophet doings good and avoiding engaging in harmful activities. Prophet

Muhammad (pbuh) further encourages Muslims to be beneficial to others and to engage in charitable works. The principles of beneficence and non-maleficence are usually grouped together. The main concepts of the principle of non-maleficence include; avoiding inflicting harm or doing evil, preventing harm or evil, removing harm or evil and lastly, promoting good.¹⁰⁴ This is in line with Prophet Muhammad's teachings that order Muslims to promote good, remove harm and preventing evil or harm by doing good. The principles of beneficence and nonmaleficence are usually found under the concepts of "no harm, no harassment". Furthermore, the "no harm, no harassment" principle is one of the most frequently used principle in social ethics and in Islam.¹⁰⁵ On the other hand, Islamic encourages individuals to avoid doing harm and instead practice doing good. This means that if a certain action is to end in both good and harm, removing the harm is the most preferred course of action. Physicians are therefore advices to never recommend or give their patients harmful treatments or materials.¹⁰⁶

The principle of justice is often viewed as being synonymous with fairness and can be summarized as the moral obligation to fairly when adjudicating between competing claims.¹⁰⁷ The right to justice is also one of the basic human rights that are described in Islam.¹⁰⁸ Justice can be divided into three key categories; distributive justice, right-based justice, and legal justice. According to the Holy Quran, prophets were raised for the purpose of establishing justice and enforcing it in all aspects of life. The Quran also encourages Muslims to stand firmly for God and to avoid being swayed by the hatred of others and depart from justice.¹⁰⁹ Overall, it is evident that the four principles of Bioethics are also present in Islamic teachings.

3.2.2. Value of Life in Islam

In Islam, life is considered sacred and among the greatest gifts from God.¹¹⁰ Thus, every moment of life has value and must be appreciated and protected. The Quran further emphasizes on the value of life by stipulating that saving life is an obligation and the unwarranted act of taking a life a crime. All forms of life are also extremely precious however, human life is placed above all others. To God, human life is extremely important to the extent that he develops it step-by-step as highlighted in the Quran. Life must also be appreciated and respected. Committing murder is not only considered a criminal act but is also considered to be an insult to human life in general. According to Islam, God is the only source of life and it is a gift, for which mankind is held responsible. Knowing the source of life is particularly important when answering one of the basic questions in bioethics, ‘who gives life and death?’¹¹¹

3.2.2.a. Life and Death in Islam

Death is considered to be an inevitable and irreversible experience. An individual’s set of beliefs and values significantly influences their attitude towards life and death.¹¹² Muslims believe that health is God’s gift to them and sickness comes in only through God’s will.¹¹³ Dying is usually a time to reflect and repent. It is also a time for one to get closer to God by immersing themselves in prayers and in reciting the Quran. Dying is also a time where the faithful seek forgiveness from others for past transgressions. At this stage, Muslims are encouraged to be steadfast when dealing with pain and suffering since perseverance will result in the expiation of sins and access to the afterlife. When illnesses occur, there are several expectations that are placed upon others to take care of the sick. Relatives and friends are encouraged to visit the sick individual to honor them, pray for their welfare, seek forgiveness, and offer support in whatever capacity they can.¹¹⁴

The Quran talks about God being the ultimate owner of everything. Therefore, based on this explanation, humans do not own their lives. Furthermore, the human body is considered to be a trust from God. Therefore, when one falls sick, they are obligated to seek appropriate care.¹¹⁵ However, this concept is not fully compatible with the concept of informed autonomy, where a terminally ill individual may refuse treatment, preferring to let death take its course. The Quran also states that God created death and life a way to test humans on how they live their earthly lives. Furthermore, the Quran states that God predestines the moment that everyone will die even before they are conceived in their mothers' wombs. Lastly, the Quran makes it clear that death is inevitable for everyone.¹¹⁶

Islam also teaches that life exists even after death. This is known as *Al Akhirah*. Furthermore, individuals believe that when they die, they will remain in their graves until *Yawm al-din*, or the Day of Judgment. On that day, Muslims believe that they will be raised from their grave and brought before Allah to be judged on how they lived their lives. This is referred to as the resurrection of the body.¹¹⁷ A Muslim's life is made up of trials and tests through which, their final destiny is determined. As such, Muslims believe that death is the act of the soul returning to its creator, God. With the inevitability of death etched in their consciousness, Muslims ensure that they keep their life in line with God's teachings as they also live in preparedness for the inevitable. The Holy Quran equates death to sleeping claiming that is complete with dreams and the period between death and resurrection is equated to a single night of sleep at the moment of one's death, they are able to know their destiny.¹¹⁸ Life, as the Holy Quran teaches, does not end with death.

3.2.2.b. Seeking Treatment and End of Life Care

Islam views disease as a natural phenomenon that is used to expiate sin. The patient who suffers in dignity stands to be rewarded in the hereafter. Furthermore, the family members who gave the patient support when they were sick will also be rewarded in the hereafter.¹¹⁹ Evidence also shows that Muslims believe that God is the one who controls health and illness and provides the cure. As such, ritual prayers and reading the Qur'an can improve the health of a believer and thus, utilized as the primary source of healing and as complementary medicine.¹²⁰ In addition to the Holy Qurans, there are hundreds of *Hadiths* or sayings of the Prophet Mohammed that encourage believers to forebear when they face calamity or diseases. However, they are encouraged to seek remedy for their ailments.¹²¹ Furthermore, Muslims are encouraged to seek new and modern forms of treatment when the old ones become ineffective. Whenever Prophet Mohammed (pbuh) fell sick, he would seek treatment for himself, and when his family and companions fell sick, he also encouraged and advised them on the appropriate remedy to use.¹²² Furthermore, Prophet Mohammed would state that Allah would never send a disease without sending a cure also.

Seeking remedy in certain situations may be considered mandatory or may be highly encouraged or preferred. In other situations, seeking remedy may be optional and might not be preferred or even may be considered to be Haram (not allowed).¹²³ As discussed earlier, it is expected that everyone should seek treatment to save their own life. However, if an individual is unconscious or if they are a minor, then there is no need to obtain consent before administering a remedy. On the other hand, treatment is encouraged only in cases where the remedy is likely to be successful and when the ailment is expected to hinder the duties of a Muslim to his family or even to the community. Seeking treatment is considered optional only when the benefit is proven

and when the remedy is expected to cause harm.¹²⁴ Muslims are also encouraged to abstain from seeking remedy when it is highly unlikely that the remedy will bring any benefits.

Islam strongly encourages believers to treat illness with both prayer and medicine. Religious scholars always insist that individuals use scientifically established medical procedures in combination with praying and asking God for assistance.¹²⁵ By doing so, Muslims avoid exclusively relying on prayer alone and refraining from taking vital medication. Furthermore, verses from the Quran can be used as a form of emotional healing. Muslims can also use verses from the Quran and prayers which are used to treat the sick to complement modern medicine. This practice is referred to as *ruqya*. While scientific medication should be taken first, *ruqya* is a form of treatment that could be used to reduce emotional stress. Lastly, while all might fail, individuals are always encouraged to draw from the healing powers of the Quran and seek God's assistance.¹²⁶ They should not rely on frauds who claim that they have the ability to heal.

From the point of view of Islam, the rules that govern the care of terminally ill patients are obtained from the principle that stipulates that injury and harm should be avoided at all costs. Death is viewed as the end of life in the current world and an effective transition to life after death. Illness is seen as a chance for one to get closer to God and a divine reward for those who endure hardship.¹²⁷ While artificial nutrition and hydration has been documented to have significant advantages for certain groups of individuals, the benefits of the treatment for patients at the final stages of a disease is not clear. Artificial nutrition and hydration have been shown on other occasions, to reduce quality of life. Additionally, they have been shown to cause harm to terminally ill patients since they bring about aspiration pneumonia among other infections. Furthermore, individuals who are terminally ill do not experience hunger or thirst and might not benefit from artificial nutrition and hydration. In addition, for patient's whose condition worsens,

artificial interventions such as artificial nutrition, may be withdrawn to allow for the patient's vital organs to stop functioning independently.¹²⁸

Dying in Islam is a time to reflect and to repent. It is also a time to seek forgiveness. However, with Muslims encountering incurable diseases, they are faced with the question of deciding on whether to seek pain relief found in modern medicine.¹²⁹ Palliative care interventions are essential especially for Muslims who are in their final stages of illness since euthanasia is prohibited in Islam. Moreover, palliative care is an approach that "is known to improve the quality of life of patients who are facing life-threatening illnesses."¹³⁰ Palliative care also identifies and assesses treatment of pain among other problems. The physician must therefore ensure that the patient is fully informed of their condition for them or their surrogate, to make informed decision on whether to receive palliative care in accordance with Islamic beliefs and teachings.

As discussed earlier, Muslims are compelled to get treated for any form of illness. Pain relief, involving taking opioids is permitted. In some instances, Muslim patients may wish to remain conscious in order to worship God as long as possible.¹³¹ Among the five duties of Islam, is *wudu*, or ceremonial cleansing. However, if a Muslim is not feeling well enough to perform *wudu*, there are several alternatives for this including; using a dry ablution kit. A DNR or "do-not-resuscitate" order is a modern medicine issue. As such, it not mentioned in the Quran, the Sunnah or Hadith. To provide guidance on this, Islamic scholars, through a fatwa, claim that if three respectable physicians agree that a patient's condition will not improve, life-supporting machinery can be switched off, and thus, implementing a DNR.¹³² However, removal of life-sustaining treatment is only allowed in specific situations such as when death is inevitable.

3.2.3. End of Life Issues

Due to recent advancements in biotechnology, genetic screening and life-support technologies, several bioethical issues have been raised. In the current healthcare setting, end of life issues are one of the main challenges the public is facing. Some of these issues include; euthanasia, physician-assisted suicide, withdrawal of treatment, DNR orders, and consent.¹³³ Decision-making especially in terminal care can be stressful for everyone. Issues such as euthanasia, while regulated widely, is still being performed across the world. Furthermore, for individuals nearing their death, continuing to feel pain may appear to be worse than death. The suffering can be so great that the patient may wish to end their life either through euthanasia or physician-assisted suicide.¹³⁴ In light of religious beliefs, mankind does not have a right to determine their own lives but has autonomy to do what they want to, with their health.

3.2.3.a. Contemporary Issues

Muslims across the world, oppose the use of euthanasia. For them, human life is sacred and is a gift from Allah. Only Allah determines how long an individual will live. However, doctors can stop trying to prolong life in certain where there is a little to no hope for a cure. This is further emphasized by the Islamic Medical Association of America (IMANA), which emphasizes that when death is an inevitable outcome, the patient should be allowed to die without additional and unnecessary procedures.¹³⁵

Physician-assisted suicide (PAS) and euthanasia from both the ethical and legal perspective is therefore not allowed even if it is done with the purpose of relieving pain and suffering.¹³⁶ According to the Islamic code of law, taking one's life is highly forbidden. Life is considered a gift from God and should be preserved. Besides, all Islamic doctrines view PAS and euthanasia as going against their teachings. However, if the individual is fatally ill, withholding

futile medical treatments is permissible. From a legal standpoint, Islamic countries have not legalized PAS and euthanasia.¹³⁷ Overall, there is absolute rejection of any act that deliberately terminates life. This is based on the belief that God is the only one who has power over life and death.

3.2.3.b Brain Death and Foregoing Treatment in Islam

Islamic scholars and other respected medical experts have relied on concepts borrowed from Islamic law to create ethico-legal opinions regarding brain death. For some juridical councils like “the Organization of Islamic Conferences’ Islamic Fiqh Academy, brain death is similar to cardiopulmonary death.” However, for other organizations like “the Islamic Organization of Medical Sciences (IOMS), brain death is the state that exists between life and death.”¹³⁸ Other councils also have different notions entirely while the ethico-legal assessments are also not in agreement especially in matters regarding the conceptualization of brain death. The conclusions that the aforementioned councils have an impact on Muslim clinicians and patients who struggle with brain death.¹³⁹ According to the Islamic Fiqh academy, brain death can be considered legal death only if all the vitalities of the brain stop working irreversibly and the brain starts to degenerate. Some proponents argue that brain death is death simply because it indicates departure of the soul from the body and it is the soul that animates the body. Others, on the other hand, believe that brain death cannot be considered to be death because the brain is separate from the soul. There needs to be renewed interdisciplinary investigations to explore Islamic beliefs regarding brain death.¹⁴⁰

The idea of brain death introduces several challenges to healthcare providers who are required to fill the gap that exists between religion, law, and medicine. The First World Meeting on Transplantation of Organs had representatives from the Muslim faith and representatives from

other religious denominations.¹⁴¹ During the meeting, ethicoreligious issues that focused on the definition of death were intricately discussed. The agreement on what cerebral death was an agreeable concept for physicians to focus on. In line with this, a definition of brain death was agreed upon. A person was to be considered dead if there was an irreversible cessation of brain functions such as brain stem. However, currently, the criteria used to determine brain death varies significantly.¹⁴² In Islam for example, the idea of brain death is still subject to great debate.

Medicine of the Prophet is made up of several divinely inspired therapeutic words by Prophet Muhammad (pbuh). The prophet made statements on 37 ailments and approximately 61 medical plants and shrubs while making prescriptions for the sick. Although the prophet did not arrive as a physician, he was inspired by Allah to make over 1000 statements on healing since man should remain well and should be free from any form of sickness to be able to fulfil their mission on earth.¹⁴³ Over the years, the traditions of the Prophet (pbuh) on healing have been proven through research to be true especially for *Nigella sativa* or black seed, which was a favorite of the Prophet.

3.2.4. Covid-19 Deaths in Islam and Judaism

According to statistics by UK's office for National Statistics, "Muslim males in England and Wales have the highest death rates from Covid-19 of all the religious groups."¹⁴⁴

Furthermore, the figures show that during the first months of the epidemic, Muslim male mortality was about 198.9 deaths for every 100,000 people while for females the rate was 98.2 deaths for every 100,000. On the centrally, individuals who viewed themselves as having no religion had the lowest death rate with approximately 80.7 deaths for every 100,000 males and

47.9 deaths for every 100,000 females.¹⁴⁵ On the other hand, the impact of coronavirus on the Jewish community involves significant contrasts. In Israel for example, COVID-19 deaths are in the thousands with over 10,000 individuals actively living with the virus. The country has also been hit with the second wave of the virus that has resulted in even higher deaths.¹⁴⁶ However, what is clear is that the Jewish rate of COVID-related deaths is significantly higher in the diaspora compared to the death rate in Israel.¹⁴⁷

Doctors and other healthcare providers are at the forefront in fighting COVID-19 and in so doing, they are endangering their lives. According to Jewish ethics, the obligation to care for the sick is found in both the Bible and in the Responsa teachings. Moreover, the Babylonian Talmud and the Bible all relate to the obligation that life must be saved.¹⁴⁸ However, the ethical dilemma arises when there is real risk to caregivers and their loved ones. Over the years, many rabbis have provided guidance on caregivers can provide care to infected individuals. In their recommendations, the rabbis warn against taking risks especially where there is insufficient protection or danger to the lives of medical professionals and their families. Ultimately, a balance must be struck between the duty to avoid danger and the obligation to take care of the sick.¹⁴⁹ The Islamic bioethical framework on the other hand, assigns all the moral authority to God. During a state of emergency such as the COVID-19 pandemic, the wellbeing of the community takes precedence over individual benefit. As such, any decision made must delicately create a balance between observing the wellbeing of individuals, and that of the community. For this reason, when there is a shortage of healthcare providers, as is currently the case due to COVID-19, healthcare providers that are well equipped to handle COVID-19 patients can take the first priority over others for the greater benefit of society.¹⁵⁰ Similar to Judaism, Islam bioethics stipulates that life should be protected, the life of healthcare providers and the life of

patients. However, as stipulated earlier, clear guidelines and fatwas should be set to guide healthcare providers during COVID-19.

According to Islam, when a loved one dies, close friends and family members are encouraged by the fact that the deceased is a martyr (shuhada). A question then arises, can COVID-19 deaths be classified as martyrdom? There are several categories of individuals who are ranked as martyrdoms in the hereafter. For someone to acquire the rank of martyrdom, there are several factors that must be achieved. For example, the individual must have undergone through a painful ailment, an acute illness, or a sudden tragedy. Based on this classification, then individuals who die from COVID-19 is not clear enough to say that they are martyrs, but they might be. This determination is also in line with the message of the Prophet (PBUH), that martyrdom is not only associated with a specific disease but rather with the sacrifice that humans endure for the sake of God.¹⁵¹

3.2.4.a Epidemics in Islam and Judaism

Since the first case of coronavirus was confirmed, the novel virus has spread to every corner of the world, and religions across the world have played a significant role in this spread. Mosques, Churches, indoor activities, and other religious congregations that defy health directives to combat the virus significantly endanger the lives of their members and their loved ones. Since collective worship has been identified as an effective mechanism for accelerating the spread of the virus, religion may then be viewed as being complicit in one of the most deadly global health crisis of the current generation. For many individual, the expression of faith is done through being close to each other in the form of hand holding, sharing of communion as seen in Christian churches, standing next to each other during prayer in Mosques and touching and kissing religious objects at synagogues.¹⁵²

The discussion on how to observe public distancing strategies (PDS) during the COVID-19 pandemic is already in place among Scholars. For example, “the international Islamic Fiqh Academy, which is affiliated to the Islamic Cooperation (OIC) recommends adhering to PDS including closure of mosques and suspending *Tarawih* and *Eid* prayers.”¹⁵³ Additionally, to further implement the recommendations of the OIC, educational institutions have been closed and pilgrimage cancelled. Able-bodied adult Muslims are also encouraged to fast during Ramadan in line with the recommendations of the Quran. However, when one is ill, they are discouraged from fasting. Moreover, all fatawas agree that illness is a valid reason why an individual should be exempted from fasting. When it comes to fasting during the COVID-19 pandemic, clinicians who are not strong or who are caring for their patients, may break their fast. However, they are encouraged to still adhere to the principles of atonement.¹⁵⁴

The Muslim Council of Britain also concurs with the recommendations of the OIC. They note that healthcare workers who are wearing personal protective equipment and are subjected to long shifts are at an elevated risk of being dehydrated, which could result in them making medical errors. For these healthcare workers, fasting is exempted.¹⁵⁵ In addition to exempting fasting for healthcare workers, The Muslim Council of Britain recommends organizing prayers at home during the holy month of Ramadan. Muslims may arrange virtual iftars with their loved ones. In North America on the other hand, the National Muslim Coalition Statement on Coronavirus Pandemic has encouraged all Muslims to practice self-quarantine and to social distance as stipulated by their public health authorities and local governments. The coalition has also advised Muslims to conduct Friday prayers in the homes.¹⁵⁶

Besides affecting the weekly Sabbath, several Jewish holidays have been affected. These holidays include; “the Purim, Passover, Shavout, Rosh Hoshanah, Yom Kuppur, Sukkot, and

Shemini Atzeret.” However, decisions on how the Jewish community observes COVID-19 stipulations are complex because decisions made different denominations differ. However, in this time of coronavirus, most denominations are leaning towards using technology on such holidays such as the Shabbat. The Committee on Jewish Laws and Standards together with the Rabbinical Assembly office have encouraged the ill to stay at home and self-quarantine. This is mainly based on the principle of Pikuach nefesh which translates to saving lives instead of observing the Sabbath. For individuals who wish to participate in the weekly minyan and to recite prayers including the mourner’s kiddish, may do so virtually either through audio and video with a minyan. This can be with members of their own congregation meeting preferably within their time zones. They can recite Kaddish, barkhu, or the kedushah while hearing Torah readings. Furthermore, congregational leadership should advice on how individuals can attend Shabbat or Yom Tov services.¹⁵⁷

Coronavirus infections among Israel’s ultra-orthodox Jews is disproportionately high compared to other denominations. Over 40% of residents in ultra-orthodox neighborhoods are infected. Furthermore, Synagogues in these neighborhoods act as sources of the increased spread of COVID-19 infections.¹⁵⁸ Since the coronavirus was declared a pandemic, the Middle East has seen a rapid rise in the number of confirmed positive cases. Although there is little to no coordination in some Middle-Eastern countries with regards to COVID-19 response, affected countries are doing their best to ensure that their citizens are safe. For example, many of the Gulf Cooperation Council’s countries are increasing testing measures.¹⁵⁹ Current evidence is of the view the spread of COVID-19 can be reduced significantly if religious leaders integrate prevention measures into their teachings. Lastly, countries should also prepare Standard Operating Procedures (SOPs) especially during times of infectious disease epidemics.¹⁶⁰

3.2.4.b. End of Life and Foregoing Treatment in both Islam and Judaism

Spiritual care plays a crucial role in holistic patient care. The awareness of a patient's beliefs for healthcare providers, should facilitate discussions about spirituality. Besides, all clinicians are more likely to encounter Muslim patients, yet a majority of them lack basic skills and information regarding the Muslim faith and how to apply the concepts in palliative care.¹⁶¹ Furthermore, a majority of the positive concepts in Jewish approaches regarding palliative care are also not fully understood. One of the most important bases of palliative care is the knowledge of how serious illnesses are treated. In Judaism, the Biblical commandment that requires individuals to return lost objects to their rightful owners acts as a source for physicians to heal their patients. If a doctor has the ability to return to a patient their lost health, then they must ensure that they do so. Furthermore, based on this scripture, doctors must return to a patient their lost quality of life and ultimately to a life that they enjoyed and one that was not full of suffering.¹⁶² In Islam on the other hand, suffering plays a crucial role in the life of a believer. Furthermore, sickness and suffering are considered to be part of life and a spiritual test from God. When one suffers from emotional and physical pain brought about by illness, they view it as a test of their faith. In sickness, Muslims are encouraged to be more thankful to Allah and take care of themselves and their health.¹⁶³

In Islam however, treatment to reduce pain during sickness is obligatory. Islamic teachings compel believers to seek treatment whenever they fall sick. Furthermore, pain relief using morphine is allowed with balancing of harms as this is crucial in Islamic jurisprudence.¹⁶⁴ Death is also inevitable in Islam and only occurs when God commands. Death should be accepted and should not be fought against. The promise of an afterlife consoled the dying and encourages them to take as they enter a new world of the divine. Since death can happen at any

time, Muslims are required to always be prepared for this inevitability. When their time comes, they should not delay death. In Judaism on the other hand, there are contradictory views especially when it comes to death. According to the Jewish faith, death is evil and life is a gift and an opportunity to serve the God. As such all Jews are required to do their best to preserve life. The Torah teaches that man can fulfill the commandments of God better than the angels.¹⁶⁵ Furthermore, in Judaism, death ensures that have an attitude of gratitude for their lives and the fact that time on earth is limited should motivate all to live their lives well.

A common theme in Jewish law is the view that all human life is important. Observing the Sabbath and other religious traditions may be violated to protect and save life. Furthermore, there is a widespread belief that the *halakha*, or Jewish law, stipulates that the life of a dying person should be extended at all costs. However, Jewish law stipulates that in the case of terminally ill patients who are in a lot of pain, life-extending measures should not be implemented.¹⁶⁶

One of the main concepts of palliative care is that it avoids treatments that increase suffering and add onto the amount of suffering without any hope of a cure. So, what do Islam and Judaism say about palliative care? The perspective of Jewish healthcare providers varies significantly based on the level of conservatism. For example, Jewish healthcare providers who are highly religious are less likely to remove life-sustaining treatment during terminal illness.¹⁶⁷ According to Orthodox Jewish law, the deceased must be rapidly buried and physicians expected to contact family members as fast as possible. Burial also occurs within the day unless the following day is a Sabbath. The Jewish Burial Committee should also be contacted immediately. Islam on the other hand, tries as much as possible to avoid conducting postmortem examinations that could distort or even deform the deceased.¹⁶⁸

COVID in Both Religions and Ethical Obligations

The practice of religious rites has had to change with the introduction of the COVID-19 pandemic. Gravesite gatherings, close up prayer sessions, consoling the bereaved, and other timeworn rituals have been cancelled or transformed for fear of the pandemic. However, with the creation of this vacuum so has tradition been transformed.¹⁶⁹ The Qur'an and prophetic hadiths have developed an effective approach for coping with crises. "This Islamic approach to manage crises is based on several steps including; crisis definition and cause determination, assessing manifestations, adopting methods to deal with the crisis, and lastly planning on how to solve the crisis. Overall, a wise approach to crisis management is to focus on the main goal."¹⁷⁰

In the age of the pandemic, medical triage decision-making has been greatly affected. Clinicians are facing shortages in life-saving ventilators among other resources. As such, they are forced to determine who urgently needs ventilators and who does not. When determining Jewish ethics with regards to resource allocation especially in a pandemic such as COVID-19, Orthodox Jews use the Talmud as a source of guidance.¹⁷¹ Normative Jewish law on the other hand, takes the utilitarian approach associated with Rabbi Akiva. When applying these two perspectives, the decision on who should receive treatment should be made based on medical suitability. Furthermore, the individual who has better possibility of getting treated should be taken care of first. However, "many physicians make their triage decisions by looking at the balance between the patient's condition and the reversibility of the disease."¹⁷² All the above-mentioned views are in line with a utilitarian approach to triage that is based on maximizing life-saving approaches. However, once a physician has initiated treatment using life-saving equipment, they should not remove the treatment and give it to another patient.

To prevent the transmission of the disease, a whole society approach should be adopted. During this time of uncertainty, religious leaders must turn to their religious texts and theology to find comfort for their communities and to encourage adoption of safe practices.¹⁷³ Furthermore, to slowdown the spread of the virus, religious leaders from Islam and Judaism have taken to media to conduct their daily prayer and worship sessions and to mobilize individual volunteers to take care of the less abled in society. Additionally, religious leaders have ensured that they engage in discussions that focus on personal well-being and the importance of adhering to safety guidelines as promoted by health organizations such as the WHO and governments.¹⁷⁴ For the Jews, religious texts such as the Talmud, encourage them to preserve human life above all else. Muslims, on the other hand, are encouraged to save lives since by doing so, they are saving the life of humanity. Muslim clerics are also supporting governments by creating fatwas that call for the cessation of religious gatherings and encourage adherence to already set preventive measures. All these teachings emphasize on the significance of taking action and following government-implemented measures and interventions such as social distancing to protect oneself and also to protect the community.¹⁷⁵

3.3. Conclusion

The human response regarding developments in birth is largely shaped by religious beliefs. The logic of *Humanae vitae* offers a religious vision of human sexuality and conjugal love. It has also played a critical role in catalyzing the field of natural family planning, also referred to as the fertility awareness-based methods (FABMs). However, in the other hand, is contraception moral? For the Catholic Church, the use of contraception taints the true meaning of sexual intimacy, to bear children. However, scientific evidence suggests that contraception

improves the overall health and wellbeing of women. Additionally, contraception allows families to space their births thus gaining financial security. A dilemma is therefore created in the case of a religious healthcare provider who has strong views against contraception. In such a situation, healthcare providers have an ethical responsibility to respect the patient's wishes and provide all the information needed to make an informed decision. There is great moral debate on the use of emergency contraception in the case of rape and more specifically when the rape involves a teenager. Some religious healthcare facilities do not offer contraception services. However, some of these institutions designate a unique room in the facility that caters to the needs of patients seeking contraception services. Sterilization is one of the most popular forms of contraception available. For some women, sterilization is a choice, however, for others, forceful sterilization is their reality. The ethics surrounding forceful sterilization especially for mentally challenged women and those with HIV has been debated for many years. According to situational ethics, ethical decisions should be flexible. There is no single solution to an ethical dilemma. As such, the answer to the question 'is contraception moral?' is highly dependent on the situation in which the question is being asked.

Currently, the world is facing one of the greatest disruptions in recent history. The novel COVID-19 pandemic has transformed how people live, interact, and even worship. Many religions are taking a stand and providing guidelines on how to interact with other believers and how to worship during this pandemic. Furthermore, major issues are arising that are transforming how both Muslims and Jews conduct religious rituals. The question of whether healthcare providers should risk their lives to save COVID-19 patients is also being hotly debated. Regardless, both the Qur'an for Muslims, and the Bible for Jews, put a lot of value in one's life and acknowledges that God is the giver of life and ultimately, the taker of life. As highlighted in

this section, Muslims across the world are disproportionately affected by the virus. Therefore, future studies should investigate this phenomenon and provide guidelines on how Muslims can prevent COVID-19 deaths moving forward. Additionally, more fatwas should be developed to guide healthcare providers on matters of palliative care especially for patients with COVID-19.

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CHAPTER 4. Disease Management

4.1. Surveillance and Outbreak Response

Infectious disease management is a serious issue highlighted by public health authorities. While public health authorities understand the principles of public health practice ethics, somehow, relevant individuals are not fully involved in the decision-making process.

The emergence of new infectious diseases or variants of old ones has created a set of new public health problems. Scientists often struggle to create a balance between prevention and treatment. Additionally, scientists often struggle in emergency situations on whether to ignore or override traditional ethical concerns. While treating common infectious diseases is relatively understood, treating emerging infectious diseases creates several ethical concerns. There is a lack of a readily available framework to discuss the ethical questions raised by the policies designed to deal with the diseases. In this section, the public health authorities' response to outbreaks, the ongoing surveillance in disease prevention and control, and individuals' freedom will be critically discussed with close attention (given to) on ethical challenges. Also, recommendations will be proposed on future work on how health workers and other caregivers may be effectively involved in the infectious disease management cycle.

4.1.1. Ethical challenges

Scientific research often involves humans. As such, researchers must be aware of the principles and ethical considerations associated with human participants.¹ An analysis carried out by Ayoub et al. on ethics associated with human research at two Jordanian universities sheds more light on the ethics of using human beings in research. The study assessed attitudes,

knowledge, and practices that research ethics committees (REC) use during the review process. The faculty members of the two universities reported not receiving any form of training on research ethics. However, the participants reported having a general knowledge of RECs duties and responsibilities. Being members of the REC, the faculty members should receive ethical training to avoid potential conflicts of interest.² The principles of public health research expect research participants to observe protocol when dealing with human research participants.

Public health officials are expected to demonstrate principled leadership to integrate ethics into practice. Often, public health officials face ethical tension and conflicts when making decisions and when managing their departments.³ Principled leadership requires a continuous approach to ethics that focuses on the relationship between officials and the community and the ethical aspects associated with public health activities. To achieve this, public health officials should gain education and competencies in ethics. To provide a structure and to facilitate decision making in health departments, applying practical ethics creates a focus on public health values and helps the organization align its activities with their mission statement. Additionally, setting performance measures integrates ethics and values throughout the organization.⁴ Overall, ethical frameworks help public health officials integrate ethics into their organization's activities.

4.1.1.a. Values and beliefs

The mandate to ensure public health is often a moral one. With it, healthcare providers are obligated to care for the health of the community. In recent years, several ethics governing the use of human beings as test subjects have been developed.⁵ In line with this objective, guidelines, and legislations that prioritize the rights of individuals over the rights of the community have been developed. The guidelines also provide stringent rules and protocols to guide voluntary participation and the provision of informed consent by adult participants.⁶ Public

health ethics involves the use of ethical theories and empirical analyses to justify interventions done to improve public health. In practice, all public health providers make decisions in their everyday life that have ethical implications.⁷ There are several ethical issues in public health policies, including; the way problems are handled in practice, analyzing the benefits, risks, and cost of intervening, guaranteeing that public health interventions result in positive outcomes, promoting or undermining human rights, and being transparent about public health interventions.⁸

Public health ethics guides healthcare providers on appropriate interventions to use in practice. Additionally, ethics provides guidance on the use of moral norms to guide behavior.⁹ Ethics also examines questions that guide individuals on how to live with others in society. Education in three key spheres of ethics is helpful in practice as it provides structures for health departments and community stakeholders to discuss public health concerns. The three spheres include; professional ethics, organizational ethics, and public policy ethics. Professional ethics highlights the professional relationship between officials and the community. Organizational ethics, on the other hand, focuses on the mission and values within an agency that encourages ethical behavior and practices. Public policy ethics offers deliberate frameworks and processes that guarantee public satisfaction. To frame deliberation with the community, healthcare providers should “analyze ethical issues in a situation, evaluate the ethical dimensions of any alternative course of action, and provide justification for a particular action.”¹⁰

4.1.1.b. Treatment and vaccination

Acute humanitarian crises have complex ethical dilemmas inherent in the response activities, including measures to control the spread of infectious diseases. In the emergency response, measures to control the spread of infectious diseases like vaccination should be

provided.¹¹ Before a vaccine is deployed to a community, several factors must be considered, including; disease burden, vaccine-related risks, the desirability of prevention, duration of vaccine effects, and cost of the vaccine Programme. With emergency vaccination, several ethical dilemmas arise. The need for ethical guidance on the administration of vaccines in emergency situations is paramount. At the core of ethical issues is the conflict between individual good and the common good. Additionally, issues including the allocation of limited vaccine supply, balancing both benefits and harms, and obtaining informed consent.¹² When conducting mass vaccinations during emergency situations, healthcare providers are obligated to uphold ethics.

Healthcare providers have a duty to uphold ethical principles during emergency vaccinations. According to the principle of beneficence, healthcare providers must prepare vaccines against the most infectious diseases. Additionally, care providers and institutions must follow the rules of rescue, which requires them to rescue individuals who are facing imminent death.¹³ Governments and other organizations are expected to maintain a continuous supply of vaccines against infectious diseases that have serious outcomes. Decisions made during vaccine administration must strike a balance between doing good (beneficence) and nonmaleficence or avoiding harm. Vaccines that have been proven to be effective and safe should be considered for mass administration. Not only do these vaccines protect people against diseases, but they also reduce disease transmission.¹⁴ Since vaccines have several side effects, they should be administered when the threat of pathogens is detected. Therefore, variables to determine the risk magnitude of vaccines should be set. Distributive justice requires the fair distribution of resources and vaccines in short supply.¹⁵ When vaccine supply is limited, it should be equitably distributed while also prioritizing susceptible groups and people who are most likely to spread the infection. Procedural justice, on the other hand, requires healthcare providers to be

transparent in their decision-making process and to involve communities affected by their decisions.¹⁶ To ensure that procedural justice is upheld, guidelines and legal frameworks must be put in place. Obtaining consent from individuals before any medical intervention is administered, is stipulated by the principle of respect for autonomy. Vaccination should be voluntary unless it becomes paramount to prevent serious harm to the population.¹⁷

A major concern in modern-day medicine centers on the issue of administering vaccines and medications. Young et al. carried out a cross-sectional survey on “the use of the human papillomavirus vaccine” and its administration by “gynecologists and family practitioners”. The results of the survey show that gynecologists are administering HPV vaccination at rates similar rate to family practitioners.¹⁸ The development of antimicrobials illustrates a classic problem in ethics. Conflict arises between public interest and private interest of people's entities. In the United States, the conflict between public interest and private interest is even greater. This is mainly due to the fact that antimicrobials are produced by private entities like pharmaceuticals and biotechnology companies.¹⁹ Additionally, for the public, antimicrobials might reduce mortality and morbidity brought about by pathogens like MRSA. Overall, vaccines, antimicrobials, and other forms of medication are required to control infectious diseases.

4.1.2. Public health ethics

Public health ethics is pivoted on designing and implementing measures to measure and improve the health of entire populations. Additionally, public health ethics goes beyond health care to analyze the structural conditions that either promote or inhibit the creation of healthy societies.²⁰ It combines the field of practical ethics and public health.²¹ Based on scientific evidence, public health ethics guides the policies, standards, and values of what is right and what

is wrong. Public health ethics is a systemic process that clarifies, prioritizes, and justifies possible courses of action that are based on values and ethical principles.²² Public health has undergone through several changes and faces new ethical challenges. Public health ethics frameworks have been developed. All the frameworks have several common assumptions and beliefs with the aim of preventing harm and promoting health.²³ Additionally, the frameworks are designed to observe respect for individual autonomy.²⁴ Public health practices and policies protect the population against harm and improve overall public health benefits. Likewise, public health practices are evidence-based, are just and fair, respect everyone, maintain privacy, confidentiality, encourage community empowerment, and maintain transparency.²⁵ The themes mentioned above and norms act as ethical guides towards the development of effective public health policies.

Public health ethics can be further analyzed under two broad sub-sections; necessity vs. individuals' freedom and infectious disease control.

4.1.2.a. Necessity vs. individual's freedom

The main role of public health is to provide appropriate conditions needed to promote and protect human health. To provide these conditions, efforts must be directed towards assuring access to high quality care and improving the health of the population.²⁶ In today's society, improving public health is increasingly more important than ever. Establishing public health ethics mainly lies on sustaining liberal frameworks.²⁷ Society continually faces the threat of emerging infectious diseases and decreasing vaccination rates. With many arguing that liberal approaches are congenial to bioethics, liberalism often lacks processes and tools that tackle intricate issues associated with public health ethics.²⁸ The question then arises on who should be responsible for the health of the community. To address this, liberalism should be designed to go

beyond addressing standard constraints like respect for individual choices and allowing freedom of choice.²⁹ The dilemma then arises on who should guarantee liberalism. Central in this dilemma is how to balance respect for the government's role in providing health-related services to its people and observing individual freedom.

An individual's decisions about their health might be interfered with on several occasions. The act of interfering with another person's autonomy without their intention with the goal of improving health is referred to as paternalism.³⁰ When the state interferes with an individual's health, it is known as narrow paternalism. Broad paternalism, on the other hand, is not concerned with who is interfering with an individual's health. Under broad paternalism, the state or an organization can perform the coercion. Moral paternalism aims to promote the moral wellbeing of individuals.³¹ When an individual's actions are harmful, it is permissible to intervene. This is known as hard paternalism.³² Public health problems are considerably reduced when an individual's quality of life and life expectancy is maintained.

Public health ethics provides a basis to justify moral actions. Ethics and more specifically, civic ethics, is a philosophical reflection that allows citizens of different morals to coexist peacefully.³³ Bioethics is used to advice health sciences and other disciplines and to regulate their activities. Bioethics is linked to morally plural societies, democratic settings, organizations that work closely with qualified professionals and knowledge societies where public opinion is valued.³⁴ According to the principles of bioethics, problems, the ones affected, and their interests all play a role in deciding on the action to be taken.³⁵ Bioethics recognizes human rights and acknowledges that they are shared moral convictions and they should be upheld.

4.1.2.b. Infectious disease control and the role of healthcare authorities in managing infectious disease

The present capacity to develop and effectively distribute medical countermeasures like vaccines does not meet the burden of infectious disease outbreaks. To slow down the spread of infectious diseases, the combined efforts of clinical research and public health interventions are required. Additionally, machine learning and disease modeling play an important role in the decision-making process.³⁶ Forecasting is, therefore, important, especially when dealing with infectious disease outbreaks. Forecasting, as an analytical tool, informs policies and manages decisions to improve outbreak outcomes. During the Ebola virus disease outbreak of 2014, real-time forecasts of the disease highlighted several challenges in the design of clinical trials. The results of the forecasting were used to inform decisions by trial officials to design better trials.³⁷ During the forecasting process, there are key steps; data analytics and communication. In the data stage, information is collected, cleaned, stored, and shared. During the analytic process, training and forecasting take place. Lastly, the communication stage requires decision-makers to visualize potential control measures to prepare for reoccurring disease outbreaks.³⁸ The three steps in the forecasting workflow are used to generate infectious disease forecasting results used to manage disease outbreaks. By using the forecasting workflow, decision-makers are better positioned to plan for effective responses when a disease outbreak takes place.

The largest Ebola virus disease outbreak, since it was first described, was the 2014-2016 outbreak in West Africa. A majority of those affected by the virus, include healthcare workers who were infected while taking care of Ebola patients. Similar to the severe acute respiratory syndrome (SARS) outbreak in Toronto, healthcare workers were largely affected by the Ebola outbreak.³⁹ The unpredictable nature of the Ebola virus contributes to its rapid spread. Fearing

for their safety, healthcare workers have raised concerns about the right procedure to follow to guarantee appropriate clinical management of patients with Ebola. While ethical frameworks have been put in place, including the use of personal protective equipment, isolation, and administering of fluids and electrolytes, great uncertainty still surrounds ethical considerations of care. In line with this, however, looking back in history when Ebola outbreaks occurred and when researchers critically discuss issues related to it, this will create endless debate and arguments. Thus, two ethical questions are raised; is it ethically appropriate for healthcare workers to decline providing care to patients suffering from Ebola? How should treatment decisions be made regarding the care offered to patients with Ebola?

Should healthcare workers decline to provide care to patients with Ebola? Official reports from the World Health Organization (WHO) indicate an up to 90% fatality rate in patients with Ebola in the past outbreaks.⁴⁰ Therefore, more aggressive measures must be implemented to control Ebola. However, the devastating effects of the infection and lack of effective treatment approaches further proof that aggressive measures are not the best way forward.⁴¹ A majority of healthcare workers, including nurses, intensive care personnel, and laboratory technologists, are the most vulnerable to Ebola infection. This is a high level of risk for all healthcare workers involved. Ethical considerations state that healthcare workers have an obligation to treat patients and provide treatment options that are the most beneficial to their patients. Thus, healthcare workers must decide whether the codes of conduct and duty of care that they abide by applies to scenarios that put their personal health at risk.

How should health care workers make treatment decisions for patients with Ebola? With increasing the seriousness of diseases, come more invasive therapies to treat the infections. Treating patients with Ebola often involves an aerosol-generating procedure that puts healthcare

workers in harm's way. Ethically, caregivers have obligations to their patients to provide therapeutic options that have maximum results for the patients.⁴² However, with such an aggressive disease like Ebola, and with more aggressive interventions, healthcare workers are left with an ethical dilemma of whether these aggressive interventions are the best option for their patients.

The devastation that was seen during the Ebola virus disease outbreak in West Africa has introduced several ethical concerns on how health officials should respond to disease outbreaks. A bulk of the ethical issues is related to disease prevention and control, the role of healthcare workers in controlling the infection, clinical care, and the design of the research.⁴³ Some of the West African countries affected by the Ebola virus struggled to maintain ethics during the treatment process. Coupled with several challenges, including; increased cases of Ebola virus infection, poor standards of care for patients with Ebola in health facilities, high cases of fatalities, and healthcare facilities turning away people who sort treatment in their facilities. A majority of individuals affected were forced to self-care at home.

In addition to the challenges above, ethical debates on quarantine in affected regions also emerged. Quarantine is used to contain new infections in the case of an infectious disease outbreak. In line with this objective, quarantine conditions should be of quality to achieve the intended purpose. However, the quarantine conditions in the areas affected by Ebola were poor.⁴⁴ Quarantine of entire communities is ethically justified more accurately if the quarantine covers the whole area that individuals quarantined travel within. This allows for better distribution of medication as resources are directed towards a targeted population. In West Africa, the spatial quarantine process for the Ebola virus was not in line with the principle of least infringement that controls interventions and interactions in restricted areas.⁴⁵ Additionally, the increased tension

between applying quarantine as a public health measure and maintaining individual rights, including the right to privacy, should be recognized and a balance between the two struck.

Quarantine is effective against infectious disease outbreaks. Infectious diseases pose a threat to the population's wellbeing and when simple measures to prevent the spread of these diseases fail, other strategies, including quarantine, should be administered. Since the spread of infectious diseases is well known, population-based strategies, including contact tracing and isolation, are the best strategies to use.⁴⁶ However, on its own, it might be ineffective. Thus, it should be used in conjunction with other strategies. During quarantine, two clear ethical challenges emerge; whether quarantine is ethically viable and whether it is effective.

Additionally, a clear distinction should be made between isolation and quarantine. There are two main goals set during a quarantine activity. The first goal is to stop the chain of transmission and the second goal is to allow individuals who are under surveillance to be identified and given appropriate care immediately they start showing symptoms of the infection.⁴⁷ Quarantine is justified when diseases can be spread from person to person and is ineffective when the diseases are non-infectious. Likewise, least-restrictive means should be applied when conducting quarantine. Reciprocity should also be upheld and transparency maintained. Therefore, Public health authorities have a duty and a responsibility to communicate to the public about quarantine activities to allow for any appeals to be made.

4.1.3. Surveillance and outbreak response

Disease surveillance is the process of collecting, analyzing, and interpreting large volumes of data obtained from a variety of sources. Information obtained is then used to, evaluate how effective the control and preventive health measures are, monitor any change in

infectious agents, support the allocation of resources within the healthcare system, identify areas that need interventions, and to provide an activity that can be used for future reference.⁴⁸ Risk assessment is, therefore, an essential aspect of any infectious disease surveillance program. Detection of outbreaks increases situational awareness and initiates outbreak management. With the emergence of outbreaks, including Ebola, the necessity for the development of an infectious disease surveillance system is high. In line with this objective, the International Health Regulations (IHR) was created to encourage the surveillance of infectious diseases. The IHR strives to improve early warning systems, specifically for the World Health Organization member states. IHR focal points enable timely communication between countries and the WHO. Additionally, the focal points are used to notify WHO on events that are considered a public health emergency.⁴⁹ An effective infectious disease surveillance system across countries requires corporation between all member states.

4.1.3.a. Ethical review of surveillance activities

Public health surveillance is, sometimes, done without informing patients and asking for patient consent. Public health surveillance is different from other forms of surveillance. Since the main duty and responsibility of public health is to prevent and control the spread of disease or injury, surveillance is a major tool used in public health.⁵⁰ Public health surveillance is used to quantify the rate at which health problems are affecting the public, to describe the natural history of diseases, to detect outbreaks, to demonstrate and document the distribution of health events, to monitor isolation and to change the infectious agent. Public health surveillance involves seven systematic activities carried out in three steps. The steps include; developing systems, collecting data and analyzing collected data, and lastly, using the data collected to provide continuous feedback used for system improvement. Public health surveillance systems differ according to

their main purpose, conditions being monitored and the intended use of the data collected. While some systems employ the use of non-name-based reporting tools, others use names and other personal identifiers in their reports.⁵¹ The question of whether public health surveillance systems should use names or other identifying information is an ethical one.

Public health surveillance is a legal requirement and is dependent on healthcare providers who report on healthcare conditions affecting the community. The reports are a legal requirement and the patient's consent or knowledge is not required.⁵² Thus, public health surveillance is justified scientifically. In some systems like those for HIV, healthcare providers and laboratories are supposed to report all cases of new HIV incidence cases. When more than one event is reported, recording this data is necessary and crucial to maintaining a copy database that could be used within and across states. The data collected is then used to link patients to health actions. Such action could involve the enrollment of patients with HIV or other infections into treatment programs or partner notification services. Aside from public health surveillance being legal, there are additional ethical justifications.

The ethical justification for carrying out public health surveillance without the patient's consent has several challenges, more specifically, principles of public health ethics. On one side, healthcare providers are expected to observe the ethical principle of respect for patient's autonomy and avoid disseminating their health information without their consent. On the other hand, it is the responsibility of healthcare officials to use the data to improve the health and wellbeing of the population. With the HIV/AIDS pandemic, questions have been raised on whether public health surveillance violates individual privacy and whether the violation of privacy is justified ethically.⁵³ The debate is strife on whether surveillance systems should use name-based identifiers or non-name-based identifiers. After the non-name-based systems failed

to meet the performance standards, name-based systems were eventually adopted. HIV/AIDS surveillance further highlights the conflict that exists between bioethics and public health ethics.

Biomedical ethics mainly operates on “the principles of autonomy, nonmaleficence, beneficence, and justice”, while public health ethics focuses on the population and the community's wellbeing rather than a single patient. The four main approaches are widely integrated into hospital ethics committees across the world.⁵⁴ Healthcare providers must therefore identify relevant principles and weigh them against the concerns of cases justifying their clinical decisions and recommendations. Public health ethics has two main approaches; an outline of main principles and justificatory conditions or filters to be used when ethical challenges arise. According to public health ethics, healthcare providers have a social duty and an obligation to address suffering, equity, and proportionality. On the basis of public health ethics, principles have been outlined that serve as ways to operationalize foundational values into a practitioner's decision-making process.⁵⁵ Based on the reasons mentioned above, when public health surveillance practices refrain from negatively affecting operating ethical principles, these practices can be considered ethically permissible.

4.1.3.b. Research during outbreak

The Ebola Virus Disease outbreak in Western Africa and the efforts to control it highlighted several ethical challenges for healthcare providers. According to a study carried out on Nigeria, the weak health systems used to control Ebola and the limitations of the ethical obligation for healthcare workers to provide care to patients with Ebola played a critical role in the disease progression.⁵⁶ Healthcare workers have a right to protect themselves against infectious diseases.⁵⁷ The government should also work tirelessly to guarantee that healthcare workers are protected. In the case where the government cannot offer protection, healthcare

professionals are only morally obligated to provide care and are not professionally obligated. To effectively control the spread of infections, institutionalized policies that protect healthcare providers should be developed.⁵⁸

Infectious disease outbreaks expose vulnerabilities that exist in healthcare systems and in other structures of governance. When an outbreak occurs, healthcare professions are the most affected. Demands are placed on their skills and expertise and their personal commitment to their patients and their jobs are tested.⁵⁹ During these infections, many healthcare providers are exposed to serious risks, with some even dying. In the aftermath of the Ebola virus outbreak in West Africa and the SARS outbreak, the obligations of healthcare professionals to their patients must be reconsidered. Thus, organizations that represent healthcare professionals should give a clear indication of the standards of care and what is expected of healthcare professionals.⁶⁰ There is an urgent need to clarify the rights of caregivers in the case of infectious disease outbreaks and these rights must be clearly represented in professional codes of conduct. Despite these risks and challenges, codes of ethics that govern professionalism are silent on issues related to duty of care.

The knowledge of infectious diseases, the creation of vaccines, and the discovery of antibiotics are among the greatest achievements of the twentieth century. Due to these achievements, mortality rates associated with re-emerging infections have been reduced.⁶¹ Among the major outbreaks in recent times is the Ebola epidemic that hit West Africa. The scale and magnitude of suffering witnessed had a considerable impact on the way emergency responses were framed. As a result of the epidemic, scientists conducted several trials to find drugs and vaccines to control Ebola Virus. However, the drugs researched did not produce any positive results since they were not effective against Ebola Virus Disease.⁶² The trials showed

that internationally set standards could be met during highly infectious disease outbreaks.

However, the studies and trials conducted during disease outbreaks have several issues under discussion.

There is a high concern about the social value of carrying out research during an outbreak that has high rates of mortality and morbidity. Additionally, the concerns question the justification for carrying out randomized placebo-controlled trials (RCTs), how resources are going to prioritize, the use of unapproved therapies and balancing of research, and the researchers' responsibility to ensure public health.⁶³ The researchers of the Ebola outbreak in West Africa also noted that the weak healthcare systems, lack of adequate resources, and the presence of civil wars and political violence played a critical role in the epidemic response and the clinical trial design. During an infectious disease outbreak, many participants are not motivated by altruism, as might be seen in other studies. Due to the scare of highly infectious diseases, many participants choose to be part of research studies to seek health-related resources.⁶⁴ Likewise, for individuals who volunteer to participate in studies during infectious disease outbreaks, assume that the State will protect them at all times. Research carried out during disease outbreaks focuses more on providing immediate responses to patient care and controlling the outbreaks.

An effective and efficient response to disease outbreaks requires adequate research capacities. Maintaining ethical principles and values, as stipulated by international research ethics guidelines is crucial during infectious disease outbreaks. Additionally, researchers and public health workers should carefully balance resources allocated to emergency treatment activities with approaches that rely on research as an outbreak response mechanism. In line with this objective, research ethics preparedness should be an important aspect of any response to the

disease outbreaks program.⁶⁵ The use of effective surveillance mechanisms is essential for controlling and preventing diseases. Traditional methods that highlight individuals with infectious diseases provide researchers with the necessary information that allows for appropriate public health research to be conducted. Big data-based electronic surveillance that uses mobile or internet-based sources has also been used widely by researchers. Similar digital sources also have information on syndromes that can be analyzed using customized algorithms, to help in the rapid prediction of infectious disease outbreaks.⁶⁶ However, due to the misleading nature of the data, public health authorities are encouraged to use the online sources in combination with patient's personal health records to have a more accurate understanding of infectious disease events. The main goal of public health is to eliminate health disparities that exist in segments of the population.⁶⁷ Despite the apparent urgency to eliminate health disparities, strategies and practices that would eliminate these health disparities are lacking.

4.1.4. Future work: policies and plans

Digital epidemiology or “digital disease detection (DDD)” provides methods and strategies “for using information technology in infectious disease monitoring and surveillance. Due to the availability of internet access, digital devices and a variety of online sharing platforms, DDD has acquired a lot of traction.” Often times, these technologies are collecting data to be used in public health. Social networks, instant messaging, and discussion groups are being used as valuable sources to pass public health alerts to the public.⁶⁸ Additionally, studies have proved that awareness of diseases passed through these technological devices influence people's behavior and reduce the spread of disease outbreaks. However, with the development of any new technology, there are increased functional and formal challenges. Some of the technical

challenges include the urgent need for technologies, hardware, and appliances that can process large volumes of data to identify important pieces in data. Some of the functional challenges include the need for the development of user interfaces and personalization techniques that filter information to avoid overwhelming users with too much information. The quality and reliability of the information, payment options, and ethical issues are some of the formal problems affecting DDDs.⁶⁹ With the development of digital platforms, several issues associated with ethics in public health arise.

Digital epidemiology or digital disease detection (DDD) uses emerging electronic data sources introduced with the advent of information technology. Reports show that emerging outbreaks have been detected by digital surveillance platforms even before official reports have been filled. Furthermore, information obtained by the datasets is used for purposes other than the early detection of disease outbreaks. Some of the additional purposes include; pharmacovigilance and assessments on health behaviors and attitudes.⁷⁰ With the increased use of DDD, there are several ethical challenges involved. Public health surveillance and research are governed by legislation and guidelines. However, the guidelines were developed under historical conditions and technologies that have since been superseded. These mechanisms may not be effective against ethical challenges introduced by DDD. Three key challenges are affecting DDD; “context-sensitivity, nexus of ethics and methodology, and legitimacy.”⁷¹ At the center of the controversy surrounding big data is the question of how big data can be utilized to improve health while also maintaining individual liberties and rights.

Additionally, when is it acceptable for individual rights to be violated for the common good of the community? The scientific methodology involves the use of algorithms and filtering systems to separate noisy data, to manage biases, and to select appropriate data streams. Some

skeptics claim that DDD has little to no effect on public health practices in their early stages of development.⁷² As an ethical issue, methodological robustness could result in the wastage of resources, especially if defective results are created. Legitimacy concerns of DDD highlight on whether DDD is ethically justified.

The ethical issue of human security and the role governments and private institutions play in safeguarding human security. International health regulations focus on disease detection and response and how quickly information about outbreaks can spread to create awareness for all individuals affected. Current ethical oversight mechanisms are not well equipped to address DDD and all the activities associated with it.⁷³ Therefore, more needs to be done to address ethical issues associated with digital disease detection.

4.1.4.a. Involving individuals in surveillance and outbreak activities: the future of public health surveillance and technologies

Public health surveillance is referred to “as an ongoing systematic collection” of health data, analysis of the data collected, and its interpretation. Additionally, surveillance involves close integration with the distribution of the data to anyone who is responsible for diseases prevention and control and injuries.⁷⁴ Public health Surveillance as a tool is used to estimate the health of populations. Ministry of health and finance in low income-earning countries are increasingly recognizing that data obtained from public health surveillance is useful for allocating resources and evaluating ongoing programs. For infections such as HIV and “severe acute respiratory syndrome (SARS)” epidemics, there was limited surveillance carried out to protect the countries affected. After understanding the benefits of public health surveillance, China began expanding its surveillance capabilities by creating a Field Epidemiology Training Program.⁷⁵ Likewise, countries like Brazil and Argentina have acquired loans from the World

Bank to boost their surveillance capacity. “The U.S Agency for International Development (USAID)” has developed a surveillance strategy to focus more on using data to improve interventions.⁷⁶ When implemented correctly, public health surveillance can be used to control and prevent the spread of diseases and infections effectively.

The future of public health surveillance cannot be completely predicted. Initially, public health surveillance focused on infectious diseases. Later on, public health surveillance was broadened to include chronic diseases like cancer and diabetes. In the 80s and 90s, public health surveillance broadened its horizons to include occupational health, environmental health, hazard surveillance, injury control, and infectious disease management. It is expected that future public health surveillance will include new infections and diseases like mental illnesses. Accounting for a large proportion of disability burden on a majority of the world's population, mental health measures are currently being included in scientific surveys. However, there are challenges that exist in the way different surveys define mental illness. For freeman and other researchers, future public health surveillance programs should include measures of positive psychological functions to act as protective factors against poor health outcomes.⁷⁷ Currently, surveillance techniques focus on disease symptoms. However, future surveillance programs will collect data on protective factors, coping skills, and resilience. This data will be used to diversify strategies used in disease prevention and control. Just like current strategies, future public health surveillance strategies will focus on the overall health of the population.

Computer technologies will continue to improve future public health surveillance strategies. Computer technologies have evolved in recent years and are expected to continue evolving in the future. From the National Electronic Telecommunications Systems for Surveillance developed in 1991 to link all state health departments in the United States to the

implementation of the National Electronic Disease Surveillance System (NEDSS) by the CDC, computers play an intricate role in public health surveillance.⁷⁸ The United States has developed integrated public health surveillance systems in line with the NEDSS vision. In the future, NEDSS will be fully implemented across all the states in the United States. As a result, public health agencies will be able to quickly recognize disease outbreaks and respond to them in real-time. France has developed the Minitel system, which is an office-based surveillance option for a variety of health-related conditions.⁷⁹ Computer technologies can be used in collaboration with other public health actions to improve public health surveillance.

Public health research involves the evaluation of population-based data collected by local or federal governments. However, with recent concerns about patient privacy and confidentiality, many researchers are prevented from accessing patients' data. These restrictions have a negative impact on public health surveillance activities.⁸⁰ Public health surveillance, "the continuous collection, analysis, and dissemination of data to provide information used to ensure the health of populations."⁸¹ Critical to public health surveillance is the identification of a target population and an adequate sampling strategy to represent the data effectively. Additionally, patient information should be collected using appropriate information-gathering tools like patient interviews or clinical records reviews. In all the cases, it is paramount that ethical principles are applied during the data collection step. Participants' privacy should be maintained throughout the data collection process.⁸² After data is collected, it should be stored in a secure database under proper data management processes. Data should be periodically evaluated to guarantee accuracy and maintain consistency using data management strategies. Data integrity should be protected at all times, from natural and environmental threats. Analysis of the data should link disease

outcomes and risk factors.⁸³ Overall maximum benefits can be obtained from public health surveillance strategies that guarantee confidentiality and integrity in collected data.

4.1.4.b. Health workers training

Healthcare delivery has become more complicated in recent years as patients expect healthcare workers to be professional and accountable in their practice. It is, therefore, imperative that healthcare providers should be aware of their duties and responsibilities to their patients. This level of professionalism is dependent on the depth of knowledge and the how medical ethics are applied in practice.⁸⁴ Education of healthcare workers about the nature of medicolegal matters is crucial in improving the quality of care they offer to patients. Ethics is crucial in clinical practice. However, some educational facilities may not allocate enough time to teaching ethical principles and medicolegal issues.⁸⁵

One way of supporting healthcare providers to deal with ethical challenges is through the development of “clinical ethics support (CES)”. CES is a method used to provide advice and support to healthcare workers on ethical matters arising during clinical practice.⁸⁶ CES has become increasingly acceptable, especially due to worldwide awareness of the significance of ethics in practice. CES operates with the goal of supporting institutions, healthcare workers, patients, and their next of kin.⁸⁷ The approaches are often divided into top-down and bottom-up approaches. Under the top-down approach, ethical experts have influential advisory roles as primary ethical decision-makers, giving advice and recommendations. A majority of those supporting CES claim that ethical issues in practice are too complex to be controlled and managed by healthcare workers alone.⁸⁸ Thus, caregivers facing ethical issues require experts to help them navigate these complex ethical challenges. Bottom-up approaches, on the other hand, healthcare workers are encouraged to take experiences from their everyday practice and use them

to inform decisions.⁸⁹ An ethicist is tasked with the responsibility of facilitating discussions with personnel that focus on ethical considerations. According to the bottom-up strategy, ethical issues must be critically reflected upon by healthcare personnel themselves. This is because healthcare personnel are morally responsible for the outcomes of their decisions.⁹⁰ All healthcare providers should be familiar with the ethical principles that govern their practice; thus, they stay aware of their duties and responsibilities to their patients.

Ethics education provides a critical foundation for highlighting ethical problems that arise in practice. A majority of the questions often revolve around concerns on upholding truth, informed consent, and protecting the patient's rights and their families.⁹¹ To solve some of these questions, task shifting has been employed, among other interventions. In institutions that practice task shifting, production costs have been greatly reduced, and quality of care improved.⁹² With the urgent need for healthcare providers to maintain ethics, there is a more urgent need to include ethics in public health education in schools.⁹³ Additionally, ethical education should be included in competencies associated with professionals in the public health sector.

4.2. Genomic Surveillance

With increasing progress in nucleic acid sequencing technology, genomic surveillance is used in epidemiological investigation of infection sources, transmission, and determinants of antimicrobial resistance.⁹⁴ Genome sequencing in combination with epidemiological investigation provides precision and accuracy in determining transmission pathways, revealing sources of epidemic infections, and drug resistance.⁹⁵ In the recent past, numerous viral and pathogenic agents have emerged resulting in outbreaks and pandemics with high morbidity and

mortality rates, COVID-19 for example. This section will provide an overview on genomic surveillance and its importance and benefits . The section will also explain how the information obtained from genome sequencing with sample metadata greatly improves the efficacy of genomic analysis techniques. This research section will also discuss how public health is able to more precisely implement individual and population-based interventions that ultimately improve the health of populations using such surveillance.

On the other hand, genomic surveillance has significantly impacted public health microbiology by enabling outbreak identification, prediction of antibiotic resistance, and timely diagnosis. Despite the importance of Whole genome sequencing in public health, its implementation is affected by more complex human factors that are beyond clinical and laboratory practices.⁹⁶ As such, it is critical to examine other challenges related to this technology, for the sector to fully realize the benefits. Issues like government regulations and privacy concerns prove that public health is not a mere scientific move, but also an endeavor that is based on social justice and ethical considerations. However, considering the different ways that genetic data is handled, coupled with the diverse interest, it is increasingly challenging to develop widely accepted principles that govern genetic privacy.⁹⁷ The current genetic privacy landscape will be examined to identify the role that laws play in public health by focusing on federal regulations and statutes like “the Genetic Information Nondiscrimination Act (GINA)” and “Health Insurance Portability and Accountability Act” (HIPAA).

4.2.1. Genomic surveillance and genome analysis

Genomic surveillance is increasingly being used for the analysis and control of pathogens mainly due to its increased accuracy, decreased costs, and faster turnaround time.⁹⁸ In addition,

genomic surveillance conducts high throughput sequencing of genomes resulting in the accumulation of whole genome sequences (WGS). The WGS obtained provide data for epidemiological surveillance of viruses and bacteria.⁹⁹ Genome analysis has the potential to transform clinical and public health management of pathogens and other infectious diseases.

Whole genome sequencing (WGS) is increasingly being used to detect genes linked to clinically relevant bacterial pathogens and to group isolates into clonal groups or detect clone-specific markers.¹⁰⁰ In the laboratory, genome sequencing is used to accomplish tasks that are performed by polymerase chain reaction (PCR) or by restriction enzyme and electrophoresis.¹⁰¹ In addition to being effective, whole genome sequencing can be applied simultaneously to large samples of bacterial isolates without the need for target-specific reagents. Likewise, WGS data is readily sharable and easily comparable to data sets from the past and the future.¹⁰² One of the areas that genomic surveillance has been applied is in cancer screening. In his analysis, Klein, in collaboration with Genomic Health Inc. successfully developed a strategy for the molecular profiling of breast and colon cancers.¹⁰³ According to the results, sampling the expression of genes found in multiple biological families allows for the prediction of outcomes used inform clinical decision making.¹⁰⁴ Ingle and colleagues analyzed “genotypes and antimicrobial resistance (AMR) determinants” obtained from “whole genome sequencing of *S. Typhi*” to determine resistant strains and movement of each strain from one geographical area to the next.¹⁰⁵ Through whole genome sequencing, routine data for travel associated cases can be obtained from industrialized countries and used as informal sentinel AMR genomic surveillance data for countries, where whole genomic sequencing is not routinely performed.¹⁰⁶

4.2.1.a. History and background

Public health has evolved over the years to include advancements in genomics. The field of public health emerged as a way of protecting the health of individuals and communities to minimize morbidity and mortality.¹⁰⁷ In recent years, the field of public health genomics has undergone through rapid developments. The developments have enhanced knowledge on how human genes interact with the environment and with each other. “The Human Genome Project completed in 2003” led to the proliferation of knowledge about the human genome and a reduction in the estimated number of genes in the human genome.¹⁰⁸ Additionally, genomics has improved scientific knowledge on disease etiology, prevention, and treatment. Increased knowledge about diseases provides critical insight into how diseases develop and thus inform effective treatment and prevention interventions. Genomic knowledge is used to offer new ways of differentiating sub-groups within groups of people and re-inventing the core principles of public health. Building upon the work of public health genomics completed 20 years earlier, precision public health integrates genomics into public health strategies.¹⁰⁹

Whole genome sequencing has significantly transformed the field of public health microbiology. Whole genome sequencing is used for the rapid diagnosis of infections, outbreak identification, and the prediction of antibiotic resistance.¹¹⁰ In the past, clinicians were hesitant to adopt whole genome sequencing in outbreak analysis due to its expense and cumbersome nature. However, with recent “improvements in sequencing technologies and analysis tools”, increased outputs, improved speed, and reduced overall cost, whole genome sequencing is increasingly being used.¹¹¹ Often, during infections by “antimicrobial resistant strains”, “genotypic tests” are used to detect antimicrobial resistance genes. However, genotypic tests require additional phylogenetic information to improve outbreak analysis. To overcome these challenges, “novel

technologies” that provide a higher genomic resolution and “entire bacterial genetic information” are required.¹¹² Whole genome sequencing has gone through several changes to ensure that it overcomes the aforementioned challenges. Currently, there is an overwhelming body of evidence showing that whole genome sequencing is fast and affordable and provides higher resolution compared to other conventional methods.

Modern forms of government are constantly seeking ways of using knowledge about their citizens to improve security. DNA profiling has been adopted by governments and law enforcement agencies for the identification and differentiation of individuals. Between 1900 and 1980, the acceptable mode of identifying individuals was based on blood groups. Subsequently, the identification of polymorphic markers based on enzymes and serum proteins transformed the identification process.¹¹³ In the early 1980s, molecular biologists began using DNA sequences to confirm or disconfirm the involvement of individuals in crime. DNA profiling allows scientists to analyze forensic samples from crime relevant objects containing DNA. Further technological advances have resulted in the adoption of DNA profiling in criminal jurisdictions. As a result, there has been a rapid worldwide introduction of DNA databases used by crime investigators to facilitate the identification of unknown individuals.

The current therapeutic tools used to control viral infections is limited and often has poor efficacy and thus is inadequate to face the challenge of emerging drug resistant strains. One of the main shortcomings of direct-acting drugs is resistance.¹¹⁴ To eliminate this limitation, antiviral drug discovery is exploring the possibility of developing host-oriented molecules that will act on cellular functions that allow viruses to replicate.¹¹⁵ Since the 1980s, associated methodologies have been adapted to several studies. Among the most frequently used technologies is Yeast to-hybrid (Y2H) and co-affinity purification. To facilitate these

technologies, high-throughput screening is conducted to provide a comprehensive landscape of viral human protein targets. Overall, by obtaining a bigger picture and developing a more effective treatment plan, treatment of drug-resistant infections is easily managed.

4.2.1.b. Genetic surveillance; its importance and benefits

Malaria parasite continues to kill thousands of people annually primarily in sub-Saharan Africa. Due to their large populations, Malaria parasites in Africa are more genetically diverse than other parts of the world. As such, useful metrics and monitoring techniques are essential to monitor antimalarial interventions. Genetic surveillance has been proven to be effective in monitoring the effectiveness of interventions against Malaria. Additionally, genetic surveillance acts as “a real-time gauge of the control, elimination, and eradication processes”.¹¹⁶ The use of genetic surveillance in determining the impact of interventions to control malaria has several implications. Firstly, it improves the understanding of the parasite’s biology and other emerging variants. Secondly, it permits the identification of novel loci found in clinically relevant phenotypes including drug resistant phenotypes. In addition to analyzing the parasite, genomic surveillance can be used to analyze vectors to inform tools to “monitor and evaluate interventions” against them.¹¹⁷

Whole genome sequencing is an essential tool for the surveillance of infectious diseases drug resistance. Molecular typing methods include; “pulsed-field gel electrophoresis, multilocus variable number tandem repeat analysis (MLVA) and gene sequencing.”¹¹⁸ The results obtained from the typing methods are then used for surveillance and disease control of drug-resistant pathogens.¹¹⁹ The effectiveness of interventions designed to control diseases is often limited by “the lower resolution of molecular typing methods.” Next generation sequencing (NGS), on the other hand, “has higher accuracy for tracing and identifying sources” of infections, “has high

reproducibility” and throughput and it is timely.¹²⁰ Additionally, technological advancements have transformed whole genome sequencing to become more efficient and cost-competitive. Despite these advantages, implementing NGS is costly, lacks expertise and much needed epidemiological investigation methods.¹²¹ *Klebsiella pneumoniae* is considered as one of the most crucial antimicrobial resistant pathogens that require new control strategies. Some of the strategies include; “rapid identification and containment of high-risk AMR clones, augmentation with vaccines, bacteriophages, and immunotherapies” that focus on surface antigens. However, due to its high diversity, *K. pneumoniae* hinders the use of the control strategies and the ability for scientists to study its molecular epidemiology.¹²²

Antimicrobial resistance

“Antimicrobial resistance” poses a major threat to the global public health and has both economic and social consequences. Among the most worrisome group of resistant bacteria is Carbapenemase-producing Enterobacteriaceae due to its reduced sensitivity to antibiotics and its ability to accumulate resistance factors that limit the effectiveness of therapeutic options.¹²³ The complete analysis of genome sequences has great power to answer scientific questions. Therefore, the continual adoption of WGS as a routine technique in clinical laboratories greatly affects epidemiological surveillance. Likewise, efforts to standardize laboratory procedures are necessary to facilitate interlaboratory exchange of genomic data.¹²⁴

Recent advancements in new and affordable “DNA sequencing techniques” have revolutionized the field of microbial surveillance. A major advancement that has enabled resistance surveillance is its ability to predict AMR using genomic data.¹²⁵ According to studies on foodborne pathogens, there is a high concordance between the presence of mutations and minimum inhibitory concentration found in several strains of antimicrobials.¹²⁶ Additional

evidence shows that it is possible to predict microbial resistance by applying machine learning to genome sequence data. One of the most obvious advantages of WGS for microbial typing is the attention to detail and how every level of detail in one essay can be used to inform current trends. There are several tools and databases used for antimicrobial resistance (AMR) detection. These tools play an intricate role in the real-time detection of AMR determinants which are essential in the overall identification, control, and prevention of infectious diseases.¹²⁷

Overall, whole-genome sequencing of pathogens provides an unbridged examination of the genetic content of pathogen isolates allowing laboratories and other public health institutions to benefit from analysis of the entire genetic content. Combining the information obtained from genome sequencing with sample metadata such as mortality and morbidity greatly improves the efficacy of genomic analysis techniques. By incorporating genomics into public health, public health is able to more precisely implement individual and population-based interventions that ultimately improve the health of populations.¹²⁸

4.2.2. Technology for genomic surveillance

General health information and genetic data privacy majorly involve two factors, the ability to control sharing and distribution of data and the assurance that people need to get on privacy to ensure they do not withhold critical details that could be risky. As will be discussed, an individual's phenotype is more pertinent to privacy; however, the law's protections are more illusory. For instance, in case of a public health emergency in infectious disease, genetic privacy would not be guaranteed, and patient data will be shared to assist in developing vaccines and containing the spread of such conditions.¹²⁹ Regulations like HIPAA privacy rules have various

exceptions that permit access to individual health data hence indicating the challenging aspect of privacy protection.

4.2.2.a. Technology and data

Often, people tend to hold on to genetic information as highly private since each genome is unique and different. But, in each individual's genome, there are specific variations that are either shared with biological relatives or other people in the population, hence making this private information significant to the public. Further, with the increasing need to understand the cause of diseases and health promotion techniques, sharing personal data has been identified as necessary in enabling low-risk research.¹³⁰ At the same time, privacy in the health sector is increasingly becoming crucial with the traditional view of secrecy, getting a more advanced meaning in the modern information age. Through the advanced communication technologies, it is possible to share personal details even without one's consent, and with the increase in genetic information and studying in the recent past, so is the growing concern for privacy. The advances in technology have enabled effective and accurate examination of one's DNA, thus contributing to the development of genome-based approaches like genome-based sequencing, which provides more detailed information.¹³¹ However, adopting such technologies has a significant impact on people's privacy since genomic data can be examined for different genetic variants that are beyond the original testing reasons.

In other instances, private genetic information may be analyzed and used in other contexts that are not health-related, such as direct-to-consumer (DTC) testing, clinical genetics, and forensics. Genetic information is identified as a critical tool in other specialties like behavioral health, pediatrics, obstetrics, oncology, and neurology.¹³² However, as more genetic information is accessed, stored, and used in these fields, it is possible for privacy breaches to

occur hence making it impossible to guarantee patients maximum confidentiality. In a healthcare setting, the use and disclosure of patient information leads to issues concerning if consent is needed, the limits on information sharing according to laws and government regulations, and the allowed group of researchers who can access private information.¹³³

Genomic data is generally distributed across different public and private frameworks. Genetic privacy is breached through the introduction of trait or identity attacks that occur by aggregating data like GWAS statistics, metadata, DNA sequences, and genotypes. Therefore, various techniques like ethics education, controlled access, cryptography solutions, differential privacy, and laws and regulations have been proposed to enhance the protection of private information.¹³⁴ Noncompliance with the terms of data usage and transfer agreements results in a privacy breach, and such scenarios cause generic problems of data sharing. However, when it comes to genetic privacy protection, there are other cases where the set privacy techniques are not applicable. For instance, with methods like DE identification, organizations such as hospitals and research consortia are able to publish sensitive information as well as genomic.¹³⁵ An example is the 1000 Genomes Project (1000GP), which allows the public to access and download DNA sequences and other genetic variations of anonymous participants like gender information, geographical locations, and demographic populations.¹³⁶ DE identified genomic data is said to have additional metadata that is crucial such as the criteria for inclusion and exclusion, basic demographics, health conditions, and the pedigree structure. However, such pieces of data can also be manipulated, exploited, and used to trace unknown genomes.¹³⁷

4.2.2.b. The “trust-but-verify approach”

Another technique for ensuring genetic privacy is controlled access, which only allows specific users to download data after being approved and under specific conditions. An

alternative for the access-control model is the trust-but-verify approach whereby users are not allowed to download any form of data but can execute queries based on their privileges, and the system records and audits from such queries.¹³⁸ Through such monitoring, it is possible to detect adverse events early and prevent malicious users. Access control can also be attained by ensuring that it is only the original participants who are allowed to grant data access rather than delegating such duties to the access committee. Through such participant-based accessibility, researcher-participant communication is mediated without necessarily revealing the participant's identity.¹³⁹ However, privacy protection using controlled access majorly focuses on data control and requires extensive processes of auditing, paperwork and data verification.

Differential privacy preservation technique is also used to ensure data privacy in public health. It involves a processing queries output to ensure that there no statistical differences to the results in case an individual is included or excluded from a data set. Through differential privacy, it is not possible for an adversary to possess auxiliary information, hence providing a guarantee against arbitrary attacks.¹⁴⁰ The technique mainly focuses on comparing the risks that one is exposed to if they are included in a given database; this differs from the traditional privacy-preserving models like *k-anonymity*, and *l-diversity* which only provide a comparison on adversary's prior and posterior views of an individual.¹⁴¹ Various studies have been conducted to expound on the importance of differential strategy in the protection of data; however, regarding genetic privacy, the technique is still at the early stages. One major challenge is the large scale of human genomic data that may make it challenging to identify privacy protection techniques that are fast and efficient to balance utility and privacy in genomic research.¹⁴²

The cryptographic solution is another form of maintaining genomic privacy; the technique allows third party access to genetic information without disclosure of critical details to

service providers.¹⁴³ Through Cryptographic works such as homomorphic encryption, secure genetic interpretation is guaranteed since the genomes sent by users are in an encrypted version.¹⁴⁴ Due to the special properties that the homomorphic cryptosystem has, the user is in a position to decrypt interpretation service results to come up with the analytical results. Through the process, users are able to withhold sensitive information or genotypes to service providers and interpretation companies. Secure multiparty computation is also another technique and it enables entities with private genetic data to compute private inputs without disclosing to third parties. It was initially developed to identify genetic relatives using cryptographic constructs to maintain privacy.¹⁴⁵

4.2.3. Privacy regulations

The use and disclosure of genetic information in healthcare raises more issues such as the type of information that can be disclosed as per the laws, whether consent is required, and the individuals who are authorized to access such information. In most cases, people believe they would be discriminated against if their health information is shared beyond the healthcare setting or disclosed; contrary to this, the aim of health organizations is protecting their dignity, autonomy, and privacy.¹⁴⁶ Although such concerns might appear to be indirect, people are still concerned with being discriminated against due to their health conditions, and such concerns have a significant impact on the patient's health outcome. The desire to maintain secrecy may also limit a patient's willingness to disclose sensitive information hence risking their health.¹⁴⁷ Therefore, besides providing ethics education to health providers, the government has also enforced laws and regulations to ensure patient privacy is maintained.¹⁴⁸

4.2.3.a. Data access and distribution

Technological advances have improved the public health sector, but such improvements are accompanied by controversies and more concerns regarding ethics and regulations on the protection and preservation of genetic privacy. Such laws and regulations play a significant role in clinical practice and research on personal genomics, although in most cases, they have lagged behind. However, recent research indicates that the protection of genomic anonymity is becoming more challenging since researchers tend to combine patient data in genealogy databases with other data from social media posts.¹⁴⁹ As such, it is necessary to develop measures where learners, medical practitioners, and researchers are trained on the available genetic privacy protection resources, as well as the existing laws and regulations.¹⁵⁰ However, it is important to note the regular modifications to these regulations since the anecdotes related to genomic data sharing lead to changes in data access and distribution. For example, during Homer's attack, the National Institute of Health was encouraged to use the dbGaP and move phenotype and genotype data to controlled access from the public domain. Further, studies were conducted using the 1000GP and individual information like triangulate age, surnames, and geographical location was also moved to a controlled access from the public domain.¹⁵¹ As a result, this promoted the publishing of various articles by the leaders of the 1000GP consortium to review ethical considerations in such studies.

In genomics, the legal paradigm places significant value on privacy, and this may conflict with the public health framework where the benefits for others are more important than individual rights. Currently, genetic privacy legislation has been enacted in all states, but each state provides a different scope of protection.¹⁵² Various Acts and laws have been put forward to govern and limit disclosure of genetic information. For instance, the Model State Emergency

Power Act was proposed to enumerate state and local officials' powers to protect patient safety in case there is a public health emergency and provide mandatory vaccination if necessary.¹⁵³

According to the provisions of this Act, host genomic factors are critical in determining various issues like; high-risk individuals who should be vaccinated in case of an outbreak, those who might have adverse effects from the vaccination, and individuals who need quarantine due to the increased risk to themselves or others.¹⁵⁴ In such circumstances, it is possible that state emergency powers would override privacy protection on genetic information, and under current laws, privacy provisions will only prevail a disease outbreak does not affect public health emergency levels. Similar to the model power Act is the Genetic Information Nondiscrimination Act (GINA).¹⁵⁵

4.2.3.b. The Genetic Information Nondiscrimination Act (GINA) and HIPAA

GINA was lined into law in 2008 to address undocumented discrimination due to health information disclosure. According to section 2(5) of GINA, its purpose is ensuring public protection from potential discrimination by enabling them to take advantage of research, technologies, and genetic testing.¹⁵⁶ GINA's legislations also have provisions that prohibit discrimination by preventing employers from accessing, purchasing, or requesting an employee's genetic information or that of the relatives. The law also expounds on HIPAA privacy rule by defining genetic information as health information that is subject to important limitations.¹⁵⁷ In some instances, one might be suited to work in a high-risk job during an outbreak because they are likely to respond positively to the vaccination, or their genotype has a lower risk of being infected. On the contrary, an individual might also increase the risk of severe infection. In both cases, GINA provisions limit the use of potential employees' genetic information in case of disease outbreak to determine their position for high-risk job placement.¹⁵⁸

Healthcare disclosures are mostly covered entities under the privacy rule for HIPAA; initially, the 1996 enactment HIPAA made it an insurance statute to enable employee transfer from different employers and still maintain their health coverage benefits for the employees or their dependents. HIPAA privacy rule was later established to address factors on using and disclosing protected health information by providing cover to organizations that are subject to privacy rules, while at the same time giving standards for individuals to be in control of their medical information. The privacy rule covered entities include data clearinghouses, health providers, business partners, and insurers; as such, HIPAA does not cover any health data that does not originate from these entities.¹⁵⁹ Genetic screening and new commercial sequencing companies may possess identifiable data and sensitive health information, but all that is not covered under HIPAA. Further, the use and disclosure of de-identified information are not protected, and metadata such as geographical region, race, and age can be accessed by the public hence posing risks to genetic privacy.¹⁶⁰ Therefore, there have been more suggestions on the need to revise HIPAA regulations and ensure recent technological advances are properly encoded.¹⁶¹ Also, consent forms from Human Genetics Society should be revised (since they form the main source of genomic data collection) and redevelop them in a way that reflects genomic research advances, potential risks on genetic privacy, and provides interaction between individual feedback and research findings.¹⁶²

General health information and genetic data privacy majorly involve two factors – the ability to control sharing and distribution of data and the assurance that people need to get on privacy to ensure they do not withhold critical details that could be risky. As discussed, an individual's phenotype is more pertinent to privacy; however, the law's protections are more illusory. For instance, in case of a public health emergency in infectious disease, genetic privacy

would not be guaranteed, and patient data will be shared to assist in developing vaccines and containing the spread of such conditions. Regulations like HIPAA privacy rules have various exceptions that permit access to individual health data hence indicating the challenging aspect of privacy protection.

4.2.4. Ethical considerations in genomic surveillance and infectious diseases

Infectious diseases are regarded as one of the major causes of deaths since pathogens rapidly spread hence making it challenging to contain. Traditional methods that have been applied in the past to assess infections include, “pulsed-field gel electrophoresis (PFGE), multilocus sequence typing (MLST), and antibody-based testing.”¹⁶³ However, in the recent past, infection control practices have evolved and significantly improved to identify diseases early and prevent the spread of infections. With the adoption of genomic surveillance in controlling infections, public health providers are able to understand pathogen evolution, antibiotic resistance, and host-pathogen interaction.¹⁶⁴ As such, the professionals have changed how they research, monitor, and prevent high-profile infections like Ebola, tuberculosis, and influenza. Further, with techniques like molecular epidemiology, it is possible to genotype pathogens hence enhancing the ability to detect outbreaks and important factors in transmission.¹⁶⁵

4.2.4.a. Detection and prevention

Genomic surveillance applies various infection detection techniques that differentiate and isolate pathogens for comparison purposes; laboratory techniques in genotyping range from identifying a single nucleotide variant (SNV), to analyzing genome fragments length. Such techniques include DNA or RNA fragments separation through electrophoretic, Polymerase chain reaction (PCR), hybridization, and DNA sequencing. Such methods are used to support

epidemiological investigations that identify the potential epidemiological relationship between two isolates; this enables health researchers to confirm the clusters involved in case of an infectious disease outbreak.¹⁶⁶ Although genetic and epidemiological cluster identification of related cases is sufficient to identify prevention measures for future outbreak occurrences, critical details like delineation of individual transmissions, the pathogenic potential of the etiologic agent and phylogenetic origins are necessary to identify better intervention measures. Therefore, in the recent past, genomic surveillance has become widely accepted and used in outbreak investigation.¹⁶⁷ With the improved technology in sequencing, bioinformatics algorithm standardization, and continuous optimization, it is possible for nations to apply genomic surveillance even during an ongoing outbreak and get reliable details to use in infection control interventions.

In genomics, Next-generation sequencing (NGS) makes it possible sequence pathogen genomes in a timely manner. One of the most successful NGS applications is the use of WGS to manage the outbreak of infections. The technique does not only confirm the disease outbreak but also allows researchers to identify the most effective interventions that target a particular infection. With limited conventional genotyping techniques, determining transmission dynamics or discerning clusters is always challenging; for instance, if isolates have indistinguishable patterns, it is not possible to determine whether or not isolated cases are sporadic.¹⁶⁸ However, applying genomic sequencing on the isolates provides nucleotide data to differentiate such cases, as well as giving higher-resolution hence ensuring that outbreak characterizes are addressed through genomic analysis. Further, with genomic epidemiology, transmission chains have been analyzed in addressing infections like pneumonia and other hospital-acquired infections.¹⁶⁹ Therefore, during an outbreak, sequencing and epidemiological evidence are used to track

transmission chains between environmental sources or patients. Besides, genome analysis gives an outbreak hypothesis (whether related or unrelated) in instances where epidemiological linkages are non-existent.¹⁷⁰

Although genomic data does not guarantee infection control in all infections, integrating sequence data in outbreak investigations provides more clarity that guides other responses in health promotion like shutting down a ward or drafting new policies to prevent future outbreaks. For instance, in the UK, after the outbreak of salmonella enteritidis, genetically unrelated and epidemiologically unlinked isolates could be associated with community isolates, hence suggesting an unknown source of salmonella transmission.¹⁷¹ In such a case, if there was no routine salmonella sequencing community, salmonella would not have been identified. Through a routine sequence of health-associated pathogens, researchers are able to lay the foundation for identifying new pathogens by studying epidemiology changes and quickly attributing clones. At the individual patient level, infection control measures tend to be similar, but with genomic analyses, institutions are able to formulate high-level policies. High-resolution genomic sequencing also enables critical epidemiological observations. For instance, in hospital-associated MRSA, genomic sequencing was applied to prove the role of hospitals in transmitting the infection to the community.¹⁷² As a result, there are more implications in areas where patients with low socio-economic status and high community-associated MRSA, especially in the admission screening criteria.

Despite the effectiveness attained by genomic surveillance techniques, the organism's diversity in a single host also limits tracking the transmission dynamics. According to various studies, conducting a sequence on multiple colonies for an organism from one person indicates the people tend to have various unrelated species, for instance, the diverse MRSA sequences.¹⁷³

In a single nucleotide variant, diversity has been seen in MRSA and *K pneumoniae*; the findings indicate that reconstructing the transmission chain from an isolated colony may be insufficient for epidemiologically unlinked patients.¹⁷⁴ Pathogen diversity does not just affect infected patients; rather, asymptomatic carriers have also been identified to harbor potentially diverse pathogens.¹⁷⁵ Further, high-throughput sequencing gives more insights on healthcare-associated pathogens and the epidemiology.

Although genome sequencing proves to be significant in the provision of the outbreak investigation, its full implementation in health facilities would only be done after overcoming its barriers. First, the technical factors require molecular laboratories to have access or possess computational infrastructure, upgraded software for storage and analysis of large datasets, and the necessary sequencing equipment. The continuous improvement of sequencing technology and the development of computational strategies will be significant in addressing the challenges.¹⁷⁶ Another challenge is the need for highly trained staff that can translate epidemiological data and bioinformatics to ensure real-life infection control. This is necessary since genomic information needs to be interpreted in a way that infection control and prevention professionals can understand.¹⁷⁷ Considering such hurdles, the implementation, and maintenance costs of genomic programs and required genomic techniques, it can only be used in facilities with better resources.

4.2.4.b. Ethical considerations and future work

There are incidences when health care practitioners are needed to break confidentiality, particularly in cases where others will be harmed if privacy is maintained. For example, if the patient refuses to share the information about genetic risk, the physician may share with the family members to avoid risks of harm. However, information on the genetic risk should be

disclosed to allow the family to avoid the risk in the future.¹⁷⁸ Thus, confidentiality and privacy are unique to genome sequencing and have guidelines that are appropriate within the genetics field.

With the adoption of genomic surveillance in controlling infections, public health providers are able to understand pathogen evolution, antibiotic resistance, and host-pathogen interaction.¹⁷⁹ The issues highlighted in this section are unique to Genome surveillance and the ethical concerns and its future implication with infectious disease.¹⁸⁰

According to a literature review that was conducted by “the Canadian Agency for Drugs and Technologies in Health (CADTH)” in collaboration with the Health Quality Ontario, there are five key ethical principles to Genome Sequencing. They include, “the duty to create benefits and minimize harms for patients, families, and others; the duty to respect individual autonomy and personhood; the duty to maintain confidentiality; the duty to promote fairness and justice; and, finally, the duty to respond to vulnerable populations.”¹⁸¹

Beneficence and Maleficence;

The principle of beneficence and maleficence are at the core of bioethics and health ethics, including the principle of justice and autonomy. They are considered the duty of healthcare providers to patients, family members, and society. The effect of technology is essential in the context of genomics because the human genome is part of the genetic information and substantially overlaps with the DNA of related family members or relatives.¹⁸² The duty to reduce harm and create benefit is applicable in medical care and research. However, in research, the duty of justice and autonomy is complex because research is not primarily aimed to benefit the research scientists.¹⁸³

Duty to benefit and reduce harm to the patient;

Genome sequencing for individuals with multiple congenital anomalies and unexplained developmental disabilities is a promising process that will provide benefits. Its use yields more informed prognosis such as medical management and active therapy that can improve patient's health. Genome sequencing provides medical management that includes a series of clinical visits and tests that the patient endures when determining the cause of anomalies and delays.¹⁸⁴ The diagnosis relieves stress for the patient and the facility by determining that particular genetic anomalies are unlikely. Testing during clinical visits can be replaced by ongoing monitoring that replaces a patient's burden and stress.¹⁸⁵

Genome sequencing reduces harm to patients by preventing or reducing ineffective treatments that may have adverse side effects or exacerbate symptoms. For example, in neonatal context, a diagnosis may shift the ongoing treatment towards comfort-oriented or palliative measures. However, Genome sequencing may expose patients to harm. Studies have shown that “patients with disabilities are sometimes taken to be candidates for particular medical intervention, such as in the case of organ transplanting.”¹⁸⁶ Genetic sequencing can yield a genetic variant that shows that the patient may develop a particular disease in the future.¹⁸⁷ As a result, the patient may be placed under painful and invasive medical procedures that may not yield any advantages. Besides, genetic sequencing may result in psychological and emotional stress for patients with sufficient cognitive capacity when its expectations are not met. It is also possible that genome sequencing may lead to discrimination by employers and insurers. Some organizations require genetic information as a condition for services or employment. Therefore, there is a potential that genetic sequencing can create harm to patients regardless of their duties to protect them.

Duty to benefit and reduce harm to the family;

Genome surveillance always requires the patient's family to be tested because they can reveal traits that could be found in biological relatives. Genetic information obtained through genome sequencing can assist the family in planning their future based on reproductive decisions. Diagnosis may relieve stress, especially for parents who do not know the reason for their children's anomalies. Diagnosis marks the end of a diagnostic odyssey that alleviates the guilt that may be experienced by parents, particularly for mothers who may blame themselves for making their children disable.¹⁸⁸ Thus, diagnosis yields social benefits to parents and lead to emotional and social support in caring for the patient within the family.

Genome surveillance raises questions of psychological harm on caregivers and relatives. Diagnosis may relieve genetic variants that may show the potential of developing certain diseases in the future. Healthcare providers should inform the family about the risks involved so that they may know the familial genetic risk. Genome surveillance can also lead to psychosocial harm to the family, such as unrealistic expectations and stress. If genome sequencing reveals that a child is vulnerable, parents may be stressed.¹⁸⁹ This may lead to threats of integrity within the family. Given those concerns, there is a potential that genome sequencing creates and prevents harm for family members. The duty to protect the family depends on how the technology is implemented and utilized.

Informed Consent;

Similar to other medical tests, genome sequencing requires seeking informed consent to guarantee that the decision is made in an uncorked and informed manner. The patient may decide not to proceed with the tests. It also means that the decision can be made by the patient or surrogate decision-maker who understands the discomforts, benefits, and risks involved in the test or intervention.¹⁹⁰ Providing informed consent should unfold through several conversations

between the patient and the healthcare provider to ensure the patient understands the authority within the decisions and the nature of decisions they are making. Genome sequencing may be different for different patients. Some may want to be informed about its significance, while others may require understanding variants of uncertain significance (VUS).¹⁹¹ It is estimated that the informed consent for genome surveillance can take about eight hours of genetic counselor time. The implementation of informed consent procedures also requires the surrogate decision-maker to determine how confidentiality and privacy would be managed.¹⁹² However, it is the patients to decide how they want to share the results of the diagnosis. Patients with unexplained anomalies can make decisions for themselves either because they have limited cognition.¹⁹³ Thus, the consent process during genome sequencing can take more time because of the complexity involved. The respect of autonomy needs robust informed consent led by skillful professionals.

Duty to protect the confidentiality;

The duty to protect the confidentiality of the patient is essential because it reduces stressors on how their patient's personal information is used and shared. Privacy is relevant in genomics because data is obtained through genetic testing that can reveal an individual's DNA and those related to the person. Physicians have a duty and responsibility to protect the privacy of patients and their families. The ethical concern regarding genome surveillance deals with how DNA should be managed and who should access the data.¹⁹⁴ The concerns include access to other institutions, other healthcare providers, and the patient's family members. However, sometimes, data may be shared if the patient may benefit from the information, but these are exceptional circumstances that need specific criteria. In addition, there are instances when the information may be shared with the family members.¹⁹⁵ For example, if the information would

protect the patient and prevent them from harm, then physicians may find themselves in a dilemma whether to share with the family members or not.

4.3. Conclusion

The chapter has critically discussed public health authorities' responses to outbreaks. The recent Ebola Virus outbreak in West Africa has been analyzed and the healthcare worker's views about ethical principles and when it is appropriate to protect oneself from harm have been reviewed. The chapter has also highlighted the ongoing surveillance strategies in disease prevention and control and issues associated with individual freedoms versus public good. While ethical challenges exist in infectious disease management, health workers are expected to observe ethical principles and maintain patients' safety. The future holds several opportunities for infectious disease management practices. Big Data technologies and computers are being used to store public health data. Overall, healthcare providers are bound by local, state, and international ethical principles and codes of conduct that guide decision-making in infectious disease management.

Human genomics and genetics have, in the recent past, received more focus as an active source of data used in explaining human health and disease prevention. With genomic surveillance, disease detection has been possible as well as a timely response to infections, despite the effectiveness of this technology; various factors limit the use of genomics with patient privacy gaining more attention. As discussed, people tend to view genetic information as highly private since each genome is unique and different. But, in each individual's genome, there are specific variations that are either shared with biological relatives or other people in the population, hence making this private information significant to the public. Various regulations,

like HIPAA and GINA, have been enacted to ensure patient privacy protection. Nonetheless, the use of genome surveillance requires more technology advances in health institutions and ethical considerations for full implementation.

Endnotes

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CHAPTER 5. Research Protocols

5.1. HIV Research in Developing Nations

Ethical standards that govern human research are clearly set in both “international and national” codes of ethics. Ethical standards are designed to protect everyone, especially the most vulnerable human subjects in society. The debate about the ethics of clinical HIV/AIDS research conducted in developing countries has been raging for a long time. Many researchers who are not permitted to conduct research in developed countries prefer conducting them in developing countries. Developing countries provide easy access to patients, less strict regulations, and reduced costs of operation. As a result, a double standard is created for medical research that is both humanly and ethically unacceptable and more specifically, when other options do exist. To avoid abusing the least able in developing countries, researchers must have an ethical responsibility to observe ethical standards and to uphold integrity. Failure to uphold ethical standards today may have negative impacts on humanity in the future.

Developing countries, especially in the Caribbean basin and sub-Saharan Africa, lack resources to offer healthcare and essential prophylactic medications to citizens living with HIV. Current antiretroviral therapies are limited in that they slow the progress of the disease instead of curing it. Therefore, any research towards a cure or vaccine requires ethical guidelines to affect individuals in the clinical trials. The trials should incorporate basic ethical principles, including; the principle of beneficence, autonomy, non-maleficence, and the principle of justice.

This section will review the history of HIV research in developing nations and the reasons why developed western countries prefer conducting research in developing nations. Additionally, the section will investigate ethical issues involving human subjects in HIV research and the role

of research institutions in observing ethics. Lastly, the section will analyze existing research frameworks in developing countries and propose a suitable framework that will facilitate human protection.

5.1.1. HIV Research in developing countries

In developing countries, where there is a very limited access to HIV therapies, HIV infection is considered a death sentence. In recent years, the debate has revolved around the “ethics of research in developing countries.” The debates have focused on the standard of care offered during research, availability of interventions that could be useful, recruiting, sensitivity to minority groups, and the quality of informed consent.¹ Developing countries provide researchers with a large pool of individuals living with HIV. Additionally, conducting trials in developing countries is cheaper and faster compared to conducting clinical trials in developed nations. HIV research on human subjects has an economic and social impact on the population under study. Therefore, balancing ethical imperatives against the social and cultural realities is of the utmost importance.² According to universalism laws, there should be little to no difference in how research is conducted in developing countries and in developed countries.³ Furthermore, studies should adhere to globally-accepted ethical standards that govern clinical research. However, according to researchers who support local particularism, differences between developing and developed countries should be taken into account during HIV trials.

5.1.1.a. HIV interventions in developing countries

Among the developing countries that are hard hit by the HIV epidemic, is South Africa. South Africa is one of the leading countries in Africa, with the highest HIV prevalence rates.⁴ To combat this menace, South Africa has launched national treatment, testing, and prevention

campaigns and has intensified its HIV testing campaigns.⁵ However, increasing access to HIV treatment in Africa is still a major issue due to several challenges. Firstly, many African countries struggle to transition from an emergency response system to a robust healthcare delivery system. Additionally, cultural factors still pose a significant threat to the success of care interventions. Access to HIV treatment is often affected by increasing social, political, and economic factors that highly influence the rate of investments in healthcare delivery systems.⁶ Resources are also limited in many African countries. As a result, there is increased competition for infrastructure, personnel, and other resources between donor-driven HIV programs.⁷ In addition, developing countries often struggle with providing evidence-based care to citizens. According to a systemic review conducted by Alemayehu and colleagues, there are several barriers to conducting clinical trials in developing countries. These barriers include “lack of financial and human personnel, ethical and regulatory system challenges, lack of a research environment, barriers in operations, and competing demands.”⁸

According to “the Joint United Nations Programme on HIV/AIDS” (UNAIDS), over 20.6 million people in East and Southern Africa are living with HIV/AIDS.⁹ Therefore, it is extremely important that new measures, therapies, and preventatives are created and that these measures and therapies are made accessible clearly to populations in clinical trials. In previous years, clinical trials that were conducted in regions without proper healthcare infrastructure were referred to as helicopter research.¹⁰ “The helicopter would come in, drop drugs, and when the study was over, the helicopter would take everything out.” To facilitate the building of needed infrastructure, the National Institutes of Health offers the countries hosting HIV clinical trials 8% of the grant’s cost for overhead. In building the infrastructure needed to provide standard care, the affected patients must be considered.¹¹ In the case of an HIV infection, it the researchers

responsibility to provide care in the form of combined antiretroviral therapy and CD4+ monitoring. In addition to the lack of infrastructure, informed consent is a major ethical issue affecting HIV research in developing countries.

5.1.1.b. The history of HIV research in developing countries

Before 2005, “regulation on clinical trials was nonexistent” in African nations. Where the legislation was present, little specification existed on who had the authority to approve the clinical trials, do inspections, and to end non-compliant research.¹² Besides, when the trials were authorized, follow-ups were rarely. In September of the same year, the World Health Organization (WHO) developed a workshop that highlighted “regulatory procedures for the clinical research of vaccines”.¹³ Before 2005, there were limitations regarding the regulatory framework for clinical trials. In developed countries, the stages of vaccine development, including clinical trials, are highly governed by “legislative and regulatory measures”. However, when it comes to the regulation capacity of African countries, the rules are not so stringent.¹⁴ According to a report by the WHO Regional Office for Africa, about 36% of African states lack national regulations to govern medical research. Furthermore, very few countries have ethical regulation measures to govern sponsored research. Overall, before 2005, many African countries lacked frameworks for regulations of medicines and clinical trials.¹⁵ Over the years, there have been significant improvements in the regulation of clinical trials in Africa.

Several interested parties have participated in the development of regulations to govern clinical trials. Initiatives by the WHO to support African countries focus more on uniting the countries to enable them identifying “common challenges, share their expertise, and harmonize regulatory procedures” that govern clinical trials.¹⁶ Additionally, the Department of Immunization, Vaccines, and Biologicals of the WHO have strengthened initiatives to regulate

clinical trials. Some of the fields regulated include; observance of ethical standards, observance of international scientific standards, advocacy for regulatory oversight, and regulatory oversight of clinical trials.¹⁷

The Middle East and North Africa region (MENA) has been notorious for the lack of HIV/AIDS epidemiological data. To analyze the progress of HIV research in these countries, Saba and colleagues implemented four indices, including; “PubMed Indices, Embase Index, MENA HIV/AIDS Epidemiology Synthesis Project Index, and HIV prevalence Index”.¹⁸ The researchers utilized the four indices to capture different aspects of HIV/AIDS research in MENA region. The results show that MENA contributes to only 1% of the global HIV literature. Additionally, the results show a rapid increase in HIV research in the region over the past years in spite of noteworthy challenges.¹⁹

In Africa, traditional healers have long been considered as primary healthcare providers. The WHO has also recognized the important role that traditional medicine plays in improving health outcomes. Traditional medicine has also been widely used in the treatment of HIV/AIDS.²⁰ In some instances, many people claim that traditional medicines can actually cure HIV/AIDS. However, traditional medicine and traditional healers are not regulated or registered with relevant drug regulatory bodies. More effort should be directed towards the creation of ethical regulations and to ensure that traditional medicine is at par with orthodox medicine.²¹ African traditional medicine is comprised of supernatural traditional medicine and herbalism among others. While study participants are protected against harm during traditional research trials, there are no regulations that govern the administration of traditional medicines.²² The need for doable, achievable, and well-designed scientific studies on traditional medicines is much needed. Studies like that should address issues related to efficacy and side effects of drugs as

well as standardization of herbal medicines.²³ Appropriately designed studies are expected to maintain the principle of non-maleficence. The same principles of non-maleficence should apply to traditional medicine to prevent exposure to toxic chemicals. Traditional medicine also suffers from the conservation of intellectual property issues. The use of traditional medicine is increasing due to increasing demand from both local and international markets.²⁴ The economic impact of HIV/AIDS on the affected is fueling the increasing demand for traditional herbs. Therefore, to enhance trust between traditional healers and research scientists, intellectual property rights issues must be addressed.²⁵ Overall, many loopholes exist in the practice of African traditional medicine in treating HIV/AIDS. Therefore, to prevent patient harm, measures and regulations should be put in place.

5.1.2. Reasons why developed countries conduct research in developing countries

Ethical issues in research have been the subject of considerable discussion. For researchers, there are several elements that are commonly recognized as being fundamental. These factors include; “relevance of the research to the local issue being investigated”, sensitivity to the local culture, feed from and to the community, and the actions taken after research is completed.²⁶ There is increased concern about the 10/90 gap. The 10/90 gap implies that 90% of all global research is conducted in regions, with 10% of the population. Additionally, 90% of research dollars are directed towards treating 10% of the world’s leading morbidity.²⁷ Rules that govern international research are impacted mainly by biomedical ethics principles of beneficence, respect for autonomy, avoidance of harm, and justice. It is a common belief in the research community that research incentives should not be used to unduly induce research participants into participating in clinical trials.²⁸ Potential research participants should freely

participate in research without being coerced by rewards and compensation. While issues concerning, ethics are a major concern to researchers conducting research in developing countries, other issues of benefit sharing arise.

5.1.2.a. Pharmaceutical companies

The issue of custody of bio-specimens collected in developing countries and if they should be analyzed and stored in developed countries is a significant concern. Additionally, conducting health research in recent times is a collaborative process between individuals and institutions. Sharing skills and resources is especially important in research conducted in developing countries.²⁹ Conducting ethical research requires that researchers consider the unique circumstances and constraints found in host countries. After identifying these unique circumstances, researchers must ensure that they uphold research standards to address the needs of the marginalized.³⁰ The question then arises on why clinical research is conducted in developing countries. According to the Global Forum for Health Research report, “about 10% of research funding is spent on 90% of global health problems”. As a result, funds from developed countries should be used for health issues in developing countries.³¹

Pharmaceutical companies prefer to take their research protocols to developing countries. The cost of acquiring labor in developing countries is relatively cheaper compared to developed countries. In addition, conducting research in developed countries requires researchers to adhere to stringent regulations that increase the cost of research even further.³² In developing countries, endemic diseases coupled with poverty and low levels of investment in healthcare systems affect the ease of selection and performing of clinical trials that have immense benefits on the population. However, the central ethical question should focus on the provision of successful interventions in developing countries that have become the standard of care globally.³³

Developing countries became a big place for business in clinical trials due to minimal obstacles. Additionally, poverty and level of education play a critical role in encouraging clinical trials. To avoid the re-occurrence of medical issues, the highest ethical standards must be observed, regardless of where the research is being conducted.³⁴

5.1.2.b. Underrepresentation of research

Developing countries represent a major part of the world's population. These countries represent nearly 90% of the world's disease burden.³⁵ The healthcare systems in such countries require "evidence to guide decisions" about the best and efficient interventions.³⁶ Despite the fact that "developing countries suffer the greatest burden of disease, substantial research, and development activities designed to address inequalities" are lacking. Additionally, developing countries are sufficient representation in research because of the lack of research capacity and commercial viability. However, most impoverished regions offer the best solutions that bring the greatest impact to high rates of preventable deaths.³⁷ Furthermore, developed nations drive the research agenda of institutions and pharmaceutical companies. This results in disturbing the underrepresentation of research issues affecting these countries. Diseases that are relevant to developed countries are eight times more likely to be investigated in clinical trials than diseases that burden developing countries. Likewise, a majority of trials conducted in less developed countries strive to solve significant issues affecting developed worlds.³⁸

In the 1990s, accusations arose against systems that failed to regulate U.S. research carried out in developing countries. More specifically, the argument was focused on several placebo-controlled studies referred to as the "short course" of AZT for the control of HIV transmission in the U.S.³⁹ American scientists carrying out research in developing countries were accused of violating the ethics of human research. As a result of these ethical issues, the

declaration of Helsinki was created, more details will be provided in the next subsections, to block future studies from conducting unethical human studies. Critics of the short course study argued that if researchers had provided AZT interventions to the pregnant mothers, there would have been fewer babies born with HIV.⁴⁰ In low and middle-income countries, there is a lack in epidemiological data to facilitate the development of high-quality surveys. However, researchers can overcome these barriers by applying critical interventions, including; working closely with communities and their leaders, using simple and easily understood instruments, organizing community interviews, and offering rewards for participants.⁴¹

5.1.3. Human subjects in research in developing countries

Clinical research conducted in developing countries is beset with several challenges. One of the critical challenges affecting research is that these countries are still establishing ethical standards that guide human research. Among the main groups of people affected by HIV/AIDS are adolescents. According to the WHO, “over 30% of all new HIV infections worldwide are among youth” ages 15 to 25 years.⁴² To keep up with this global burden, biomedical HIV research involving children and adolescents is intensifying in developing countries. In many parts of the world, research involving adolescents is highly sensitive. Understanding the complex legal and ethical requirements of clinical trials requires specific principles and benchmarks.⁴³ The set benchmark principles include; “scientific validity, collaborative partnership, favorable risk-benefit ratio, fair selection, independent review, informed consent, social value, and respect for participants”.⁴⁴ During independent reviews, scientists might encounter contradictory ethical and legal requirements implemented in different countries. Such disparities must be thoroughly audited to determine international, national, and local laws. Researchers might also need to

consult additional bodies that review adolescent protocols. Additionally, obtaining informed consent from adolescents require researchers to analyze the legal and ethical requirements of the host country.⁴⁵

The involvement of human subjects and participants in healthcare research raises several concerns. Over the years, relevant regulations have been developed to prevent ethical violations in clinical research. The Declaration of Helsinki was the first official document to achieve international standards in research ethics. In the document, standards of care are clearly highlighted and they require researchers to provide the best-assured care and therapeutic interventions to participants.⁴⁶ This is in line with the core concept of standard of care that every known condition has recognized treatments and interventions. The standard of care is the basis against which other forms of treatment are compared. Standard of care is the best available treatment; it is the most commonly used form of treatment, it the treatment that is proposed by relevant authorities, it is the treatment proposed by common textbooks, and it is the best treatment available.⁴⁷ It is, therefore, the responsibility of researchers to identify whether a proposed treatment falls below the standard of care or if it meets the criteria as mentioned above.

According to the principles of the standard of care, researchers have to meet their obligations to participants in trials. The question then arises on what these obligations are. One of the strongest obligations to research participants is to refrain from harming referred to as the obligation of non-maleficence. Besides, researchers must never allow participants to suffer if there is any way they can help them.⁴⁸ Likewise, it is not ethical to leave participants with poorer standards of care if better standards could be provided to them. Investigators also have an obligation to study participants entering drug trials. They are expected to observe the principles of beneficence and justice. When researchers take charge of study participants, they are expected

to take their obligation of beneficence more seriously. While the issue of observing ethics is important in maintaining standards of care, researchers must also avoid exploiting study participants.

Exploitation is a significant issue affecting study participants, specifically in low-income countries. High-income countries are exploiting low-income countries by carrying out research that only serves their needs and not the needs of individuals in low-income countries. Additionally, some researchers are conducting research in a way that would not be permitted in their own countries.⁴⁹ When research is funded by high-income countries, it often distorts the priorities of healthcare systems by focusing on negative issues in these countries. However, biomedical research involving humans cannot be neglected. Therefore, human subjects involved in research should provide consent and be protected against exploitation.

The declaration of Helsinki proposed by the World Medical Association is one such regulation. The declaration is a morally binding document for many national statutes and for physicians.⁵⁰ The most basic principles of the declaration include; respect for individuals, test subjects have a right to make informed decisions regarding research participation, the subject's welfare should always take precedence over the researcher's interest, research should always have a likelihood to benefit the population being investigated, an independent ethics committee should always supervise research involving human subjects.⁵¹ When it comes to research involving human subjects, regulations have been put in place to ensure human beings are protected. While billions of dollars have been spent on foreign aid, there is still little to show about it. One of the main reasons behind this is the fact that Western policymakers fail to consider major differences that exist between developing and developed countries.⁵² Therefore,

important factors, including cultural and educational differences, must be addressed if clinical trials involving humans are to be successful.

5.1.3.a. The research site's role

Federal regulations require any research project that plans on using human subjects to be reviewed by an Institutional Review Board (IRB). IRB reviews and approvals are required for research projects that involve human subjects, involve an interaction with human study participants or their private information.⁵³ With increasing amounts of research involving human subjects being conducted in developing countries, the question still remains on whether ethical standards are adhered to. According to a survey by Klitzman and colleges, approximately 5% of the world's medical journals follow guidelines set by the International Council Medical Journal Editors (ICMJE).⁵⁴ These guidelines stipulate that authors should include a statement that addresses compliance with an IRB review. However, compliance with this guideline has not been absolute. Likewise, many questions still arise on whether research carried out in developing countries obtains IRB reviews.⁵⁵ As researchers, it is important to include IRB compliance for transparency and assurance purposes.

IRB approval process is the same across all IRBs. According to current federal regulations, the maximum approval period for board projects is 12 months. However, expedited studies require annual renewal.⁵⁶ The IRB reviews research protocols based on the following criteria: the risks to test subjects are significantly minimized either by applying procedures that are consistent with sound research designs or by applying procedures that are already being done on the test subjects for treatment or diagnostic purposes, the risks to test subjects are within reasonable limits when compared to anticipated benefits, selection of subjects is equitable, the research will obtain informed consent from all prospective participants, the research plan clearly

stipulates how data will be collected, the research has adequate provisions to protect the test subject's privacy. IRB submissions are reviewed under exempt review, expedited review, and/or full board review.⁵⁷ A study is listed as being exempt when it is not bound by the requirements of the federal regulations. Expedited review means that the study is classified under one of nine categories. On the other hand, full board review means that the study has more than minimal risk and is not eligible for an expedited review. Full board reviews must meet specific deadline submissions. Lastly, the IRB analyzes the sponsor's financial and personal relationships to rule out any conflict of interest.⁵⁸

Studies that are conducted "with offsite institutions often require approval by the offsite institution's IRB." A dual review process means that studies are reviewed by both IRBs of the institutions involved. While IRB approvals are essential, tension has always existed between institutional review boards and researchers.⁵⁹ IRBs have the power to approve, disapprove, or delay studies and as such, frustrate researchers. As a result, many researchers view IRBs as "the moral police."

Additionally, researchers believe that IRBs overstep their ethical oversight role and focus on minute details that delay research studies.⁶⁰ In the U.S. and other areas, IRBs are notorious for extending their review into social sciences, delaying research studies and impeding data comparison. Additionally, critics claim that IRBs have become extensively Bureaucratic, focusing on the ethics of documentation. Researchers also claim that IRBs are inefficient and continue to frustrate research activities.⁶¹

Researchers have an integral role to play in maintaining ethics during research involving human subjects, research in Africa is no exempt. There are seven ethical requirements to be considered. Firstly, researchers must ensure that the research will enhance health or derive

knowledge towards improvements of overall health and wellbeing. The research must also be scientifically valid, and researchers must be fair when selecting study subjects.⁶² While research is designed to improve patient's wellbeing, other times research does not result in direct benefits to the patient. During this time, researchers must find a favorable risk/benefit ratio. Approval from the local ethics committee is also necessary when conducting research involving human subjects.⁶³ However, if research is sponsored by organizations from developed countries, consent from relevant bodies in the developed countries must be obtained. Patients must also give their informed consent before any research can proceed. Lastly, researchers must respect their test subjects.⁶⁴ Clinical trials performed in developing countries often struggle to provide healthcare benefits for the patients. Researchers must, therefore, provide the same care as they would in developed countries. Without validity, research fails to generate relevant information and risks exposing patients to even higher risks.

5.1.3.b. Vulnerable subjects

In recent years, there have been several provisions and rules that offer guidance on the ethical conduct of biomedical research involving human participants. From the Nuremberg Code developed in 1947 to recent guidelines for good clinical practice in the conduct of clinical trials, human participants are protected in research settings.”⁶⁵ However, there are several flaws that the guidelines fail to address. For the most part, the ethical guidelines were developed after the occurrence of an adverse event. Therefore, they only focus on what was believed to be the negative consequences of the adverse event. For example, Nuremberg Code was designed to address the atrocities committed by the Nazi physicians. In addition, regulatory guidance has a narrow focus. As such, it only highlights specific events and fails to address the overall ethics of research. The use of sparse, oracular statements also fails to address relevant ethical issues.

Lastly, a majority of ethical guidance regulations are mistaken about several important issues.⁶⁶ Thus, they end up providing a blanket condemnation.

With the overall purpose of avoiding exploitation, ethical principles provide a comprehensive and systemic framework to guide ethical clinical research and avoid the exploitation of human participants. In line with this goal, there are eight key principles and benchmarks for ethical clinical research. They, as mentioned above include; scientific validity, collaborative partnership, favorable risk-benefit ratio, fair selection, independent review, informed consent, social value, and respect for participants.⁶⁷ It is presumed that all eight benchmarks must be fulfilled. However, in some instances, like during emergency research, informed consent might be waived. When any biomedical research upholds these eight principles, the research is considered ethical. Applying these principles might be difficult. However, any research involving human beings must adhere to appropriate ethical standards.⁶⁸ In developing countries, for example, most of participants in HIV research are women and adolescents.

According to “the Joint United Nations Programme on HIV and AIDS (UNAIDS), 37.9 million people were living with HIV by the end of 2018.”⁶⁹ From the same source, 20.6 million people were living with HIV in Eastern and Southern Africa, where 58% are women.⁷⁰ Statistics also show that 80% of the new HIV infections in Sub-Saharan Africa are women aged 15-19.⁷¹ One factor attributed to increased incidences of HIV/AIDS in young people is increased sexual activity. Several research and interventions are designed operating at the individual level to manage HIV rates in young people. These interventions target the psychological, biological, and familial factors that affect the rate of HIV spread among adolescents. However, for the interventions to work, key populations must be involved the designing, implementing, and

evaluation stages of selected interventions, young population for example. To respond to the increasing rate of adolescent and youth HIV infections, several organizations have been developed. The Joint United Nations Program on HIV/AIDS and the United Nations Children's Fund have partnered with the President's Emergency Plan for AIDS Relief (PEPFAR) to provide needed relief to those affected. As more attention is focused on adolescents living with HIV (ALHIV), interventions that allow partnerships with affected adolescents should be considered.⁷²

One of the main impacts of HIV infection is the high number of orphans it leaves behind. The death of parents as a result of HIV leaves children under heightened risk. Orphaned children often struggle with depression, anxiety, and loss of opportunities.⁷³ Additionally, orphaned children suffer from stigma and discrimination associated with HIV diagnosis. Research conducted on orphaned children has been used to design poverty reduction programs.⁷⁴ Some of the programs include giving the orphaned children money, providing education support, conducting home visits to encourage and mentor the orphans, and different forms of psychotherapy and counseling. However, while a majority of the efforts are directed towards helping orphans under 18, orphans older than 18 are often forgotten. Individuals between 18 years and 24 are known as OVC (Orphans and Vulnerable Children) since they have different needs than children and adults.⁷⁵ To cater to this group of individuals, youth-specific programs have been developed by profit and no-profit organizations such as (PEPFAR). In addition to experiencing loss from the death of a parent, youth experience heightened threats of chronic diseases, drug and alcohol addiction. In Sub-Saharan Africa and other regions with high prevalence rates of HIV, clinicians and other healthcare providers will benefit immensely from information about orphaned youths.⁷⁶ Additionally, by analyzing data about youth-specific

programs, clinicians have the opportunity of custom-making their own interventions to improve the quality of care.

HIV surveillance systems in the Middle East and North Africa (MENA) note a significant increase in the number of new HIV infections in women. In Djibouti, the number of women with HIV is more than the number of men with HIV. Additionally, in Algeria, Sudan, and Yemen, the number of new HIV cases is increasing in women than in men.⁷⁷ Due to weak healthcare systems in this region, many of these infections are often undetected and unreported. As a result, many women with HIV are denied access to treatment. A lack of policies and overdependence in men results in many women failing to seek treatment and care.⁷⁸ However, initiatives like the MENA-ROSA are striving to form “a regional network of HIV positive women.” In Algeria, efforts are being directed towards encouraging women living with HIV to re-enter the workforce.⁷⁹ Women are also encouraged to access testing services, and for those who test positive for HIV, “treatment and sexual reproductive health services are provided.”⁸⁰ For these interventions to be successful, there needs to be concerted efforts from the affected and the community in general.

There are several behavioral risk factors that predispose women to HIV/AIDS. They include; unprotected sex, relationships with men living with HIV, history of sexual abuse, and violence. Additionally, women who have transactional sex are at a higher risk of contracting HIV/AIDS. Underlying “common risk factors associated with women’s greater risk of contracting HIV”, is gender inequality.⁸¹ According to epidemiological evidence from research studies conducted in Sub-Saharan Africa, greater inequalities place women at higher risk of contracting HIV. Likewise, in the context of relationships, women are not empowered to negotiate at a relationship level. Furthermore, women who experience any form of sexual violence are at greater risk of HIV/AIDS infection.⁸²

Obtaining consent in low and middle-income countries is a complex process. Coupled with low levels of education and confusion about essential research elements, many questions about whether consent in these regions is wholly informed.⁸³ Additionally, socio-economic conditions make it impossible for low-income individuals to access medical care. As part of the trial, medical care is provided to all participants. This, in turn, creates confusion on how to differentiate medical research and care. HIV research in Africa conflicts with local treatment options such as holy water, prayer, and herbal medicine. As a result, researchers struggle to explain to study participants about the benefits of studies. During the early stages of care, clinicians must develop strategies to manage expectations. One way of doing this is by developing education videos.⁸⁴ Education videos are better placed to bridge the divide between researchers and participant communities and ensure that those study participants are aware of the implications of research and therefore provide informed consent.

5.1.4. Critical analysis of existing research framework models in low-income countries

The proximate-determinants framework is a conceptual framework used to analyze the determinants of HIV infection in groups of people by combining both epidemiological and demographic approaches. Key to the framework is “the identification of variables referred to as proximate determinants that can be influenced by changes in interventions or contextual variables.” The proximate determinants affect biological mechanisms, which ultimately influence health outcomes. This biological mechanism, in HIV research, act as a larger whole that “determine the reproductive rate” of the HIV infection.⁸⁵ The “proximate-determinants framework” can be used during “study design, analysis, and interpretation of any risk factors.”

Additionally, the framework can be used, therefore, in intervention studies that have biological and behavioral data. Lastly, the framework can be used in ecological studies.⁸⁶

Implementing Research (IR) efforts have the potential to support evidence-informed interventions used to achieve sustainable development goals. With growing attention being directed towards IR and how its concepts could be applied to achieve health, more research needs to be done on its impact in low and middle-income countries.⁸⁷ During the 2004 WHO Ministerial Summit on Health Research in Mexico, a call was made for more IR in health systems. While many debates are still ongoing with regards to IR boundaries, the consensus on the several principles that apply in IR. For example, the need to carry out the research under real-life settings, the need for that research to respond to implementation problems, the need to inquire about the context, and for the development of a diverse group of stakeholders to respond to implementation problems.⁸⁸ However, there is a big difference between the principles of IR and what has been published in research journals.

In addition, North-South Research partnerships inform the ethics of carrying out research in developing countries. The North-South collaboration strives to ensure equity of research funding given to developing countries. Aside from funding HIV research, the North-South collaboration also funds research in tropical diseases and the improvement of the poor state of research in developing countries.⁸⁹ Accessing ART results has been proven to be effective in reducing mortality rates compared to no interventions. Therefore, scaling up the use of ART therapies is of the utmost importance. However, scaling up models to improve ART uptake faces several challenges.⁹⁰

eHealth has been identified as “an effective approach to spread HIV information.” In conjunction with “the Consumer Health Informatics (CHI), the Web-to-Public Knowledge

Transfer Model (WPKTM)” has been used to identify the needs of consumers for AfroAIDSinfo.⁹¹ Based in South Africa, AfroAIDSinfo uses eSurveys to determine whether the needs of patients are met. An analysis of these surveys shows considerable high rates of satisfaction associated with the content and the mode of delivery. The information that contained in the system is reliable for reuse, for education, and for information referencing. Then, using CHI and WPKTM will ensure that consumer needs are met. Likewise, using Information and Communications Technology (ICT) and other theories in eHealth can be enlarged to deliver the best information to inform other public health sectors.⁹²

Over the last couple of years, phylogenetic analysis has played an intricate role in helping researchers understand the characteristics of many diseases and epidemics. “Phylogenetic analysis is a scientific process used to analyze disparities in viral genes using computational techniques to determine the genetic distance between different strains.⁹³ The technique is commonly used to identify potential sources of HIV-1. As a result, scientists are able to confirm a possible contact source of HIV infection. Phylogenetic techniques were used to identify the origin of the HIV virus from strains found in West-Central Africa during the early 1900s.”⁹⁴ Currently, phylogenetic analysis is being used to identify underlying drivers of the transmission of HIV-1 at a population level across the world. The technique has been used to derive interventions that reduce HIV-1 transmission. Nonetheless, with it comes complex ethical issues that might hinder its success.

5.1.4.a. Framework’s contribution to protecting human subjects

According to the Joint United Nations Programme on HIV/AIDS (UNAIDS), as mentioned, 37.9 million people were living with HIV by the end of 2018 worldwide. The most affected region in the world is sub-Saharan Africa, where approximately 70% of new HIV

infections occurred in 2012.⁹⁵ As such, there is a serious need to unite for HIV/AIDS prevention efforts. While seeking for innovative ways to improve care, ICT has been leveraged in low and middle-income countries, which were considered appropriate and showed the potential to provide preventive HIV/AIDS education.⁹⁶ However, the uptake of e-Health solutions has been marked with several issues, including; ease of use, usefulness, comprehension, reliability of content, accessibility, and ICT acceptance.⁹⁷ Nowhere has the concept been undertaken better than in South Africa. The South African Medical Research Council (MRC) has tailored information according to targeted groups in an eHealth intervention. In contrast to how ICTs are used, knowledge sharing, and communication provides healthcare providers with needed information to improve patient outcomes. Studies analyzing the effectiveness of data use revealed that there are negative outcomes when there is insufficient knowledge of diseases. Therefore, linking language and understanding provides consumers with the best information to make healthcare decisions.⁹⁸

Effectively controlling the HIV epidemic is a battle that can only be won by collaboration from multiple levels. Assessing the impact of multiple level impacts has often been viewed as being expensive. Interventions in low-income countries with the objective of improving counseling and testing should address “the stigma associated with getting a positive test result, the quality of the patient-counselor relationship, facility capacity and environment and infrastructure to access the facilities.” Multilevel interventions are complex and specific and should not be replicated. Randomized controlled trials (RCTs) are “the gold standard” in healthcare research. Interventions addressing healthcare factors are often not attempted because RCTs are not feasible or appropriate.⁹⁹

Antiretroviral Treatment (ART) has helped in saving millions of lives by lowering HIV incident rate of new. Nonetheless, using ART access has been shrouded in logistical and behavioral challenges.¹⁰⁰ WHO recommendations stipulate that ART should be initiated at the time a positive diagnosis is made. Developing HIV vaccinations is a complex and scientific challenge. This is mainly due to the fact that HIV mutates rapidly which allows the virus to escape the body's immune responses. Of the few candidates in clinical trials, they have not demonstrated any efficacy.¹⁰¹ Models that combine epidemiological information and existing new interventions could help guide strategic decision-making to expand HIV/AIDS initiatives. One framework that was designed to achieve these goals is the UNAIDS Investment Framework (IF). IF provides guidance to Low-Income and Middle Income Countries (LMICs) and donors towards enhancing interventions programs that, therefore, could reduce the spread of HIV/AIDS and to reduce mortality rates.¹⁰²

The protection of human subjects requires that no private information be revealed outside the research study. The need-to-know principle stipulates that every member of the research team should know the true identity research participants only when it is absolutely necessary.¹⁰³ This principle is essential, especially when access to participant's information by unauthorized personnel could do harm. The Belmont Report "(National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research)" designed basic ethical principles in research studies involving human subjects.¹⁰⁴ The main principles of ethical research outlined in "the Belmont Report include; respect for persons, beneficence, and justice." According to the principle of respect for persons, individuals with diminished autonomy should be provided special protection. The principle of beneficence on the other hand, requires participants to be treated with consideration and respect by acknowledging that they have rights and voices.

Additionally, study participants must be protected from harm at all times. Their protection must be guaranteed, possible benefits maximized, and potential harms minimized. The principle of justice guarantees protection against any form of targeting based on economic, racial, or social disadvantage that study participants might have. Researchers must maintain equity in selecting research subjects by ensuring that all research subjects have a relationship to the matter under investigation.¹⁰⁵ The aforementioned principles are universally accepted.

5.1.4.b. Future work to protect human subjects and people living with HIV

Due to the changing context of ethics debate, controversies have directed towards difficult ethical dilemmas that arise from HIV/AIDS research and interventions. Due to the rapid increase in HIV research in multiple countries and the development of strict standards applied to control controversial cases, protecting human participants is of the utmost importance.¹⁰⁶ As a result, the ethical review process has become longer and more complex. Additionally, the increased availability of antiretroviral therapies and the duty to provide to all individuals in research studies has transformed the way in which research is conducted and how ethics are maintained. Ethical guidelines have long been used to protect human subjects during research.¹⁰⁷ While conducting research, healthcare professionals must observe the principle of confidentiality. A patient's medical information should always be considered confidential and should also be protected by law. Due to the sensitivity of HIV information, "additional protection has been given to medical records. Healthcare providers have a duty to report HIV infections to public health authorities." In addition, study participants should always provide informed consent. Researchers must give adequate time to research participants to consult other individuals before they give their consent. Research ethics have also been used to protect human participants in research.¹⁰⁸ The ethical principles of autonomy for individuals, beneficence, non-

maleficence, and justice are widely accepted as the standard benchmarks that guide ethics in research.

Study participants should leverage the use of internet technologies in participant tracking and study retention. Successful participant retention is important in all randomized clinical trials. By using technologies, researchers are able to protect patient data and track the progress of interventions.¹⁰⁹ During the conduction of mHealth studies, there is the risk of mobile digital data exchange. Therefore, privacy and confidentiality must be ensured and more will be discussed in section 5.2. below. The confidentiality of research data must be protected. Therefore, by obtaining a certificate of confidentiality, researchers are better placed to improve the confidentiality of data collected.¹¹⁰ Overall, best practices and existing standards need to be aligned with guidelines to ensure that human subjects are effectively and appropriately protected.

5.2. Surveillance & Privacy in Global Research Ethics

5.2.1. Introduction

Public health surveillance is the foundation of all public health interventions. In this light, public health surveillance involves the systemic collection and analysis of data for the purpose of timely dissemination of information that is used to inform public health response.¹¹¹ Similarly, public health surveillance relies on several data sources including; health surveys, reports by health professionals or social media data. These data sources are used to inform activities designed to address public health issues as they arise.¹¹² However, of importance to note is that public health surveillance faces several ethical challenges including issues surrounding informed consent that have elicited mixed reactions and debate. At the center of the debate is the issue on whether infringing on privacy and autonomy rights results in a more complete data set.¹¹³

Despite developments in creating guidelines for ethical research, more needs to be done to bridge the gap between the priorities of research institutions and how they carry out research in the field.

Public health surveillance is not considered to be ethically neutral and yet, surveillance programs sometimes lack ethics guidance and training. However, in addressing ethical issues associated with global health surveillance, several inquiries arise.¹¹⁴ First, is it possible that everyone would share the same religious values and principles? Second, is there a possibility to implement global bioethics that is internationally accepted by everyone? Last, is there any relationship between religious values and global bioethics?¹¹⁵ To answer the aforementioned inquiries, this section will provide a historical background of modern-day debates on the issue of surveillance and privacy in global health research. Additionally, the section will compare and contrast religious ethics and global health research ethics and conclude by providing a creative ethical argument on ethical issues associated with global health research.

5.2.1.a. Issues in Global Research

The field of bioethics has grown out of the need for controlling global change especially in this time of transformation. Technological advances in the field of medicine have raised concern on how individual rights and freedom will be ensured. Bioethics is concerned with the ethical issues in healthcare, medicine, biotechnology, and the environment.¹¹⁶ As a result, individuals who contribute to bioethics discussions are drawn from different fields such as the sciences and the humanities. Moreover, the issues facing bioethics are drawn from different fields with each field contributing significant insights, resources, and efforts to address identified issues. Some of the issues that have been of concern include issues related to organ transplants, genetic research, and factors affecting the environment.¹¹⁷ While health research has been used

to advance global justice, issues of global justice in bioethics are often discussed under conditions where clinical research is permitted. As a result, “international guidelines fail to link international research to broader aspects of equity” in healthcare.¹¹⁸ Bioethicists, therefore, have to contend with the dark side of technological advances such as cyberization, gene editing embryos, and brain implants that threaten the ethics and safety of research with human subjects.

The current technological advances have raised several issues for public health surveillance. IT systems have been shown to be successful in improving early warning especially using new media sources such as social media. However, the implementation of these systems to monitor real world surveillance is lacking. Furthermore, the sharing of data with the purpose of warning others to support risk assessment is one of the major ethical challenges of public health surveillance. Sharing of public health data is often hampered by high levels of public mistrust. This in turn creates a challenge on how to define the legal frameworks that govern public health data sharing.¹¹⁹ An additional challenge is seen especially when stricter regulations of the IT industry are implemented with regards to user data manipulation. Evidence also shows that population-level surveillance data sharing has the potential of improving the speed and coordination of responses during healthcare emergencies. However, allowing access to public data and implementing an internationally accepted framework to govern public health, is still a major challenge.¹²⁰ Therefore, to mitigate these challenges, active public engagement must be implemented to ensure better understanding of the advantages and disadvantages of data sharing. Additionally, notification mechanisms that inform the public about violations of privacy should also be put in place.

Health research offers several benefits including; improving clinical practice and reducing public health threats and complications. However, for health research to fully achieve

its goals, there needs to be access to a large pool of individual's data. On the other hand, the public's desire to keep their health information private might affect the outcomes of the research.¹²¹ The public should have a reason to be concerned about the privacy of their data. This is because, currently, there are lack of laws protecting health information confidentiality. Furthermore, there is a large amount of research that is conducted without review or regulation by the Federal government. Researchers should also be aware of the potential privacy issues that might arise throughout the research process. By doing so, they will be able incorporate privacy and confidentiality measures and thus, minimize potential data breaches.¹²² Additionally, public policies should incorporate standards that ensure there is accountability once a breach of confidentiality is encountered.

5.2.1.b. Effective Approaches to Address the Global Research

Ethics and privacy are key issues in biomedical science. However, privacy and ethical issues in health research are complex and thus require tailor-made approaches and interventions.¹²³ Furthermore, the commitment and adherence to research ethics relies on the efforts of the researchers.¹²⁴ To improve on ethics in research, there are several approaches that can be implemented.

There are several technologies that can be used to ensure the security and privacy and data collected during public health surveillance. Authentication technologies for example, can be used to limit access to participant's information and to protect the identity of research participants.¹²⁵ Data encryption on the other hand, is an efficient way of preventing access to sensitive information by unauthorized individuals. Researchers can use data encryption algorithms to protect ownership of data. Researchers can also use data masking technologies as a form of encryption to protect data. Data masking involves replacing sensitive data elements with

an unidentifiable. Data masking is one of the most popular data protections strategies since it is cost effective and reduces the need to apply additional security controls. Lastly, access control policies are essential since they ensure that only authorized individuals can have access to specific data.¹²⁶ Overall, while preserving the privacy of research data is essential, several issues including data breaches might arise that jeopardize the privacy. Applying data protection technologies protects data in all its stages thus maintaining the privacy of research participants.

The use of New Forms of Data creates unique opportunities for effective data collection, analysis, and application of experimental interventions. New Forms of Data such as data generated from social media, is essential in promoting a sense of public trust especially in researchers and the entire research process.¹²⁷ New Forms of Data can, therefore, be used to address research of governance issues such as the protection of research participants and privacy of research data. Ethics Review Bodies (ERBs) are a crucial element in the establishment of research governance systems.¹²⁸ Although ERBs have the ability to withhold approval from research projects, they usually operate using a system that is based on honor and where the nature of the support they receive highly affects their ability to provide independent oversight. Reviewing research proposals using New Forms of Data by ERBs is essential since it will ensure that ethical issues are thought through and addressed before any form of research is undertaken.¹²⁹ Furthermore, an ethical review will ensure that the transparency of the entire research process is maintained and public health is retained.

Public trust is essential in ensuring continued access to personalized health data to be used in health research. To guarantee that adequate protections are implemented and research participants' privacy is protected, all research should be subjected to an Independent Review Board (IRB) review.¹³⁰ Currently, there is lack of a uniform body to monitor research involving

human subjects, especially if the research is privately funded. It is, therefore, essential that all research involving human subjects be subjected to an IRB review.¹³¹ When establishing a uniform system of review, this ensures that oversight and accountability of research is observed. However, researchers argue that subjecting all research to be reviewed by IRBs is further overburdening a system that is already beyond its capacity. While these concerns are legitimate, they should be addressed separately since for adequate reform of the system to occur, a single uniform system should be implemented. All research projects should also be held to the same standards to ensure accountability and increase public trust in public health research.¹³² Therefore, private IRBs or even internal review systems should all follow a specific set of rules and standards that allow for uniformity in decision-making.¹³³

5.2.2. Bioethics and UDBHR

Over the years, the term “global bioethics” has received several meanings. On one hand, global bioethics is a call for the globalization of the study of bioethics. On the other hand, global bioethics involves a single set of global principles that are designed to promote global cooperation in research and the projects that focus on the health and well-being of individuals in society.¹³⁴ With the increase in globalization, many ethical problems are crossing international, cultural, moral, and political boundaries. Furthermore, the current consumer society creates vast possibilities for the use of genetic bioengineering and transgenic organisms. This in turn, has resulted in the transformation of global flora and fauna to a network of bio-farms and bio-factories used in the production of goods and services. While this is going on, issues associated with biological safety and the loss of biological integrity arise.¹³⁵ Scientists have also identified

real danger in modern biotechnological achievements thus making the regulatory role of bioethics even more crucial.

5.2.2.a. Ethical Principles in the UDBHR and the Moral Dimensions of Global Research

Public health surveillance raises several issues concerning privacy and civil liberties. For health officials for example, coming into contact with infectious patients might result in isolation and mandatory treatment. This in turn, creates the fear of stigmatization. For infectious diseases such as HIV/AIDS, mandating infection reporting might discourage people from being tested. In such an instance, surveillance is counterproductive. For those who assess the ethics of public health, refusal to be part of public surveillance for reasons of privacy should not be an option since this could result in skewed data.¹³⁶ Concern then arises on how surveillance data can be protected. Organizations such as the WHO have provided guidelines on the collections and use of surveillance data. For example, surveillance data should not be used by the government or other bodies for other purposes other than what it was intended for. Additionally, individuals must be made aware of the presence of a public surveillance program in their community.¹³⁷ Lastly, public health officials must report back all the information they gain from the surveillance and what they are doing to improve outcomes of individuals in the community.¹³⁸

Over the years, the field of bioethics has evolved to incorporate currently accepted norms and resolutions. This advance in the field of bioethics is accredited to the “Universal Declaration on Bioethics and Human Rights” (UDBHR), published by UNESCO.¹³⁹ Currently, the UDBHR is the only bioethical text that the world has committed itself. According to the declaration, the concept of bioethics stipulates the need to consider both the political and social aspects in addition to the life sciences that are already being addressed.¹⁴⁰ The UDBHR declaration provides “a universal framework of procedures to guide States in formulating their laws and

policies in the field of bioethics.” Additionally, the declaration guides the actions of individuals and institutions in both the private and public sectors.¹⁴¹ To achieve this, the declaration is guided by internationally accepted laws and principles on human rights and more specifically, laws on respect for human dignity.¹⁴²

To achieve its aim, which is to recognize the importance and benefits associated with scientific research while stressing on the fact that the research should observe ethical principles that respect human dignity and privacy, the declaration is guided by several principles.¹⁴³ The UDBHR emphasizes the need for human dignity and human rights to be protected at all times. Under this principle, researchers should ensure that human rights, their interests, and welfare are fully respected and upheld.¹⁴⁴ Additionally, when applying advancing scientific knowledge, “direct and indirect benefits” to study participants, researchers should ensure that possible harms are minimized. The principles of autonomy and individual responsibility stipulates that the autonomy of participants to make decisions must be respected at all times. Consent is one of the main requirements of any research.¹⁴⁵ To ensure consent is obtained, UDBHR requires all scientific research to obtain informed consent from all the individuals concerned. Furthermore, the information provided should be adequate and include modalities for the withdrawal of consent. The declaration also protects individuals who lack the capacity to consent. In so doing, the declaration requires special protections to be provided for individuals who lack capacity to consent.¹⁴⁶ Lastly, the UDBHR stipulates that the benefits resulting from scientific research be shared with society especially if the research was conducted in developing countries.

5.2.2.b. Religious Perspective on Surveillance and Privacy in Global Health Research

The acceptance of any form of new technology by the public is usually based on judgments associated with risks and benefits, and ethical issues that determine how people want

to live. Perhaps one of the most controversial areas that has elicited a lot of global debate is the area of “human embryonic stem cell research.”¹⁴⁷ Other areas such as the use of contraception, In vitro fertilization (IVF), gene editing, and synthetic biology are also raising concern about the limits of human intervention when it comes to matters of life.¹⁴⁸ Similarly, debate on stem cell research has also been rife with many championing its capabilities while others question its morality. According to a study on the impact of religion on views about the use of stem cell research, a majority of the public support its use. Furthermore, the research discovered that religion plays a crucial role in people’s lives. For many, views on stem-cell research are framed by moral concerns. For others, opinions about stem cell research are underpinned by both religious and educational cleavages.¹⁴⁹ Overall, over the years, religion has had salutary influences on population health and medicine in general.

The belief that religion and its convictions have no place in bioethics is growing. For many, the main question they ask is does religion, Islam for instance, have anything to add to bioethics? Perhaps, Islam has had an impact on the outcomes of research studies. For example, in Malaysia, a study conducted on HIV prevention policies discovered that Islam indeed plays a crucial role in designing and framing health policies and strategies related to HIV control and prevention.¹⁵⁰ However, while the country makes progress in reducing harm amongst injecting drug users by implementing needle exchange programs, it faces challenges gathering the much needed support from Imams. To overcome this challenge, the country has invested in mass sensitization of Imams. Regardless, the country still faces challenges while promoting HIV prevention tools such as condom use mainly since the activities of high risk individuals vulnerable to HIV are forbidden in Islam.¹⁵¹ However, despite the resistance on certain

interventions, Islamic traditions can still be implemented into existing and future HIV control and prevention strategies in Islamic countries such as Malaysia.¹⁵²

Religious traditions continue to play significant roles in the lives of many. Therefore, despite any existing sympathy or skepticism directed towards certain religious traditions, it is imperative that bioethicists understand how religious models of morality influence the healthcare industry.¹⁵³

Common morality perspective on surveillance and privacy in global health research

The methods of moral decision-making are mainly concerned with the moral decision and the people who make the decisions. There are several influential methods of moral decision-making that can be applied to ethical issues in the field of healthcare.¹⁵⁴ For example, virtue ethics as presented by Aristotle, focuses on the person's character as the determining factor in determining the extent that individual is a good person. According to Aristotle, the extent to which an individual's character is reflective of the moral virtues, to that same extent is that individual a good person. These moral virtues include; courage, temperance, generosity, justice, honesty, and even compassion.¹⁵⁵ Virtue ethics is applicable to the field of bioethics in that, traditionally, healthcare providers have been expected to act with compassion and be honest. Healthcare professionals with these characteristics can be relied on to participate in morally correct actions when interacting with research study participants and patients.

In addition to virtue ethics, utilitarian theories, as presented by John Stuart Mill, describe "human actions that are committed in moral decision-making situations. According to the theory, human actions are believed to be morally correct to the extent to which they promote happiness or unhappiness for the individuals affected by the said actions."¹⁵⁶ When applied to healthcare ethics, utilitarian theories are fairly standard procedures for many healthcare professionals. It is

common practice for healthcare providers to make decisions that are in the best interest of the patients. A deontological normative ethical theory on the other hand, is “evaluated in accordance with the principles of obligation and duty. These theories, in general, can be applied to several issues in the field of healthcare. Yet an additional method of moral decision-making is known as the ethics of care.” According to this method, in the process of making moral decisions, focus should be placed on the specific circumstances under which personal relationships are made. Additionally, attention should be placed on compassion, sympathy, empathy, and on a sincere concern for caring for others. Currently, healthcare institutions are applying the principles of ethics of care in treating patients.¹⁵⁷ This approach is also recommended by accrediting agencies.

Medical ethics is also founded on four core principles; autonomy, beneficence, nonmaleficence, and justice. Autonomy involves respecting patients’ privacy by being truthful and maintaining confidentiality. Additionally, autonomy requires healthcare professionals to provide all the information and opportunity for patients to make informed decisions. Beneficence requires healthcare providers to act in the best interest of the patient at all times. Nonmaleficence involves avoiding causing injury or suffering to patients while justice involves treating patients fairly and equitably.¹⁵⁸

The discipline of public health ethics mainly focuses on articulating and exploring ethical issues brought about by the pursuit of improved population health. As a result, more focus has been placed on common concepts including; equity, common good, population well-being, solidarity, and reciprocity. In addition, the discipline of public health focuses on other individual values such as individual rights, privacy and autonomy-which are also important ethical considerations. Public health surveillance is acknowledged as being done for the public good since some of the benefits it contains cannot be subdivided into individual private benefits due to

the fact that they are fundamentally shared.¹⁵⁹ In addition, public health is fundamentally concerned with the idea of equity. To ensure equity, public health surveillance can identify a particular problem in society and provide the needed evidence to allow for focused health campaigns to occur.

Public health ethics also focuses on the liberty and interests of individuals. As such, the discipline believes that whenever possible, individuals should be included in major decisions affecting their wellbeing. However, while respecting the rights that every person has, it is important to note that for individuals who are unable to make their own decisions such as children, the State should ensure that they are protected and their long-term health interests promoted. Lastly, good governance, though political, ensures that the ethical challenges introduced as a form of “public health action, are addressed systematically and fairly.”¹⁶⁰ Ultimately, accountability, transparency, and community engagement are the main means of justifying public policy structures that ensure that equity, respect for individuals and the common good are promoted when it comes to public health surveillance.

Public health ethics shares both practical and professional ethics with other fields. However, public health ethics is different from other fields mainly because of the type of challenges that it faces and in the ethical frameworks that it uses to solve the issues. Although there are no definitive frameworks, a majority are important and others are effective in certain situations.¹⁶¹ Among the core values of public health, health and health equity are the main focus of its mission. Health messaging is often used to inform the public about the science behind public health interventions. However, in the minds of individuals, scientific evidence is not always better than other forms of evidence or views about certain interests and values. Even when health messaging is provided, ethical challenges might also arise.¹⁶² The challenges often

arise in unusual situations where standards have not yet been implemented. In such situations, public health ethics provides procedures and processes to determine an appropriate course of action.

Comparison between Religious Beliefs and Common Ethics Principles on the Bioethics issue

Often times, religion and ethics are viewed as being the same. Many religious systems actively try to convert unbelievers and legislate public behaviors that are based on religious texts. While not all religions are the same, some are more conservative while others are liberal. However, all religious traditions believe that they represent a path to salvation and to enlightenment.¹⁶³ On the contrary, ethics are referred to as universal decision-making tools that are used by any individual from any religion. While religion highlights issues of cosmology, social behavior and the treatment of others, ethics is based on logic and reason and not on traditions and injunctions.¹⁶⁴ Often, bioethics contradicts with religion and offers an ideal arena where the sacred and the secular encounter one another in modern medicine. Furthermore, bioethics and religion intersect when; bioethics responds to the universal issue of suffering and when bioethics missionizes its work to make a place for itself among life sciences.¹⁶⁵

Over the years, people have purposed to be good and to do the right thing. However, where do these moral values originate from? Throughout history, religious leaders have tried to explain these ideas as revelations of what is referred to as divine command. Anthropologists, on the other hand, believe that moral values are customs that inform social interactions and interpret morality a type of a survival function that is imbedded in humanity.¹⁶⁶ Social and political leaders also note that moral concepts are a product of social conventions and can therefore, be subjected to deliberation and even change. Currently, governments are relying on health experts to investigate the factors that improve human health and overall satisfaction. Public health

science forms the basis of what is considered good for the entire population and for communities.¹⁶⁷ To address issues of privacy and confidentiality in bioethics, theological perspectives should be considered.

The debate on whether religious views should be included in bioethics, and more specifically, in research, takes into consideration several factors. In research involving human subjects, several global ethical issues arise. For example, issues of informed consent, privacy, confidentiality, and the protection of participants' personal information. To solve these issues, UNESCO developed the UDBHR declaration with 15 bioethical principles.¹⁶⁸ However, religious leaders have identified a shortcoming in the declaration; it did not give any opportunity to different religions to make official contributions during its development.

5.2.3. Privacy and confidentiality issues in public health research

Surveillance is the foundation of public health. According to the WHO, "public health surveillance is the systematic ongoing collection and analysis of data for the purpose of public health." Public health surveillance activities are differentiated along several dimensions. At the beginning, public health surveillance encounters several ethical challenges. For example, surveillance data is often collected without the informed consent of the affected population. However, debate is still ongoing on whether failure to obtain informed consent constitutes unjustified violations of an individuals' privacy or autonomy.¹⁶⁹

5.2.3.a. Public health organizations and clinical trials

With proliferation of clinical trials, opportunities arise to address several questions regarding the advantages and disadvantages of interventions. However, concerns about protecting the privacy of collected information are extremely important and should be

addressed.¹⁷⁰ Additionally, these concerns must effectively balance with the overwhelming need to obtain knowledge from data obtained during clinical practice. Traditionally, policies that are used to protect the privacy of research participants have often relied on “data anonymization” and in the case of research that uses identifiable information, consent from participants is usually obtained. However, a large gap exists between the use of informed consent and how it is obtained. Consent forms are usually extremely lengthy and difficult to understand and people may not always read them. Furthermore, people feel like they do not have alternatives to consenting.¹⁷¹ To eliminate the aforementioned issues, a balance must be struck between improving evidence base and protecting privacy.

Public health organizations are increasingly using technology to obtain and store personal healthcare information. While electronic data formats have the ability to improve performance, they pose a serious threat to privacy because they can easily be duplicated by unauthorized individuals.¹⁷² In addition, there have been concerns about confidentiality that has fueled debate about how to properly balance individual-interests and societal interests. Disease surveillance has also been surrounded by controversies especially for sexually transmitted infections and airborne infections such as tuberculosis.¹⁷³ At the top of this list of issues are confidentiality concerns. High-profile breaches of people’s health information have increased the anxiety about privacy. One of these breaches occurred when the accidental attachment of an electronic file that contained the names addresses of over 600 people living with HIV, was leaked. A separate incident occurred when a state health department computer with information on over 1500 families was stolen from an employee’s care.¹⁷⁴ The above mentioned examples highlight the susceptible nature of public health departments to security breaches and data theft attacks.

5.2.3.b. Issues in bioethics and how they are solved

Currently, bioethics is confronted with a wide range of issues including issues on abortion, euthanasia, genetic testing and assisted reproduction.¹⁷⁵ To many people, bioethics appears to be an abstract idea, discussed by official panels and committees. However, bioethics gives people hope that diseases will be overcome through technological advancements such as gene manipulation.¹⁷⁶ Additionally, global bioethics and its evolution has the ability to produce beneficial outcomes especially in the field of global health. The changes introduced by global bioethics require that interests in health and ethics be extended beyond interpersonal relationships and individual health to include ethical considerations associated with population health. Extending this ethical discourse promotes a new way of doing things which is needed to improve the health of populations and to deal with threats on a more global scale.¹⁷⁷ For change to be affected, bioethicists and other healthcare providers must acknowledge that lives across the world are inextricably connected by powerful forces that shape the health and well-being of communities.

Privacy preservation relies highly on trust. Privacy violation constitutes a risk which could eventually result in a threat to security. Furthermore, privacy breaches disrupt trust and run the risk of diluting security which shows a level of disrespect to the law and violates universally-accepted ethical principles.¹⁷⁸ Data privacy involves accessing, using and collecting data and an individual's legal right to the collected data. Data privacy also involves freedom from any unauthorized access, inappropriate use of data and the right to inspect or correct collected data. Data privacy protection also focuses on costs encountered during data privacy breaches including both hard and soft costs.¹⁷⁹ To further protect the privacy of individuals, the International Health Regulations (IHR) were signed. The IHR was designed to better address global health security

concerns involved in protecting global health. The CDC is working with countries around the world to help them meet the IHR goals.¹⁸⁰ Additionally, the CDC has implemented global programs to address multiple diseases. These programs are run by world leaders in surveillance, epidemiology, and even in technology.¹⁸¹ The IHR requires that all countries have the resources and ability to “detect, assess, report, and respond to health events” affecting the public.

To strike a balance between individual privacy interest and societal needs on public health issues, more emphasis needs to be placed on current laws and ethical guidelines. Additionally, studies, in their design, should highlight issues of data privacy and the changes made to protect the privacy and confidentiality of individual’s records.¹⁸² Similarly, organizations should continue developing codes of conduct to guide researchers and encourage them to adhere to the developed codes. Studies that use personally identifiable information should always be subjected to IRB approval before they move forward. The IRB mechanism should continue being the keystone for ensuring that individuals’ confidentiality and privacy is protected. IRBs can dismiss a requirement for written informed consent only when assurances are made that individuals will not be harmed; their information will not be made public and that the research is conducted with the interest of the public in mind.¹⁸³ The use of improved technology should be implemented to ensure that personal identifying information is kept a secret. Likewise, once appropriate safeguards have been implemented, the secondary implementation and use of datasets for activities other than what they were intended for, should be controlled. Transfer of data across countries should be allowed only when sufficient legal protections have been implemented to ensure that the person in charge of the data during the transfer, is responsible and held accountable. Lastly, legal penalties should be put in place to limit unauthorized access to personally identifiable information.¹⁸⁴

5.2.4. Principles of public health ethics, community health, and individual's autonomy

The IHR and other restrictive policies on global research data access have had a negative effect on significant and important public health research. As such, researchers and other members of the public health community should put up a united front and challenge these policies by lobbying law makers and healthcare officials to advocate for transformations that will balance between protecting the public's health and eliminating privacy concerns.¹⁸⁵ When privacy concerns are raised, often times, local institutional review bodies and the National Institutes of Human Subjects Protection, implement rules and regulations that protect patients' confidentiality. An example of such a policy is the "Health Insurance Portability and Accountability Act (HIPAA)" implemented to balance between protecting individuals' personal health information and ensuring the data is used legitimately.¹⁸⁶ However, while these standards are designed with the intention of protecting the rights of human participants, they have several unintended consequences. For example, evidence shows that policies such as HIPAA, negatively affect the conduct of public health research. Furthermore, HIPAA's Privacy Rule fails to protect the privacy of study participants but instead, it hinders the conduct of crucial health research.¹⁸⁷ With the increasing fear of privacy violations, personal intrusions, and other forms of breaches, it is not difficult for public health regulators to forget the negative impacts of the restrictions on efforts to better understand public health and to improve access to public health data.

5.2.4.a. Global health research regulators are doing more harm than good?

Too much regulation does more harm than good. In 2015, European drug regulators approved the administration of the world's first Malaria vaccines. The European drug regulators recommended that the drug was safe and effective to be used in children at risk of developing Malaria. However, before the vaccine could be administered in Africa, the World Health

Organization (WHO) said that it needed to make its own assessment to determine safety of the drug. This delay is an unfortunate example of how too much regulation harms global health.¹⁸⁸ Public health research is often made possible through “the analysis of population-based data collected by either local, state or federal governments.”¹⁸⁹ However, recent growing concerns regarding patient’s privacy and confidentiality have resulted in the implementation of more restrictive policies on access to data. This restriction often prevents researchers from accessing valuable population data which in turn, negatively affects public health research. While responding to increasing privacy concerns, organizations such as “the local institutional review boards (IRBs) and the National Institutes of Health’s Office of Human Subjects Protection” have introduced regulations that protect individuals’ privacy. For example, policies such as HIPAA’ Private Rule, regulate the use of protected health information throughout the country.¹⁹⁰ Although the above-mentioned policies effectively protect research participants’ right to privacy and confidentiality, they have introduced several unintended consequences.

Evidence generation is crucial to public health and to other healthcare service providers. Over the years, ethics issues have been addressed separately in research projects with review on the use of “non-research activities” falling outside the responsibilities of the research ethics board. All the activities conducted by public health research involve the systemic collection of data about individuals and how they have their impact on the environment. Data is collected through the use common data collection methods that pose significant risks to individuals.¹⁹¹ Furthermore, ethical issues might arise at any given step during data collection. By developing a universal framework to be used by individuals who are designing public health evaluations, the ethical integrity among reviewers and investigators will significantly increase rather than them

merely complying with rules and regulations.¹⁹² The framework should be generalizable to accommodate the unique needs of different public health organizations.

Should public health surveillance occur without explicit patient consent? There is a strong support from both the scientific and legal field to maintain name-based reporting of all infectious diseases.¹⁹³ Additionally, by applying the principles of contemporary clinical and public health ethics, researchers can override an individual's autonomy. Furthermore, overriding an individual's autonomy can be justified when analyzed from the point of view that it will improve population's health, reduce healthcare inequalities, improve the health of vulnerable communities, and prevent harm. Violating a person's right to privacy should only be done if the data elements collected will have little to no interference, must be securely maintained and must not lead to major public health action.¹⁹⁴

To participate in health research, "well administered informed consent" should be ensured. Understanding informed consent particularly during international health research is highly influenced by the research participant's own understanding of information and the meaning behind the information. Incorrect information may result in research participants becoming victims of research procedures that would result in more harm than good.¹⁹⁵ However, processing information and interpreting it differs from one culture to the next and may be problematic in some instances, even when interpreters are involved, due to language barriers. In research involving interpreters, there are dual problems that arise due to the incorrect communication of research objectives and the inability to pass on the consent information correctly to study participants.

In addition to the research participant's own understanding of the research, power differentials between researchers and participants may result in study participants becoming

victims of clinical trials that are harmful.¹⁹⁶ Informed consent is also essential to ethical health research. However, there are significant challenges in ensuring that both the regulatory and practical requirements of the entire process are met. The challenges are also attributed to the differences that exist in interpreting research concepts and the processes between researchers and study participants. Furthermore, researchers must ensure that they are compliant with the ethical principle that underpins research ethics-respect for persons.¹⁹⁷ Respect for persons requires researchers to respect study participants' autonomy and wishes and act on the notion that participants are the best judges of what their best interest is. Acting on this presumption, researchers are obliged to design consent processes that uphold participants' right to free and informed decisions.¹⁹⁸

5.2.4.b. Way Forward

Despite the recent rise in opportunities for “the development and advancement of biomedical research and the availability of data samples to exchange”, this promise is still not fully realized.¹⁹⁹ This mismatch is highly attributed to hindrances presented to researchers of having to navigate the strict regulatory frameworks governing data sharing. Particularly challenging is international exchange due to “conflicting regulations and terminologies” that are overlapping. While policies and tools have been developed to support research and researchers, many still cover a small geographical region, are not current and are not sufficiently mature. In addition to legal restrictions, other limiting factors include a reluctance by investigators as well as the interests of funders.²⁰⁰ Researchers, as key players in ensuring privacy during global health research, have a critical role to play in protecting patients and ensuring informed consent is provided.

Current laws and policies that are concerned with privacy limit access to health-related data to be used for research. Some of these barriers include; costly procedures to obtain informed consent from individuals for the information to be released and inconsistent Institutional Review Board (IRB) policies.²⁰¹ To improve the effectiveness of research, it is crucial that new policy frameworks be developed “to encourage the use of health information” in all its forms. Current HIPAA provisions, while intended to create incentives, have created disincentives discouraging the use of health data for comparative research. Additionally, HIPAA regulations contain stringent reporting requirements for research that uses protected health information or makes improper disclosures. HIPAA regulations also increase penalties for violations of their provisions. Researchers are therefore, left with the dilemma of how to ensure confidentiality when using health information, while also observing “the principle that medical information” should be shared.²⁰² To ensure that this balance is struck, new policy frameworks must be implemented.

Lastly, whilst the health informatics community continues to develop new approaches to ensure intelligent analysis and the use of healthcare data, the transfer and use of these technologies in “real world clinical environments” faces several challenges. For example, healthcare providers lack access to scientific expertise, they also lack required technology infrastructure and funding.²⁰³ For big data analysis to be effective in improving healthcare, partnerships must be formed between research organizations, healthcare providers and private organizations. When it comes to the privacy of health information, researchers struggle to determine if electronic patient information can be used for secondary research purposes and to implement protective safeguards to ensure patient confidentiality and privacy.²⁰⁴ More will be

discussed regarding surveillance in next generation and ethics of data analytics in healthcare in the following chapter.

5.3. Conclusion

Despite the increasing interest in reducing the health burden placed on individuals living with HIV/AIDS, developing countries still struggle to provide the most basic healthcare interventions to citizens living with HIV. With increasing worldwide interest in expanding research trials to develop vaccines in developing countries, there is still debate on whether ethical principles are observed. Specifically, questions have arisen on how researchers from developed countries conduct studies in developing countries. A majority of the controversy stems from the fact that HIV research on human subjects has both economic and social impacts on the patient's welfare. Advocates for universalism believe that the differences between countries should not prevent researchers from conducting clinical trials that adhere to accepted ethical global standards. However, others who support local particularism are of the view that disparities between countries should be put into consideration during HIV clinical trials. Overall, it is the responsibility of researchers to maintain ethics during research and to ensure that participants are protected at all times.

Public health surveillance, in the other hand, is the ongoing systemic collection and analysis of health-related information to be used in the planning, implementation, and evaluation of public health practices. Over the years, the world has witnessed a digital revolution in both the public and global health spheres that has created unprecedented opportunities for public health surveillance. However, with these opportunities, comes major issues as access to data, data privacy and regulation frameworks are lagging behind. While several organizations such as

UNESCO have developed policies to ensure data privacy, more needs to be done. Additionally, as some religious leaders note, the success of any policy that strives to address the issue of data privacy, is dependent on the collaboration between religion and science. Furthermore, while regulatory bodies are created to monitor public health research and ensure data privacy is upheld, often times, their intervention slows down public health research and service delivery as seen in the case of Malaria vaccination distribution. Lastly, to ensure data privacy, frameworks must be put in place that focus on the unique needs of public health organizations. Next chapter, more will be discussed regarding surveillance in next generation and ethics of data analytics in healthcare.

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6.1. Ethical Justification of Big Data Privacy in Age of Surveillance Technology

6.1.1. Big data

Big Data is fueling the ever-growing data driven and computerized the 21st century, just like oil in the industrial revolution of the 20th century. Currently, society is using big data to promote the digital revolution offering computerized intelligence-based solutions aimed at reducing the cognitive burden of processing data in large volumes.¹ Moreover, transactions and physical movements are increasingly being recorded by Big Data processors to be used to trace voters and monitor markets. Data about financial transactions, movement of people, and even their leisure activities is continuously mined, analyzed, compared, and integrated without the explicit consent of those involved. There are risks and rewards related to Big Data analytics.² However, there is limited public understanding of what Big Data analytics entails and how individuals can affect how it is used. People often assume that their data is anonymous since it lacks primary identifiers and personal data. Furthermore, the sensitive data that banks and insurance companies promise is secure, can get lost, sold to hackers, and thus result in loss of privacy.

It is paramount that society agrees on common values of protecting data and the basic human right to privacy. Finding a middle ground in the conflict between the commercial interest of companies and the protection of people's liberties is complicated.³ To mitigate this, ethics should be used as a yardstick to judge right from wrong. In addition, it will require the joint collaboration of state and supervisory regulation to monitor all Big Data activities.⁴ In line with

this, ethical principles should be based on societal consensus, developers' self-regulation, and creators of Big Data applications. With the advancements in technology, the potential for misuse is even higher. This section argues for the creation of ethical oversight and constraints to protect data privacy. Additionally, an ethical justification of the same is provided while also ensuring an appropriate balance is reached that still encourages innovation but also protects personal data.

6.1.1.a. Big data and privacy

Currently, a large volume of information is being collected, analyzed, and stored. While data analysis is essential in predictions and forecasting, it has also resulted in raised concerns regarding privacy violations. Generally, a privacy violation occurs primarily when there is a leakage or inference of an individual's private and confidential data. Big data systems might result in data privacy violations mainly due to their large and constantly growing database. As more data is being collected, individual's private information is at risk of being collected directly from one source or indirectly by linking information from several sources. For example, a service provider might scan an individual's emails thus gaining access to their confidential information.⁵ The individual might consent the provider's privacy terms without fully understanding the terms. Moreover, if the data obtained from the user's email is connected to other sources such as web searches, then more information about the user is accessed.

Privacy violations of big data can be categorized into four main groups: government tracking, data collected by service providers, identification attacks, and data breaches. Governments have been shown to run surveillance programs in a bid to improve security. Additionally, they collect confidential data from multiple sources. One example of government-run surveillance program is PRISM used by the U.S. government to collect data from key service providers. City governments also collect information to improve on services.⁶ Service providers

also collect and use an individual's private data without their consent thus violating their privacy. Auto scan can be used to scan emails and posts from social media and the information used to display advertisements. Google also accidentally shares user documents with others. Data correlation also involves linking confidential information about an individual to come up with specific conclusions.⁷ Lastly, data sources are subject to hacking resulting in the exposure of private and confidential information.

A breach in data is referred to as a security compromise resulting in the accidental and unlawful destruction of transmitted, stored, and processed data. Data breaches are caused by several factors including; data breaches, insider threats to malware, and network misconfigurations. Financial systems and public datasets are also subject to data theft. Similar to re-identification attacks, data breaches are based on several motives.⁸ They can be used to obtain information or to collect information about organizations. However, to prevent data breaches and the unlawful use of private information, laws and privacy policies have been developed.

Currently, privacy risks are becoming "more intense and the challenges to protect data privacy are even more complicated. Organizations such as the Electronic Privacy Information Center (EPIC) and Chartered Financial Analyst CFA" have enumerated several ways that big data analytics can be used to invade individual's privacy. They include; discrimination, breaches, lack of anonymity, government exemptions, and data brokering.⁹ While discrimination is illegal, it is increasingly becoming a reality for many individuals through the use of big data. Big data algorithms have become increasingly mature over the last couple of years. However, despite this growth, legal protections are still in their primitive stages. Currently, data breaches are at an all-time high. This has been made even worse by the increased use of internet of things (IoT) devices in daily lives. Anonymity is also a thing of the past. Organizations that are interested in

anonymizing data to use it for other purposes are also finding it extremely difficult to do so. Currently, IoT devices act as a massive data collection engine containing user's personal information. In addition, governments are taking advantage of big data technologies to provide exemptions. In the U.S. many citizens are in more government databases than they were a couple of years ago. A majority of these government databases have exempted themselves from Privacy acts' requirements. This lack of accountability further increases the risk of data breaches. Similarly, various companies are collecting and selling consumer data used to profile individuals without their consent.¹⁰ The question then arises, how can individual privacy be maintained in this age of big data and surveillance technology?

While long lasting data activities have been proven to have the potential of bringing several unique societal benefits, they also expose users to higher risks that their data will be misused. Evidence suggests that there are several data characteristics that are related to time increase informational risks.¹¹ They include;

- Age. This is the duration that elapses between the time original data is collected until when it is processed. Data is usually analyzed within a short period of time after it is collected as seen in mobile applications that target advertisements based on the individual's current location. However, other times data is analyzed over several years after being collected.
- Period. This is the interval within which components or subjects are measured consistently. Some information collections observe events at one moment in time while others collect data over decades.

- Frequency. This is the interval from one measure to the next. High frequency data collection examples are seen in mobile health apps which consistently track sources of information such a patient's heart rate.¹²

In addition to the aforementioned factors, other factors have been identified to increase privacy risks due to big data in both government and non-government organizations, according to the same source. They include;

- Dimensionality. This is the sum of all independent attributes that are measured for every data subject. "High dimensional data includes datasets for thousands of individuals that are maintained by several social media organizations" or data brokers.
- Analytic use refers to a type of analysis that the data is designed to support. For example, research studies are usually done to support both the causal and descriptive aspects of populations. On the other hand, government entities have broader purposes including designing interventions and recommending products.¹³
- Sample size on the other hand, refers to the total number of individuals who are incorporated in the data set. Big data collection in government settings has a larger sample size compared to traditional longitudinal research studies.
- Population characteristics on the other hand, refer to the size and diversity of the population. This in turn, facilitates data observations. Big data in corporate settings usually describes large populations.¹⁴

Privacy protection practices address or fail to address these critical factors. Therefore, more policies should be implemented to govern future interventions.

6.1.1.b. Improving data privacy

The current accepted practices used to protect data privacy are highly varied across several contexts. Businesses and government organizations have developed several approaches designed to protect the privacy of personal data. Among the most common approaches used focuses on mechanisms of consent and de-identification techniques. These interventions are usually incorporated without additional restrictions or reviews. Data analytics is the competency that ensures organizations are seeking out connections, identifying patterns, predicting behaviors and personalizing interactions to resolve issues in business and to create future opportunities.¹⁵ Some believe that for privacy to be affected, it's very notion must change and the imperative to innovate and to unlock data value be glorified over traditional concepts.

Many organizations have invested in building privacy protections and adopting them into their business strategies and operations. For example, Privacy by Design (PbD) is a framework that is used to reconcile data protection practices with the desire for more data-driven innovations. PbD is used to embed privacy directly into technologies, business practices, and organizational infrastructure thus providing a middle way whereby organizations can balance their innovative needs while also maintaining their competitive advantage.¹⁶ Other technology-based options have been developed to advance privacy while also pursuing data analytics. For instance, organizations are not collecting data minimization personally identifiable information unless a more compelling purpose is established. Other organizations are also using de-identification processes where datasets are stripped of all information that could potentially result in the identification of an individual directly or indirectly through dataset linkages. Other organizations are relying on access controls to grant or deny access to information. Enforcing access controls can help organizations reduce privacy risks and thus protect personal information

from being compromised.¹⁷ In the future, organizations will continue to use data analytics as a tool to help them advance their strategic goals. However, for businesses with effective business strategies embracing privacy will facilitate innovation and creativity and ultimately resulting in improved quality of services.

Even before the age of big data, there had been established policies on data protection and privacy. There are written rules and regulations that all data handling organizations must comply with. For example, the European Union (EU) Data Protection Directive was designed to provide a framework for the proper handling of individual's personal information.¹⁸ General data protection regulations are also being designed to allow all member EU states the ability to subscribe to common principles and the coordination of rule enforcement. Countries including; Malaysia and Singapore have designed legislation to protect data privacy. Other countries have aligned their legislation with the "Asia Pacific Economic Cooperation (APEC) the Organization for Economic Co-operation and Development (OECD)" privacy principles. The EU data protection directive contains several adequacy requirements preventing the transfer of private and personal data to individuals outside the scope of the EU standards for privacy protection. Furthermore, the APEC and OECD frameworks were designed to ensure that states develop compatible regulations for smooth interstate commerce. The U.S. on the other hand, has chosen a different approach to data privacy legislation. Specific data privacy regulations have been developed for different sectors. For the Health care industry, "the Health Insurance Portability and Accountability Act (HIPAA)" has been implemented.¹⁹ The above-mentioned written rules continue to be applied in the era of big data gaining more importance with every data being collected.

Technologies Used to Ensure Security of Big Data

Authentication technologies confirm that the claims made for an individual are authentic. Authentication serves vital functions in many organizations. For example, authentication protects the access to organizations' networks, protects the identities users, and confirming that all users are genuine.²⁰ Furthermore, authentication prevents man-in-the-middle attacks and offers additional layers of security. "Bull eye algorithms can also be used to monitor all sensitive information" in the organization.²¹ In addition to authentication technologies, encryption data technologies are efficient means designed to prevent the unauthorized access from external sources. Its interventions protect and maintain "the ownership of data throughout its life cycle." Data masking on the other hand, replaces key data elements with unidentifiable values. Since it is not used for encryption purposes, the original value of information of the data cannot be changed from the masked value. "Access control once authenticated", allows users to enter information systems but once in, their access is still controlled by "an access control policy" that is based on rights and privileges. Security monitoring involves gathering and investigating network events to identify any intrusion. Auditing on the other hand, involves recording user activities in a chronological order. However, it is quite difficult to fully detect intrusions and implement prevention procedures on the entire system.²² To address this setback, a security monitoring architecture must be developed.

6.1.2. Big data analytics

Big Data comprises of a group of sets of data that are so unique and "complex that they cannot be processed using traditional data processing methods." There are several drawbacks in the collection, analysis, and transfer of Big Data. The challenges often arise due to the large pool of sources that provide data for Big Data. The data sources include; social network data,

financial data, multimedia data, data from Enterprise resource planning (ERP) sources, Internet of Things, and data from mobile apps. Big data analytics assesses large volumes of data and uncovers patterns that are hidden determining their correlations.²³ Technology has made it possible for individuals to analyze their data and obtain answers. Additionally, big data analytics allows organizations to collect their data and use it to locate new opportunities. This in turn results in improved efficiencies, higher profits, and improved customer satisfaction Rates.

6.1.2.a. Approaches in big data analytics

Data used as inputs for Big Data analytics mainly focuses on “volume, velocity, variety, veracity, and value.” Volume is used to explain the large amounts of data generated per second. If data is viewed from this perspective, then it means that most data sets are too large to be stored in basic technology and can only be stored in big data tools.²⁴ Velocity on the other hand, is the amount of speed whereby new data is generated and moves around. Technology has made it possible for data to be analyzed while it is still being generated. Veracity simply means that the data is trustworthy. However, with the many different types of data, information quality and accuracy are not always fully controlled. Variety is associated with the different kinds of data currently being used. Big Data technology has allowed for the analysis and bringing together of different kinds of data for different sources. Lastly, value allows Companies to generate value from their big data.²⁵

Big Data analytics is increasingly being incorporated in daily practice especially for organizations purposing to construct valuable information from Big Data. The deployment of big data analytics tools is used by organizations to improve the efficiency of operations, create new revenue streams, and gain a competitive advantage over rivals.²⁶ Furthermore, to facilitate the decision-making process, organizations should adopt efficient means of processing large

volumes of data. Big Data analytics uses analytic methods to examine large datasets. However, for Big Data analytics to achieve its objectives and improve the business environment, it should use the correct tools and approaches. Some of the approaches that organizations have adopted to facilitate Big Data analytics include descriptive analytics used to scrutinize data and to define the current state of affairs in the organization.²⁷ Descriptive analytics scrutinizers produce reports and alerts.

In addition, organizations use inquisitive analytics to probe data to accept or reject a business proposition. Predictive analytics focuses on forecasting and statistical modelling for future growth and possibilities. Prescriptive analytics is concerned with the optimization and randomization of processes to assess how the business can enhance its services in a cost-effective manner. Lastly, pre-emptive analytics involves having the capacity to take action about events that have the potential to influence the performance of organizations.²⁸ These analytical methods have been shown to support the decision-making process and improve the overall performance of the organization.

Big Data analytics requires a comprehensive approach to help businesses formulate a business strategy and synergize both its technical and analytical aspects. In line with this, Big Data must agile.²⁹ For businesses, agility is the ability to identify change occurring in both the micro and macro levels. Therefore, a strategic approach to Big Data should ensure that agility is attained. Enhancing agility relies on five major modules including; business decisions, data, user experience, quality dimensions, and people.³⁰ Overall, a comprehensive framework to conduct Big Data analytics can help businesses become agile, formulate organization-wide strategies, and to optimize the process of Big Data analytics.

6.1.2.b. Benefits of big data analytics

Commonly used data mining activities involve finding unique relationships between datasets. Big data analytics on the other hand, comprises of the storage and processing of large volumes of data sets.³¹ Commonly used technologies include; MapReduce and Traditionally Hadoop. However, with advances in technology, more advanced tools are being used to process big data. These technologies include; “Google’s BigQuery data analytics service, Amazon’s Kinesis data processing service, and the Redshift hosted BI data warehouse.”³² With these advancements, there are several benefits associated with analyzing big data for organizations. First, Big data technologies are effective in cost reduction. Cloud based analytics and other big data technologies help organizations move data to enterprise warehouses and access it as needed. Second, analyzing big data improves the decision-making process. Big data analytics provides in-memory analytics that allows organizations to make decisions at a faster rate. Third, improvement of organization’s products. Big data analytics allows for the creation and improvement of products for consumers allowing offline businesses to stay relevant while competing with online businesses. Lastly, Fraud detection. Big data analytics has allowed organizations to harness data and develop solutions at a relatively reasonable and affordable cost.³³

Cloud-based big data analytics involves the provision of analytics services either by a public or a private cloud. This form of data analytics relies on a wide range of analytical methods that are accessed through a web browser. Cloud-based big data analytics has ensured that there is more data to analyze. Additionally, it has ensured that large volumes of records are available with several key attributes. For businesses, cloud-based big data analytics provides on-demand self-services allowing them to expand their services quicker and without any human assistance.

Likewise, information is made available over the network allowing anyone in the organization easy access from different devices. By using cloud-based data analytics, businesses can pool their resources and apply them in a multi-tenant model. These resources can also be increased and decreased at ease and within a short span of time. Lastly, cloud-based data analytics is cost-effective allowing resource usage to be effectively monitored and changed accordingly.³⁴ As evidence shows, cloud-based big data analytics allows for resource pooling, provides on-demand self-service, and improves cost efficiency for businesses.

One of the main characteristics of big data is dealing with large amounts data. This has allowed for high volumes of data to be processed leading to the evolution of storage systems.³⁵ For “situations where it is difficult to predict storage needs”, there is provision of horizontal scalability. Furthermore, by applying nodes, big data can improve performance and increase capacity and throughput. Big data also provides several financial benefits to organizations.³⁶ Businesses have access to large volumes of storage at relatively cheaper prices. As a result, companies can process more data at relatively the same price thus improving their competitive advantage. By adopting big data technologies, businesses can improve their products, design new business models, assess consumer behavior, improve customer satisfaction rates, increase sign-ups, provide a personalized customer experience, and create a holistic vision for their organization.³⁷ Usually, traditional organizational models store information in silos both at the departmental and technological levels. However, the use of big data allows businesses to integrate information allowing other departments to use the information. Data-driven marketing enables businesses to be more assertive and use measurable actions. Since marketing is highly dependent on customer preferences, data-driven marketing allows businesses to monitor consumer profiles and send them communication policies at the right time.³⁸ Big data allows

businesses to connect more with their consumers, increase consumer satisfaction, improve on their products and services, and facilitate inter-departmental data sharing.

6.1.3. Privacy in the age of surveillance technology

In line with current technological advancements, the amount of data created by the internet has drastically increased. With this large amount of data, privacy must be ensured. There are several mechanisms that have been adopted to improve data privacy. These mechanisms are usually grouped based on their data generation capabilities, storage, and data processing. During the data generation stage, access is restricted and falsifying data techniques used. Privacy during data storage phase is maintained using encryption techniques. These techniques include; “identity-based encryption, attribute-based encryption, and storage-path encryption.”³⁹ Big data faces several privacy concerns. In the absence of big data security, data stands the chance of being compromised easily.

6.1.3.a. Privacy issues in big data

Privacy refers to the privilege an individual has in controlling how their private information is obtained and shared. Data privacy is the ability that a person or a group of people have to prevent their personal information from being shared. The main user privacy issue associated with big data is the identification of personal and private information during its transfer. Security on the other hand, involves the process of using technology to defend information.⁴⁰ In addition, training to identify unauthorized access, disclosure, modification, and inspection further improves on security. Data privacy mainly focuses on the use and control of individual data. Data privacy focuses on designing policies that guarantee that consumers’ personal information is obtained, shared, and utilized appropriately. Moreover, data security

focuses more on providing data protection against any form of malicious attack and data misuse.⁴¹ While data security is essential towards protecting individual's information, it does not sufficiently address rising privacy issues.

There are several strategies that various organizations use to protect big data. The foundations that organizations rely on supports privacy policy management to control access to data that is stored in big data platforms. Additionally, privacy policy management supports the generation of enforcement monitors and the use of the monitors in the target analytical platforms. Businesses are continuously generating large volumes of data.⁴² And with the increased focus on large volumes of data more avenues are created to help in data processing over varying domains. However, the protection of big data puts the user's privacy in frequent danger. Furthermore, ensuring that privacy terms are adhered to is a challenge in current big data mining processes.⁴³ It is, therefore, the responsibility of developers to verify whether their applications are in line existing privacy policies and agreements and whether private information is kept private in the face of the changes in privacy.⁴⁴ To address the aforementioned challenges, organizations should identify the need to provide new contributions in the testing procedures.

With the growing power of big data analytics, new privacy concerns are being created. "Actions taken by businesses as a result of big data analytics" may result in privacy breaches for those involved.⁴⁵ Additionally, with a lot of data and more powerful big data analytics, it is increasingly becoming difficult to remove the ability to identify individuals especially with the absence of rules established for anonymous data files. The main key missing is usually the establishment of rules and policies to guide the use of anonymous data files. Moreover, if data masking is not appropriately used, big data analysis could expose individuals whose data has been masked. Organizations must therefore establish effective procedures to use in data masking

to preserve privacy. Many organizations still do not realize that there are risks associated with the use of data masking that could result in breaches in privacy. Big data analytics are also not fully accurate. “The data files usually used for big data analysis often contain inaccurate data and use data models that are not accurate.”⁴⁶ This further increases the risk of more inaccurate data being added to data sets thus affecting the decision-making process for organizations that rely on this data. Using big data analytics to narrow down on job candidates could result in discrimination. Likewise, there are few legal protections that exist for individuals whose data has been obtained without their consent. While most government organizations have called for more legal measures to be implemented to protect privacy while using big data analytics. There are also concerns for e-discovery allowing organizations to identify and produce documents that will facilitate litigation. People are also concerned that big data could make it even more difficult to obtain patents since organizations will be overwhelmed with the large amount of data analysis required to determine if submitted patents are unique or not.

Lastly, one of the concerns that is the focus of this analysis is the unethical use of big data. Big data analytics can be used incorrectly to influence behaviors. Organizations can use big data to make business decisions that fail to account for the involvement of human lives. So, when personal information exposed, then it has the potential to damage lives. Therefore, it is ethically justified to improve big data privacy in the age of surveillance technology.

6.1.3.b. Surveillance technology and privacy

While it is essential to ensure privacy in this digital age, it is also essential to analyze the normative and descriptive dimensions of this concept. Theoretically, both the descriptive and normative dimensions of digital data privacy can be distinguished. In normative perspectives, “the focus is usually on the reasons to why privacy is essential for individuals to lead a full life.

The descriptive perspective on the other hand, strives to ascertain the degree of privacy that individuals enjoy without taking a more normative stance about the concept.”⁴⁷ This distinction should not take away one key fact: privacy is not fully neutral. Rather, there is a positive side to it. An invasion of privacy results in the violation of something that is valuable and deserves protection. However, there exists questions as to why privacy should be ensured. In the digital era, the existing threats to privacy due to big data applications is widely recognized.⁴⁸ However, the feelings of resignation still exist.

Traditionally, privacy was viewed as the right of an individual. However, in the last decade, this definition has been widened to regulate the structures of social life. Organizations such as the European Court of Human Rights emphasized that data protection should be the right of an individual and it should not be taken away. In literature on the other hand, scholars have separated themselves from taking a personalized approach choosing instead to focus on the social dimensions of privacy.⁴⁹ For policies on privacy, the distinction between focusing on privacy as a social value has additional importance. On one hand, emphasis is placed on a person’s right to decide on what their personal interests and transparencies are. Emphasis should also be placed on institutional measures that ensure social interactions and relationships are protected.

In the digital age, there has been loss of autonomy. The digital age is full of hidden cameras in addition to multiple surveillance devices. This intense form of scrutiny and the resulting invasion of privacy that it causes, have completely transformed how many view privacy. What concerns many is that the constant observation that could result to one feeling the interiorized gaze of another individual.⁵⁰ As a result, the individual’s autonomy is at risk. In other scenarios where the observed individual is impeded to follow their own impulses, loosing

privacy means that they have lost their autonomy. Loosing autonomy as a result of consistent surveillance is even more striking when one considers the collection and storage of information. Collecting individual data through profiling is often beneficial for organizations. By using invisible algorithms, organizations can convince people to participate in the organization's activities thus improving their performance.⁵¹ However, this widespread use of algorithms in the decision-making process significantly contributes to the loss of a person's autonomy.

The privacy of individuals today is under threat. Online websites are full of privacy traps. This is evidenced in the way the virtual sector targets adverts to specific age groups. Additionally, there are numerous age of consent issues that arise since most sites only require one to confirm that they are 18 years or older by just clicking on a button.⁵² Other risks are seen in apps that provide free services and also review sites which link an individual's email address to existing profiles for the purpose of tailoring marketing advertisements.⁵³ Currently, individuals are living in a world dominated by targeted advertisements making it more difficult for them to access the internet without surrendering some form of privacy. People need to push politicians and lawmakers to develop clearer legislation regarding the right to privacy for all.

6.1.4. Ethical issues in big data and surveillance technology

Organizations that are using Big Data obtain data from several sources and use it to create knowledge, tailor products, and make better decisions concerning their future growth. However, big data has constantly received criticism for breaching privacy regulations and being discriminatory.⁵⁴ For example, facial recognition technology is currently used by social networking sites and other websites to identify individuals in a picture.⁵⁵ Additionally, license plate readers have been accused of being used by private investigators and placed on vehicles to

collect license plate information. GPS, on the other hand, has been used for location-based stalking and as a homing beacon.⁵⁶ In healthcare, Big Data is used to discriminate individuals applying for insurance and developing health scores from purchase habits. In law enforcement, Big Data is used to access smartphones without warrants and identifying criminal suspects by reviewing their web browsing habits.⁵⁷ The aforementioned examples illustrate the current misuse of Big Data which ultimately creates ethical concerns and privacy violation issues.

6.1.4.a. Ethical issues in big data analytics

Big Data is usually believed to be morally neutral and has unique advantages that outweigh their costs. Many reports testify to the ethical neutrality of big data but largely ignore the ethical shortcomings of big data. Furthermore, data analytics does not consider the ethical analysis in practice.⁵⁸ To fully understand the ethics of big data, it is important to analyze the big data industry supply chain. In traditional business models, supply chains refer to several organizations collaborating to deliver value by taking raw materials and transforming them into finished products. All supply chains have grave ethical issues in both their downstream and upstream transactions. The downstream uses of big data can also lead to questionable outcomes. The harmful effects of using big data include; value destruction, diminished rights for stakeholders, and disrespect to everyone involved in the entire process. There are also issues of violation of confidentiality agreements at the disclosure stage from upstream sources.⁵⁹ Harm associated with the use of big data can be determined by analyzing how value is created and destroyed for people. Finally, categorizing individuals under certain titles is extremely disrespectful. Moreover, when individuals are categorized based on the personal history, they feel objectified. Big data aggregators often classify individuals based on events that occur to

them.⁶⁰ Even without the destruction of value, individuals can be disrespected and objectified using big data.

Big data is not just a business or a commodity, it can be used as a weapon. There are cultural and ethical issues that are created when organizations negotiate how information is exchanged. Many people use Google to access the internet. However, their project called “Dragonfly”, intends on creating region-specific versions of its apps and other services that are in line with the free speech restrictions that are actively being enforced in China. By rolling out this project, Google is becoming complicit in efforts by restrictive regimes to censor their people.⁶¹ Unfortunately, with the rapid of growth in data science, the ethical issues associated with data collection, storage and use are not fully understood. When it comes to conducting research in medicine, there are multiple well-established guidelines that govern ethical issues that might arise. These guidelines act as the basis for granting ethical approvals for studies dealing with patient data.⁶² However, there are many sides of human data usage that go beyond the stipulated ethical guidelines.

Privacy self-management involving notice and consent accords users the option of controlling their data by allowing them to revoke access to their data by unauthorized individuals. However, since personal data is always collected and analyzed, it stands the chance of being abused.⁶³ Furthermore, consent is not always understood and if the user does not acknowledge that they have consented, they might not be allowed to access certain services. This, therefore, makes agreeing to terms obligatory and not optional. In an ideal world, data transparency should be ensured during data collection all through to processing.⁶⁴ Additionally, stakeholder groups should be adequately notified about the purpose of data collection, how it is collected, stored, and processed. They should also be informed of all third-party involvement in

data processing. Users should also be assured that the data they will provide will not be sold or transferred to other parties without their consent. However, this will only work in an ideal world. Therefore, new ways that can ensure that user rights are protected must be implemented.⁶⁵ Furthermore, new strategies should be implemented to define the future of data usage and how the data will be governed and supervised to avoid cases of data abuse.

It is also important to recognize that simple answers cannot be given to the complex moral problems associated with data. This is mainly due to the fact that the data environment is changing ever rapidly.⁶⁶ Instead of focusing on coming up with answers to problems, efforts must be directed towards removing confusion and ambiguity to be able to implement principles effective principles to preserve the privacy of individuals.⁶⁷ Furthermore, in investigating ethical matters, it is important to consider the current and future use of data. The misconception that technology will facilitate the development and implementation of tools to handle vast data sets and issues in big data should be changed. Many people still do not know how their information will be put to use in the future or what additional data they will be associated with. Therefore, we cannot successfully classify data sets as either being public or by their potential use.⁶⁸ Overall, while progress is being made in solving issues with big data, there is still more progress to be made.

6.1.4.b. Ethical principles to protect privacy in big data

Data privacy focuses on access, use and collection of information while ensuring that the source's legal rights to the data are observed. Additionally, data privacy refers to freedom from access by unauthorized individuals, the inappropriate data use, and accuracy when information about an individual is collected using technology. Data privacy also involves the right to correct or inspect data. Protecting data privacy is of the utmost importance.⁶⁹ This is because of the

ambiguous nature of the current information-intensive environment. Technological advancements have several benefits to businesses including increased market transparency and increased information sharing. The disadvantages include; socio-techno risks such as identity theft, cyberterrorism, and information warfare. Furthermore, opportunities have been increased for cybercriminals to exploit.⁷⁰ The need for data privacy protection is an essential information security function to ensure that data privacy policies are successfully implemented.

Ethical principles provide a wide range of high-level context that can be used to resolve ethical issues. General ethical codes protect vulnerable populations whose data can be used to harm them. Additionally, the role of ethical codes is to preserve privacy in a manner that users find acceptable.⁷¹ They should also ensure that data is used in a manner that provides maximum benefit to the public. For a start, the ethical principles should include objectives such as integrity, responsibility, objectivity, trustworthiness, efficiency, and fairness.⁷² Furthermore, data privacy protection frameworks should be based on already established models such as “the International Data Privacy Principles (IDPPs), the Hong Kong Data Protection Principles of Personal data (DPPs)” and the hexa-dimension metric operationalization framework.

According to international data privacy principles, “privacy in data can be achieved by combining both technical and social solutions. Additionally, technical solutions focus on safeguarding information from access by unauthorized individuals.”⁷³ Social solutions on the other hand, are dependent on creating awareness and acceptability among individuals about how their data is being used. Furthermore, social solutions ensure transparency and confidentiality. In addition to applying social solutions, the third element of improving privacy is ensuring compliance with laws that protect data.⁷⁴ To enforce data privacy rules globally, international data privacy principles should consider European standards including General Data Protection

Regulation, U.S. standards including the U.S. Federal Trade Commission's Fair Information Practices, Asian regulations and international benchmarks including the Organization for Economic Cooperation and Development.⁷⁵ The Hong Kong Personal Data Privacy Ordinance is usually used as the standard that many data protection laws are based on. The guidelines have eight key principles including; the principle of collection limitation, data quality principle, the principle of specifying purpose, limitation of use principle, security safeguards, the principle of openness, individual participation principle and the principle of accountability.⁷⁶ The Hong Kong Personal Data Privacy Ordinance in collaboration with other guidelines strive to do what is just and to protect individual right.

Ethical considerations associated with processing of personal information in big data have been the subject of growing global discussions. So much so that "the Council of Europe's Consultative Committee Convention 108" provided guidelines on how to protect individuals during the processing of personal information.⁷⁷ The major principle addressed in the guidelines is the ethical use of data where during personal data processing, controllers must take into account the ethical and social implications ensuring that the commonly accepted ethical values are observed. Furthermore, societal interests and norms should not be prejudiced. In the United States, "the Information Accountability Foundation (IAF)" has worked closely with big data ethics initiative for a considerable amount of time. The IAF further sets out ethical principles to facilitate innovation and to protect people's rights to privacy. The ethical principles presented should also be fair, beneficial, transparent, and just, performed with the utmost accountability. The need for an ethical-based approach largely depends on "the size of the data set and the amount of personal data processed within them."⁷⁸ A more comprehensive approach should incorporate the services of an internal ethics committee to collect and analyze data.

6.2. Surveillance & Privacy in Next-generation Personalized Healthcare

While the digitization of healthcare presents unique opportunities for the analysis of medical information, evidence shows that electronic records are easily shared and manipulated thus putting their use under intense ethical scrutiny.⁷⁹ Furthermore, while care has improved with the use of advanced technologies, concern is mounting that these same technologies are resulting in significant unintended consequences on patient safety. On one hand, the availability and use of health-related big data offers significant benefits to biomedical research. On the other hand, the use of health-related big data raises several ethical and legal challenges including; compromising individual's privacy while also affecting the public's demand for transparency and fairness in the use of big data.⁸⁰ In addition to the lack of appropriate data storage infrastructure, data heterogeneity and data protection have been listed as some of the major infrastructural issues in big data healthcare.

Over the years, some of the aforementioned issues have been addressed. However, other issues such as the academic and commercial use of big data, data ownership, data control and data access rights, have largely been ignored. It is, therefore, imperative that comprehensive regulatory policies be developed to protect big data subjects. New computing safeguards that ensure the protection of identifiable information should also be implemented.⁸¹ The goal of this section is to highlight the ethical issues associated with big data analytics in next generation healthcare. Additionally, supported by evidence-based research articles, this section will criticize electronic surveillance measures used in healthcare that offer little-to-no protection to personalized information. The section will conclude by providing effective measures that protect patient privacy and other ethical issues in next generation healthcare.

6.2.1. Review and background of personalized healthcare and big data analytics

Many patients are increasingly being drawn towards care customization. For many healthcare professionals, the doctor-patient relationship further emphasizes the need for customization of healthcare services. Some of the concepts that characterize personalized healthcare include; patient-centered care and personalized medicine. Patient-centered care involves the organization of patient management to address all the needs of the individual patients. Personalized medicine on the other hand, focuses on tailoring treatment to suit the patient's unique biological characteristics and genetic makeup.⁸² In the same light, "Augmented Personalized Healthcare (APH) is poised to improve the entire healthcare process by personalizing the integration and use of physical, cyber, and social data obtained from a variety of devices including; wearables, Electronic Medical Records and the Internet of Things (IoTs)." Augmentation is the process whereby, all the signals at the individual and population level obtained from analyzing data, are aggregated and integrated. Once these signals have been collected, they are converted into actions that ultimately results in the improvement of health-related outcomes.⁸³

The introduction of new technologies in healthcare has made it possible for large amounts of data to be captured over a period of time. However, despite the adoption of medical electronics, a majority of the data collected remains underutilized and even wasted. To solve this problem, researchers are increasingly adopting the use of big data analytics.⁸⁴ Big data analytics refers to the analysis of detailed, massive, and varied data sets with the goal of delivering sophisticated solutions. Furthermore, big data analytics has been shown to effectively convert data-scarce decisions into more data-rich decisions thus, providing effective solutions for major problems in healthcare. Evidence also shows that big data analytics has significant impacts on

patient care, diagnosis, and the treatment of diseases among other areas.⁸⁵ However, researchers are worried that privacy risks associated with big data analytics have still not been addressed.

6.2.1.a. Personalized healthcare

Due to recent advancements in technology, the healthcare sector is shifting from providing hospital-centric care to providing personalized and individualized services. Currently, several clinical procedures such as pressure and diabetic monitoring are being done remotely and in real time. Furthermore, the use of Data as a Service (DaaS) has made it possible for remote monitoring of the healthcare system to be conducted especially in developing countries. Similarly, the introduction of cloud computing, wearable technologies and fog computing, real-time monitoring of patients, diagnosis, and communication with healthcare providers has been made possible.⁸⁶ Electronic health records (HER), for example, have been used to develop “predictive models for the risk of disease onset and deterioration” thus, enabling healthcare providers to better care for individuals with chronic infections. Integrated telecare programs have also been implemented for patients who are showing signs of improved clinical outcomes.⁸⁷ However, despite these benefits, continuous evaluation must be implemented and clear outcome measures set, for best results.

The internet of Things (IoT)-enabled technology is transforming healthcare from a conventional hub-based system to a more personalized healthcare system. The rapid integration of wearable devices has also played a critical role in the adoption of IoT in healthcare.⁸⁸ Besides, the use of IoT as a source of data streams has been used as an effective source of user data for healthcare systems. By using these data streams, healthcare professionals are able to detect and even make predictions that result in improved quality of life. IoT also plays a significant role in the monitoring of ailing individuals through wearable sensors. These wearable sensors are

connected to patients and they frequently monitor users and send alerts in the case of changing health conditions.⁸⁹ However, just like other forms of healthcare technologies used in personalized healthcare, there needs to be better ways of addressing issues associated with data security and privacy.

For personalized healthcare approaches to be successful, several radical actions must be taken. Firstly, there needs to be increased education and training of healthcare professionals to achieve improved genetic literacy. Secondly, there needs to be increased patient engagement to ensure that patients are well-informed about their health and can therefore, make better healthcare choices. Thirdly, and arguably the most important approach, is improved governance, consent, and trust in the entire healthcare system. With the increasing use of personalized healthcare, concern is rife over the use and sharing of personal biological data. To improve on this, more formalized approaches must be developed.⁹⁰ Moreover, in an age where demographics, globalization, and immigration are changing, old problems are taking new forms and new ones are arising. New technologies have also introduced several ethical issues including; genetic engineering, cloning, and tissue transplant.⁹¹ Additionally, issues associated with the protection of patient data are also emerging.

While personalized healthcare is hailed as a paradigm shift in the approach of disease prevention, diagnosis, and treatment, there are several ethical issues that arise that must be addressed. For example, health-related IoT (H-IoT) raises several ethical problems originating from the risks associated with using internet-enabled devices, health-related data sensitivity, and the impact they have on healthcare delivery. One of the primary challenges of H-IoT is to ensure that all the protocols set aside for data sharing are scientifically reliable in addition to being ethically responsible.⁹² Furthermore, privacy is critical considering the fact that H-IoT have the

capability of creating activity records of great proportions. Furthermore, users might be oblivious of the extent to which their personal information can be accessed outside of the scope in which they are developed.⁹³ Protocols that govern the generation, transmission, and storage of data should be designed in ethically acceptable ways. Similarly, the psychological unavailability of H-IoT especially when it is used in personal spaces can also result in ethical problems. A H-IoT device that has been used for a long period of time may be forgotten and individuals might forget to renew their consent. As a result, the device might continue to monitor the patient without their consent.⁹⁴ Concerns over information privacy in H-IoT have also been rife. Guaranteeing information privacy involves preventing the spread of user information, health status, and history to unauthorized third-party individuals. As highlighted above, there are several ethical issues associated with the design and use of IoT in healthcare. While a majority of these issues can be addressed, many are still being seen in the actions of H-IoT providers.

In addition to H-IoT, parallel sequencing and genomic profiling have made it possible for healthcare providers to individualize care and minimize variations in outcomes. To realize the full benefits of genomic profiling, it is imperative that electronic tools capable of delivering large amounts of data be adopted. Tools such as the electronic health record (EHR), for example, can be used to notify primary-care physicians and patients of any anomalies in genetic testing results and in so doing, recommend appropriate interventions.⁹⁵ Additionally, the electronic health record could produce patient-focused literature to increase awareness and to also improve compliance with surveillance procedures. However, the inclusion of genomic data in EHR results in several ethical issues. Patient access and data security are some of the main issues in genetic information sharing. Therefore, patient portals that are used to deliver genomic results should be protected to prevent breaches from unauthorized individuals.⁹⁶ Lastly, policies should be

developed to strengthen the privacy features of EHRs and to ensure that patients and healthcare providers put in place control measures on access to test results.

6.2.1.b. Big Data and its role in personalized healthcare

Big data is associated with large volumes of data that cannot be managed using already available traditional internet-based devices and software. In healthcare, the development of wellness monitoring devices and related software has gained momentum. These devices also generate alerts and share the patient's health-related data with care providers. The generated huge amounts of data are then analyzed resulting in the provision of real-time clinical care.⁹⁷ Currently, methods of big data management are in the development process specifically for real-time data streaming and analytics. Additionally, these methods are being developed to provide visualization solutions and to facilitate a better utilization of electronic medical records (EMRs) in healthcare. However, the use of big data faces several challenges including; finding storage for the large volumes of data. Furthermore, acquiring an on-site server network might be expensive for many healthcare providers. Additionally, data cleaning should be conducted on a regular basis to ensure accuracy, consistency, and relevancy. Handling big data is also difficult especially when the data is not organized perfectly.⁹⁸ To improve on this, all the clinically relevant information should be codified using medical coding systems. Lastly, big data use in EHRs faces several accuracy issues.⁹⁹ This can be improved by the use of patient self-report questionnaires.

The healthcare industry is currently experiencing a shift from being disease-centered to a more patient-centered model. In a patient-centered model, patients are allowed to be active participants in the care process and receive care based on their individual needs. At the same time, the potential for personalizing healthcare is increasing. Advanced data analytics plays a

crucial role in this shift.¹⁰⁰ To date, data can be collected from EHRs, telemedicine, genomic data, mobile apps, and behavior and socio-economic indicators. Besides, the data sharing approach can significantly improve patient outcomes and the delivery of evidence-based decision making in healthcare. The use of big data in healthcare improves the process of diagnosis and ensures the effectiveness of treatments by ensuring that early signals of disease are identified. Big data also widens the possibilities for preventing the occurrence of diseases by identifying the risk factors of the diseases. Likewise, big data results in improvements in pharmacovigilance and in patient safety by allowing individuals to make informed medical decisions.¹⁰¹ Lastly, the use of big data in clinical settings allows physicians to predict treatment outcomes.

While the use of big data in healthcare is beneficial for both patients and care givers, there are numerous ethical challenges that come with its use. Some of these ethical challenges include; compromised privacy, lack of respect for personal autonomy, transparency, trust, and issues associated with healthcare funding.¹⁰² Big data researchers have also used consumer purchasing records and social media to determine associations between health and other daily activities. This in turn has resulted in privacy issues. Furthermore, research conducted through social media has been greatly criticized for not obtaining informed consent from participants. This information is also not subject to any form of oversight, thus, not regulated.¹⁰³ As concerns rises on the privacy violations associated with big data, countries such as Canada have adopted legislation that prohibits life insurers from using individuals' genetic data.¹⁰⁴ The emergence of bioresources to be used in future unspecified research has also raised several issues centered on consent. However, the fear of any form of misuse has been mitigated by genetic discrimination legislation in addition to already existing security mechanisms. Big data can also be subject to mass government surveillance which further threatens the privacy of individuals. Irrespective,

regulatory frameworks might struggle to respond to the abovementioned challenges.¹⁰⁵ As such, do the benefits associated with the use of big data in healthcare outweigh the potential risks?

The inability to rely fully on data masking techniques coupled with the diminishing role of informed consent threaten the use of big data in healthcare. In the same light, the issue of data anonymization remains a challenge despite the growth of data science and other platforms that determine the extent to which data has been anonymized.¹⁰⁶ Despite the existence of regulations that define what identifiable data is, the multifaceted and unique nature of big data increases the likelihood of privacy threats to data. Furthermore, there is increased risk of weakening of data masking techniques in addition to the possible risk of re-identification of individuals.¹⁰⁷ The overreliance on consent is also becoming impracticable and unachievable in big data especially due to the fact that data might be used across multiple ecosystems that are not in the same context as the initial source of information. While in some cases individuals can be contacted and informed about the data use, it might not be possible to contact all individuals and request for consent.¹⁰⁸ In such circumstances, it is crucial that alternative and also ethically correct approaches be adopted to protect individuals whose data is being used.

To answer the question; do the benefits associated with the use of big data in personalized healthcare outweigh the potential ethical challenges? One must first familiarize themselves with the history of big data use in healthcare and the frameworks that have been put in place to minimize the potential risks. As highlighted in the research presented above, big data can make a significant difference. From its use in EHRs and EMRs, big data has played a significant role in the advancement of better health. However, the risk to data privacy violation is one of the critical issues associated with the use of big data in healthcare. Regardless, when human life is under serious threat and there is an opportunity to improve quality of care by using

big data, advantages always outweigh disadvantages.¹⁰⁹ In the next sections, more will be discussed on this issue and recommendations provided to improve on the ethical issues associated with the use of big data in healthcare.

6.2.2. Next-generation technologies in personalized healthcare

Personalized healthcare has received a lot of attention in recent years especially due to the shift from a one-size-fits-all model of treatment to one that embraces new approaches, including tailoring target therapies, to achieve the best outcomes. Personalized healthcare can be described as the implementation of prevention and treatment strategies that incorporate individual variability.¹¹⁰ The effective implementation of personalized healthcare requires the incorporation of different types of technologies including; IoT, cloud computing, artificial intelligence, and cyber-physical systems. IoT facilitates the integration of several smart devices to sensors, actuators and other computing resources. Cloud computing on the other hand, provides computational resources that facilitate the execution of diverse tasks while also providing results to multiple applications. In addition, the use of Artificial Intelligence (AI) and Machine Learning (ML) has also improved the quality, scalability, and robustness of healthcare services.¹¹¹ As new diseases are being discovered, healthcare solutions must be deployed using robust frameworks that not only provide high quality results, but are also time efficient.

Mobile technology is one of the technologies that is revolutionizing healthcare. By using this technology, healthcare providers are able to remotely monitor a patient's health. Additionally, healthcare providers are able to provide cost-effective home-based care to individuals suffering from chronic conditions including the elderly.¹¹² In addition to mobile technology, next-generation-sequencing (NGS) techniques have allowed for a more cost and

time effective sequencing of tumor DNA thus improving cancer research, diagnosis, and treatment.¹¹³ However, while these technologies have improved service delivery in healthcare, it is essential that their ethical implications be assessed and recommendations provided for their improvement.

6.2.2.a. Next generation technologies

The introduction of new forms of technology in healthcare is transforming how diagnosis and treatment of diseases are being done. For example, the use of 3D printers that are capable of making any type of object, has revolutionized the healthcare industry. By using these printers, physicians are now able to custom make titanium implants to suit patients' unique features. In addition, 3D printing can be used to manufacture specialty surgical instruments, facilitate pharmaceutical research as well as manufacturing medical devices.¹¹⁴ Regardless of its potential, 3D printing faces several ethical and regulatory challenges. One of the main issues centers on 3D bioprinting techniques and the lack of regulation to govern their application in personalized medical treatments. Additionally, patients enrolling in trials that assess 3D bioprinting might find it difficult to withdraw from them. This is mainly associated with the fact that a majority of these studies are irreversible, that is, tissues and cells that have been implemented may not be removed since this will lead to further harms to participants.¹¹⁵ It is inevitable that these technologies will introduce new ethical concerns for patients. Taking patients' fingerprints and other biomedical information will become routine. As a result, gathering data for the state will be made possible. This in turn will erode the notion of patient confidentiality.¹¹⁶

Individuals are also increasingly using digital media and digital health technologies to connect with healthcare. The increasing use of algorithm-driven data systems, self-monitoring devices, and smartphone apps are transforming the traditional concepts of illnesses and the

decision-making process employed in the treatment of these diseases. Artificial intelligence (AI) and the use of algorithms and machine learning to generate big data are also examples of technologies that are being used to improve the healthcare process. For example, AI is used to create personalized advertising based on data collected from individuals' past search histories.¹¹⁷ Furthermore, the internet has created opportunities for healthcare organizations to engage in healthcare marketing. Since social networking sites are frequently visited by many users on a regular basis, healthcare organizations are using this to plan their marketing strategies.¹¹⁸ Therefore, information technologies make significant contributions towards increasing efficiency and improving the overall health of communities.

Currently, individual aspects of human performance are being replaced with robotic capabilities such as surgical robots, service robots, and even rehabilitation robots. Furthermore, the increasing capabilities of these healthcare robots will see them being deployed in healthcare settings.¹¹⁹ Since the first healthcare robot, ROBODOC was created, the field of robotics has seen tremendous changes. Today, Da Vinci systems are taking part in surgeries handling tasks that are too complex or sophisticated for human surgeons to handle. Additionally, these robots make small incisions and control minimal hand movements. Rehabilitation robotics on the other hand, aid older individuals and patients with disabilities. Other types of robots, referred to as wearable exoskeleton robots, are worn by patients and thus assist them with movement. The wearable exoskeletal robots are usually attached to a specific body part to improve muscle strength, and even endurance.¹²⁰ However, similar to other forms of technologies applied in healthcare, there are several ethical and societal issues associated with the use of robots. For many ethicists, the concern has been about the prospects of intelligent, autonomous, and humanoid robots that offer services to the elderly.

Additionally, ethicists are concerned with the fate of nurses and other care givers when the healthcare industry fully adopts robotics. Other issues include; replacement and how it affects labor and its implications for the de-humanization of care.¹²¹ Furthermore, issues of autonomy have also been under review especially since not all healthcare robots are designed to be autonomous. Autonomy in this context refers to how robots are designed to carry out tasks without the intervention of humans. Robots also lack the capacity to make moral judgments or to deal with ethically challenging situations. Hence when faced with a moral problem and the robot is autonomous, it might make decisions that are not moral and that might negatively affect the patients' wellbeing. Lastly, similar to the issues that many forms of technology face, the use of robotics in healthcare raises several privacy and data protection issues including how they will collect data, store, and distribute it effectively.¹²²

Next generation sequencing (NGS) has the potential to conduct several activities including disease detection and the identification of pharmacogenetics markers that allow for treatment customization. Additionally, NGS has been used in the study of Mendelian monogenic disorders in addition to the study of cancer and cardiac diseases. NGS is the most preferred for the aforementioned conditions mainly due to its ability to test several genes over a relatively short period of time and with manageable cost.¹²³ Several companies are also offering NGS solutions in the form of whole genome sequencing and targeted NGS panels. Whole genome sequencing involves the sequencing of the entire genome to determine the presence of genomic variants that inform the diagnosis of unique monogenic conditions. Targeted NGS panels on the other hand, sequence a specific set of clinically-relevant genes, which are associated with certain conditions.¹²⁴ Today, studies that are investigating cancer are adopting this technology, due to its ability to detect high number of variants associated with tumor heterogeneity.

However, regardless of its widespread use, NGS poses three crucial ethical challenges including; privacy, return of results, and privacy. The large volumes of “genetic data generated by NGS present unique challenges for protecting privacy in genomic data.” Furthermore, the use of NGS presents challenges associated with informed consent as well as maintaining privacy protections. NGS also grants access to an individual’s entire genetic profile without providing appropriate measures to interpret the genetic information.¹²⁵

6.2.2.b. The future of personalized healthcare

The future of personalized healthcare is in artificial intelligence and precision medicine. While care must be taken when using these technologies, they offer much promise especially in their ability to combat the realities of the human nature which include; fatigue and inattention. Furthermore, the digitization of health-related data including the rapid use of technology are some of the factors that are facilitating progress in the use of AI in healthcare.¹²⁶ Big data analytics and AI are also being adopted by several healthcare organizations. Big data plays an important role in AI’s ability to identify medical coding errors, mitigate fraud, waste, and other forms of abuses in healthcare payer programs.¹²⁷ In addition to AI, the field of precision medicine is expected to transform the healthcare industry. Precision medicine strives to personalize care for all individuals. To achieve this goal, there needs to be access to large amounts of data. However, for precision medicine to be effective, fundamental changes must be made in the infrastructure and mechanisms of how data is to be collected, stored, and shared. Patients should also be educated on the benefits of sharing data. As a result, a continuously learning healthcare system is created with seamless connection between clinical care and research.¹²⁸

The future of how the healthcare industry deals with pandemics has been greatly affected by the COVID-19 pandemic. For example, researchers have discovered that there needs to improve digital platforms that facilitate the speed of response during such pandemics.¹²⁹ This is essential since it facilitates the understanding of the dynamics and development of a pandemic and how decision-making, aid prevention and control are done. Furthermore, researchers have discovered that integrating social networks with the IoT, new concepts emerge referred to as the Social Internet of Things (SIoT). By integrating the two, value is created in the advancement of management systems that incorporate big data analytics.¹³⁰ Furthermore, while the current COVID-19 pandemic has resulted a rise in the number of people soliciting medical help, physicians are concerned about the continuity of regular care and also, the consequences associated with the already implemented antiCovid measures. At the center of their concern is that this might result in poor population health in addition to negative consequences for the provision of primary healthcare in future.¹³¹ In addition, the COVID-19 pandemic has resulted in an increase in the adoption of telemedicine in ambulatory care settings. However, scientists are not sure whether the current increase in the use of telemedicine will continue after the COVID-19 pandemic is controlled.¹³² Lastly, the COVID-19 pandemic has several positive impacts on health workforces and how they practice in the future. There will be increased attempts to increase the flexibility of healthcare workers and how they respond to future pandemics.¹³³

The use of wearable devices is also expected to increase in the future thus, enabling continuous measurement of critical biomarkers for the diagnosis, monitoring, and evaluation of healthcare conditions. Point-of-care technology (POCT) significantly improves the treatment process by providing rapid and patient-centered treatment to individuals who have limited access to healthcare services.¹³⁴ Wearable biosensors have received increased attention over the years

due to their ability to monitor physical signals including blood pressure, heart rate, skin temperature, and even body motion to generate significant clinically relevant information. Furthermore, wearable devices allow for the continuous monitoring of people thus providing enough information to allow healthcare providers determine health-related issues and provide a preliminary medical diagnosis.¹³⁵ The development of wearable devices for long-term patient monitoring has also contributed to reduced healthcare costs especially for countries that have a large elderly population. Over the years, stretchable electronic devices have facilitated the implantation of systems in the deep brain, intracardiac area, and even the single-cell interior.¹³⁶ Besides, the elderly population's medical costs will also be significantly reduced thus facilitating the development of personalized healthcare.

The healthcare field has been slow in adopting electronic platforms such as electronic health record systems. However, evidence shows that the field is slowly adopting the use of artificial intelligence (AI) and robotics in its daily practices.¹³⁷ For example, AI is currently being used to facilitate the accurate diagnosis of medical conditions such as diabetes. Additionally, AI agents through the use deep learning and neural networks have accurately diagnosed and treated congenital cataracts with similar proficiency and accuracy as ophthalmologists.¹³⁸ However, one question that many researchers ask is if AI has the potential to replace doctors and other healthcare professionals. According to a study by Semigran and colleagues, the answer to this question is not yet.¹³⁹ According to the findings of the study, physicians significantly outperformed computer algorithms in diagnostic accuracy of 84% against 51.2%. However, the researchers observed that AI systems could perform better than human doctors when it comes to proposing diagnostic and management plans, if they are supplied with relatively large volumes of data that go beyond what can be manually analyzed. AI

also faces several morality and ethics issues especially when making decisions to harm a few to save many.

While many AI manufactures claim that this has been solved with the creation of an ethical knob, which allows patients to provide guidance regarding their moral wishes, another issue arises, inherent bias. Inherent bias is the process whereby AI systems are programs to have biases based on the biases of the ones who program them.¹⁴⁰ Strategies must, therefore, be implemented to minimize these biases thus making it possible for AI to be fully adopted in healthcare.

6.2.3. Surveillance and privacy of healthcare data and other ethical concerns

Big healthcare data has the ability to significantly improve patient outcomes and reduce the overall cost of health service delivery. However, healthcare data faces several ethical concerns including; preserving the security and privacy of patients. Privacy is the ability to protect data or information that contains personally identifiable healthcare information. Security refers to the protection against unauthorized access. Additionally, security focuses on protecting data from third party attacks and theft.¹⁴¹ In many healthcare facilities, patients' data is stored in data centers that have multiple security levels. Furthermore, despite many facilities acquiring different levels of HIPAA certification, a majority of them cannot guarantee patient security. Additionally, the inflow of large amounts of data from different sources overburdens storage and processing platforms that some healthcare facilities have.¹⁴² Hence, there is an urgent need for the implementation of big data governance before patients' information is subjected to analytics.

Public health surveillance also involves several ethical issues of concern. For example, in many occasions, surveillance data is obtained and used without the consent of the individuals

who are affected. Additionally, there are several infringements of privacy and violations of autonomy rights associated with public health surveillance. As a result, data sets are rendered unreliable.¹⁴³ Experts have also warned that data collection strategies that target vulnerable populations might result in discrimination and stigmatization. Public health surveillance encounters ethical challenges through every phase of implementation. Regardless, other researchers believe that obtaining informed consent during public health research is not mandatory. Some of the reasons for forgoing informed consent include; when the surveillance is necessary, effective, and when infringement in privacy is not heightened. Overall, designing of ethics guidance should mainly focus on overviews of ethical issues and arguments.

6.2.3.a. Big healthcare data security and privacy concerns

The introduction of machine learning techniques and AI have brought great promises for the increased use of big data. Big data has also facilitated complex disease diagnosis and resource allocation. However, with the benefits comes challenges, among them being privacy. Privacy can be connected to context in that, there are stipulated rules that govern the process by which data is obtained, the frequency, and purpose of the access. When these rules are disregarded, then privacy has been violated.¹⁴⁴ The person whose privacy has been violated often encounters consequentialist concerns. Deontological concerns on the other hand, do not focus on the negative consequences of a privacy violation. Rather, the concern manifests itself even in instances where an individual's private information was not used. In such situations, it is difficult to prove that an individual has been harmed since they are not aware of the privacy violation.¹⁴⁵

The use of big data in healthcare raises several ethical challenges mainly due to the personal nature associated with the enclosed information. In addition to the privacy concerns identified earlier, big data poses risks to personal autonomy, the need for transparency, fairness,

and trust. Furthermore, researchers have identified additional issues associated with heterogeneity, data protection, and also the lack of unique structures for data storage.¹⁴⁶ Ethical Review Committees (ERCs) and institutional review boards are therefore, faced with the ever-growing challenge of effectively evaluating research projects that involve big data. These review boards must ensure that they assess both the benefits and ethical risks associated with the studies. Many researchers have also lobbied for the creation of regulatory policies and computing safeguards to address major ethical concerns including protection of subjects' identifiable information.¹⁴⁷

Healthcare data are sensitive and more centralized compared to other forms of big data. As such, data privacy is one of the most challenging aspects of big healthcare data analytics. However, to reduce the occurrence of data breaches and privacy violations, special processing interventions including; digital identity encryption and de-identification, can be implemented.¹⁴⁸ Strategies for improving data security and confidentiality should focus on developing data protections that are effective and provide additional information security rules. Furthermore, healthcare facilities in the U.S. are currently tackling privacy issues by creating secure data clouds that implement privacy mechanisms including obfuscation to safeguard data privacy and confidentiality. To address concern regarding confidentiality of personal data, informational campaigns may be applied to educate the public on available data protection mechanisms and to also inform them of their data privacy rights.¹⁴⁹ Healthcare providers are also using tools such as data warehouses and decision support databases to allow analysts to easily access it thus encouraging innovation, information processing, and ultimately facilitating the decision-making process. Lastly, for data sets to be more effective, information governance activities should draw from several organizations.¹⁵⁰

Privacy is one of the main problems related to the big data paradigm. However, big data also suffers from a variety of other issues including statistical false positives. Missing incomplete data and errors associated with other technical interferences. Additionally, researchers have pointed out that one of the major barriers to conducting big data analytics is that available statistical software are not able to analyze the large file sizes.¹⁵¹ Besides, big data is constantly evolving and as such, it presents several setbacks in storing and analyzing the huge volumes of data. Conventional databases are, therefore, not able to store, process or even extract the data. As a result, there are challenges in quality and storage of data and lastly, data security and confidentiality. In addition to the abovementioned drawbacks, big data presents unique economic challenges for a majority of healthcare facilities who are faced with the dilemma of deciding between paying their personnel and adopting new forms of technology.¹⁵² Healthcare data is extremely sensitive and must be protected from access by unauthorized individuals. Therefore, data security is considered to be one of the most difficult endeavors to accomplish in healthcare.

Understanding the ethical consequences of big data and the existing regulations is not enough to satisfy all the needs of the ever-evolving data capabilities. There are five main areas of concerns including; informed consent, privacy, data ownership, objectivity and presence of a divide between individuals who have the resources to analyze big data and those who lack similar resources. Protecting the privacy and confidentiality of patient data requires the adoption of security safeguards and data confidentiality protections. Furthermore, the conversation has significantly shifted from only assessing privacy to investigating risks.¹⁵³ Other problems that have been associated with big data in healthcare include; problems with intellectual property ownership obtained from the analysis of data sets, difficulties in allowing access to individuals

with limited resources and lastly, evidence shows that data query mediation is full of errors and is laborious thus, affecting the reliability of research.¹⁵⁴

The introduction of large datasets in healthcare has both positive and negative outcomes in data storage and analysis. Moreover, big data challenges found in traditional analytic tools requires the adoption of traditional analytic tools in addition to the novel solutions obtained from other relevant fields.¹⁵⁵ While big data analytics offers several benefits to healthcare such as medical diagnosis, hospital monitoring, and improving patient outcomes; the ethical issues associated with it threaten to diminish its usefulness in healthcare. Therefore, more needs to be done to improve on privacy and security associated with big data analytics in healthcare.

6.2.3.b. Ethical issues associated with surveillance in healthcare

Public health surveillance refers to the systemic, ongoing, collection, and analysis of data to be used in public health for assessment and appropriate response. The ultimate goal of surveillance is to inform public health practice. Furthermore, surveillance relies on multiple data sources such as data obtained from social media and data collected during health surveys.¹⁵⁶ In public health surveillance, large volumes of real-time health data obtained from informed sources facilitate the early detection and prevention of health threat and the immediate response from authorities to control them. As a result, these informal sources of obtaining data have reduced the time it would normally take to transmit information. Furthermore, internet-based reports have improved communication and ultimately surveillance and the reporting frameworks.¹⁵⁷ Regardless of its success, public health surveillance faces several ethical challenges.

Provision of informed consent is one of the major challenges associated with public health surveillance. To strike a balance between protecting individual rights and pursuing

societal welfare, consent from participants is essential. Furthermore, to protect participants from physical or mental harm, written informed consent is usually obtained.¹⁵⁸ However, the adoption of the same in public health surveillance appears to be limited. In other situations, such as when individual interests are disregarded for the better good of the public, consent might not be viewed as being necessary.¹⁵⁹ Other researchers have also adopted alternatives to the traditional way of obtaining consent. When dealing with big data research, researchers often rely on broad consent. In this form of consent, research participants provide consent for all the classes of research. However, this form of consent is only considered acceptable when; it has been approved by an REC or when the right of participants to withdraw their consent at any time has been observed.¹⁶⁰ However, many argue that broad consent cannot be considered informed mainly due to the fact that future research is highly unspecified. Seeking consent electronically has been viewed as an ethically satisfying alternative.

In addition to the issues of informed consent, protection of subjects' privacy is also a major ethical issue in public health surveillance. Often, public health research and other epidemics forecasting studies collect sensitive information on their participants to the extent where they interfere with their privacy. Others might retaliate that full data anonymization is not essential for other public health surveillance initiatives since part of the collected data is not extremely sensitive and would therefore, have minimal impact on the privacy of participants.¹⁶¹ However, even when there is full anonymization of data, cross-referencing of data with other databases has the potential to eventually result in the re-identification of the data. As such, anonymization cannot be viewed as being sufficient to protect individuals' privacy. Besides, the long-life span of certain anonymized datasets, significantly increase the risk of re-identification and the occurrence of privacy breaches seen through the repetitive nature of data enrichment.¹⁶²

Re-identification is a real risk to the privacy of participants even when their data is anonymized. It is therefore crucial that researchers ensure they observe ethics and are held accountable for sharing anonymized datasets. The concept of justice in public health surveillance has been significantly influenced by the influenzanet. This has ensured that there is fair distribution of risks and benefits to all individuals. Nevertheless, a majority of the concern about justice can only be avoided if the surveillance results are shared evenly amongst all individuals involved.¹⁶³

There are several conditions under which conducting surveillance without obtaining explicit patient consent is ethically justifiable. However, this creates an ethical dilemma especially at the intersection of principles of public and clinical health ethics. The differing ethical priorities include the healthcare provider's duty and responsibility to ensure that patient's confidentiality and privacy is protected and the responsibility of the public health authority to improve the health of the community. Over the years, there have been numerous debates on whether public health surveillance violated participants' privacy. One area that this debate has been going is in HIV/AIDS research. In the 90s when questions were raised regarding maintaining participants' privacy during HIV/AIDS research, many states in the U.S. started using non-name-based identifiers. However, after a while they realized that their studies were unable to meet the set performance standards. Seeing this, the states reverted back to using name-based HIV reporting.¹⁶⁴ While biomedical ethics focuses on the four main principles of autonomy, beneficence, nonmaleficence, and justice.¹⁶⁵ The field of public health ethics focuses on the population and the overall well-being of the community. As such, as long as public health surveillance practices refrain using negative and harmful operating principles, they are considered ethically justified.

While surveillance is crucial for effective outbreak and epidemic responses, it is often the subject of several ethical battles. Since surveillance uses name-based reporting, it often triggers concern about participants' privacy, stigmatization, and even discrimination. While there exist international guidelines on the issue, specific ethical guidelines for the surveillance of certain diseases have been missing.¹⁶⁶ To fill this gap, the WHO has developed unique public health surveillance guidelines to act as a guide on how surveillance can be conducted in an ethical manner.¹⁶⁷ The guidelines also strive to answer fundamental issues like the common good, reciprocity, equity, solidarity, and the overall wellbeing of the community. The guidelines also emphasize on the social and public values that frame the biomedical principles of autonomy, privacy, and individual rights. Overall, the WHO Guidelines for Ethics in Public Health Surveillance provide the foundation for creation of ethical national surveillance systems.

6.2.4. Protecting patient privacy in next generation healthcare

The current healthcare industry is experiencing a technology boom where many individuals are embracing mobile technology, wearable devices, and cloud computing. As a result, security measures to protect the information shared on these platforms must be implemented.¹⁶⁸ This rising use of mobile devices, the Internet of Things, and cloud computing provides several access points where data can be accessed illegally. Besides, while many healthcare organizations are adopting these technologies, they still have not realized the benefits of implementing appropriate safeguards for data privacy and security.¹⁶⁹ One approach to use to limit the privacy violations is to limit access to patient data. Under this approach, sharing of patient data should only be retained for a limited duration. However, care should be taken to ensure that overprotection of patient data does not harm data-driven innovation. In addition to

limiting access to patient data, researchers can pseudonymize data. Privacy audits can also be conducted to ensure appropriate use of data is maintained.¹⁷⁰ Overall, healthcare organizations should ensure that they implement healthcare data security solutions to protect patient data.

Next generation sequencing (NGS) has introduced several opportunities for using genomic information in both research and clinical practice. However, the use of NGS brings forth several complicated challenges associated with privacy and informed consent. At the primary level, obtaining informed consent from genomic study participants is critical.¹⁷¹ For many researchers, using a broad consent process whereby participants are informed of the general risks of participating in the research, is enough in ensuring that the participant is aware of the risks. However, this does not protect the participant's autonomy. Researchers should use a more dynamic consent process that ensures that research participants are informed of all the risks, including future ones.¹⁷² Lastly, guidelines should be developed to ensure that patients remain unidentified in re-identification studies.

6.2.4.a. Security issues with healthcare information technology

The increasing adoption of technology in healthcare has resulted in greater precision. However, improved cybersecurity interventions are still lacking. Evidence shows that cybersecurity attacks in healthcare are increasing.¹⁷³ In healthcare facilities, “Personally Identifiable Information (PII) and Protected Health Information (PHI)” are located in multiple health information systems. Cybersecurity interventions are designed to protect PII and PHI by ensuring that electronic systems, devices and networks are protected from external or internal attacks. However, while other fields have advanced their cybersecurity measures, the healthcare industry is lagging behind in implementing state-of-the-art protections. To make cybersecurity effective, the interconnected medical devices must be taken into account. Lastly, for

cybersecurity interventions to be effective, safety should be balanced with security, privacy, and compliance with already established protection regulations.¹⁷⁴

Information security refers to the preservation of the integrity, availability, and confidentiality of data. Since the introduction of electronic health records (EHRs), smartphones and medical identity theft, there has been a growing concern over patients' health data. Furthermore, many healthcare providers confess that they exchange crucial patient information with their colleagues over electronic devices such as their smartphones. These devices can easily be stolen leaving confidential information vulnerable.¹⁷⁵ Healthcare providers are therefore encouraged to transmit private and confidential information through encrypted mobile devices. In addition to using encrypted devices, other measures such as firewalls and intrusion detection software have been identified to be effective. Regardless, healthcare facilities must implement full security programs to maintain the integrity of their data.¹⁷⁶

The use of electronic devices in healthcare provides unique opportunities for healthcare providers to carry out professional communication and facilitate specialist consultation. However, the use of mobile devices raises several risks including; privacy breaches and physician liability for not acquiring informed consent from patients before sharing their information. If the mobile devices can be hacked, lost or stolen, then storing or sharing patient information on them is risky.¹⁷⁷ Electronic health records, on the other hand, are increasingly being used to improve the quality of healthcare. However, EHRs are at an increased risk of encountering security breaches. These breaches threaten the privacy of patient-information. Data encryption is, therefore, extremely important in providing protection to healthcare data. Data encryption is associated with encoding information in a manner that only be accessed by authorized individuals.¹⁷⁸ Additionally, healthcare providers can adopt cloud storage solutions

and password protection. For portable EHRs, using two factor authentication systems are helpful in improving the security of patient data. Other security measures such as antivirus software, intrusion detection software and firewalls can also be added as a means of protecting data integrity. Similarly, healthcare organizations can implement specific policies and procedures such as introducing employee IDs and appointing a security officer who will work with the IT experts. Lastly, random audits should be conducted on a regular basis to ensure that everyone is complying with the data security policies.¹⁷⁹

Health IT has the potential to make healthcare safer. However, it also generates additional safety issues that manifest long after the technology has already been implemented. One of the major data safety risks in healthcare facilities is centered on accurate patient matching across electronic health records, communities, and even nations. While many countries have adopted unique patient identifiers, several countries have not.¹⁸⁰ To improve on this, national organizations should assign every individual a unique number or more biometric identifiers such as fingerprints or retina scans. Additionally, a common set of identifying characteristics should be established. Health IT should also act as a tool making it easier for clinical application users to do the right thing and to also catch errors. Safety risks are usually introduced during EHR implementation and transition. To minimize these risks, the best practices in managing system transitions should be implemented.¹⁸¹ The information value chain in health IT starts with healthcare providers interacting with information from the IT systems before making decisions or even taking any action. It is during this interaction that errors arise. For example, errors can be seen in poor user interfaces which are sometimes made worse by machine errors. Clinical errors are also seen in several areas including the administration of medications. When such errors are encountered, they result in the delayed initiation of clinical tasks. Overall, when there are

problems with health IT, the care delivery process is interrupted and harm introduced to patients.¹⁸²

To minimize attacks and breaches, there are several actions that healthcare providers can take. For example, they can interrupt the kill chain, which is the route used by attackers to gain access to a network and extract any form of virus implanted into the system. In addition to intercepting the kill chain, healthcare providers can take other precautions such as; determining whether an attacker is in the system, preventing any form of unauthorized access to data, stopping the attack, launching a counterattack, interfering with the commands of the intruder and lastly, making network segmentation changes. Lastly, organizations can implement administrative safeguards in the form of information access policies, security awareness training and lastly, contingency planning.¹⁸³

6.2.4.b. Future work

The healthcare industry is undergoing a change. Recent technological advancements coupled with scientific breakthroughs have improved how diseases are diagnosed and treated culminating in a more precise and personalized healthcare that is unique to every person. Consequently, the use of big data in healthcare has facilitates the application of AI to mine large volumes of data. The use of Next generation sequencing is also expected to increase with the global efforts to produce more data also raising.¹⁸⁴ Personalized medicine, on the other hand, presents unique opportunities for individuals involved. Digital technology is also better positioned to be an enabler of all aspects of society. As such, the future will see the full integration of digital technology and social networks in the daily lives of a majority of individuals. As a result of this integration, future citizens will be more empowered to take charge of their health and to also participate in healthcare decision-making.¹⁸⁵

The concept of personalized sequencing and its use in the treatment of diseases such as cancer, is only beginning to be realized. Next generation sequencing technologies are now able to analyze multiple genes and include more comprehensive analyses. Furthermore, these technologies are increasingly being used to facilitate the understanding of advances disease treatments.¹⁸⁶ Personalized sequencing also impacts cancer diagnosis and treatment in a number of ways. For example, by using DNA sequencing, physicians are now able to monitor the progression of cancer. Furthermore, tumor DNA sequencing is being used to produce clinically relevant tumor profiles. This in turn, helps in identifying active signaling pathways in the tumor cells thus presenting new therapeutic alternatives that would have not been identified by traditional methods.¹⁸⁷ Furthermore, personalized tumor DNA sequencing impacts the treatment process by identifying any form of mutation that would be treated by therapeutic treatments.

Internet-connected clothing and textile is also among the most promising technologies for future personalized healthcare. This concept could play a significant role in the facilitation, advancement and adoption of IoT. Smart textiles can also perform other functions that traditional textiles cannot. For example, smart textiles can conduct tactile sensing, display communication, conduct energy, and even regulate and individual's body temperature. Textile-based sensors can also be worn for the long-term to monitor body biometrics.¹⁸⁸ The textile-based wireless biomonitoring system is effective for self-powered personalized healthcare. Lastly, these wireless biomonitoring systems are used to diagnose obstructive sleep apnea.

Currently, digital health technology plays a crucial role in the healthcare industry. For example, digital technology is providing improved and more direct information to everyone with regards to their health, provides support to healthcare workers regarding the diagnosis and treatment of diseases in addition while also providing health managers with operational and

strategic information regarding the organization's finances. However, in the future, digital technology will transform how healthcare is delivered to individuals and society in general.¹⁸⁹ For example, it is believed that in the future access to smartphones and internet-based information will be universal. The increased use of social networking sites will improve availability of information and transform the role of healthcare providers. In addition, healthcare providers will enjoy digital support and thus improve the quality of care they provide to patients. Evidence shows healthcare providers benefit the most from using decision support and digital supervision strategies.¹⁹⁰ The increased use of digital technologies in the future will also see a shift in healthcare delivery services where a majority of the care will now be provided at home and not in a healthcare facility. This will be made possible by the adoption of telemedicine to offer frontline care.¹⁹¹ Lastly, the technological advancements of the future will result in data being centralized. The move towards digital data collection in healthcare facilities will imply that data will be collected in a timely manner and its quality improved.¹⁹²

Biomedical healthcare tools, biometric sensors and smartphone apps generate large volumes of data. The analysis of this data has been shown to have tremendous benefits in healthcare and patient care in general. However, the large volume of data collected has challenged data scientists. It is therefore imperative that new strategies be developed to combine health informatics, bioinformatics, and analytics to facilitate personalized healthcare. Additionally, new technologies should be developed to derive meaning from big data.¹⁹³ The adoption of mobile health or m-health is also expected to increase in the future. AI and Big data analytics will also be incorporated into m-health thus providing a healthcare system. Currently, electronic health records and medical images are diversified and poorly implemented. As a

result, they negatively affect patient privacy and security. Future works should therefore apply intelligent agent-based systems that guarantee privacy and security in big data.¹⁹⁴

Data security is crucial to the healthcare industry. To improve on this, several interventions have been proposed. For example, cloud computing is a very useful tool for improving data security. Additionally, conservation and analytical methods should be developed to keep the patients' medical records well-preserved and in an adequate environment. Lastly, the working environment should be improved to ensure that patients have all the information about their care. This facilitates the consent process and protects them from privacy and security violations.¹⁹⁵

6.3. Conclusion

Data privacy or information privacy refers to the access, use, and collection of data in a manner that upholds the individual's legal right to the information. Data privacy, therefore, prevents the inappropriate use of data and monitors the availability of data content and ensures that the subject's right to gain access and own the information. With advancements in technology and the use of big data, protecting data privacy is both urgent and complex. Furthermore, using technology in a way that is against the ethical principles results in the creation of ethical risks. Ethical risks arise when a potential breach of personal confidentiality arises. Individuals whose data has been unlawfully obtained stand the chance of being discriminated against by both government and private sector organizations. As the chapter has highlighted, it is essential to protect data from unauthorized access, distribution, and use. There is also an urgent need for the development of data privacy protection standards that protect innocent individuals' data from being accessed illegally. Overall, viewing privacy from an ethical standpoint and the

establishment of specific codes of conducts allows all individuals involved to become accountable for protecting their data.

Surveillance, when conducted ethically, can become the foundation for research that promotes the wellbeing of individuals and the community in general. However, surveillance is not without its challenges. Ethical issues of privacy, consent, respect for persons and autonomy have been associated with public health surveillance. In their defense, public health researchers have claimed that in public health surveillance, obtaining informed consent is not necessary since the surveillance is to benefit the entire community. While this contradicts the common ethical principles of biomedical research, sadly, it is accepted and even justified. Personalized healthcare on the other hand, has improved the healthcare industry for the better. However, just like public health surveillance, there are several barriers that are impeding the collection, integration and use of secure personal health data that are impeding the success of personalized healthcare.

Similarly, healthcare providers are struggling to protect healthcare data from breaches or access by unauthorized individuals. By applying data protection interventions such as data encryption, healthcare providers have been able to protect their data albeit, not effectively. Next generation technologies such as; advanced robotics, AI, IoT, and 3D printing are also making significant strides towards the improvement of healthcare. For example, robotics have been used in major surgeries alongside physicians with great success. However, these technologies also come with their share of ethical issues. When it comes to robotics, healthcare providers are worried that they may not be able to make autonomous or even ethical decisions when faced with medical dilemmas. While technology has been shown to improve patient outcomes and facilitate personalized healthcare, more needs to be done to ensure that patients' privacy and security is protected and to eliminate the ethical challenges associated with the same.

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CHAPTER 7. CONCLUSION

This dissertation set out to discuss the ethical justification of maintaining privacy in public health surveillance. It has highlighted the significance of maintaining privacy during healthcare interaction and during disease surveillance. Regardless, privacy breaches still occur. To protect privacy, administrative, physical, and technical safeguards should be adopted in healthcare facilities. Big data has revolutionized the healthcare industry. Currently, healthcare providers are using big data to create knowledge and tailor products to suit patients' needs. However, big data has received constant criticism for being discriminatory and jeopardizing patient privacy regulations. Protecting patient data in the age of big data requires the combined adoption of technical and social solutions. Technical solutions focus on protecting information from being accessed by unauthorized individuals while social solutions create awareness of how data is being used.

It is often essential for healthcare professionals to assess an individual's capacity to provide consent to medical interventions. However, determining competency is often challenging since it requires the balance between respecting individual's autonomy and protecting those with diminished capacity from the consequences of their choices. It is also expected that when individuals accept or refuse medical treatment, they are competent enough to do so and must be accountable for their choices. Furthermore, physicians can seek the services of psychologists to determine the patient's capacity to make decisions. This dissertation provided an overview of cognitive capacity assessments and the reasons why physicians request them. Additionally, the dissertation analyzed the decision-making process in ethics consultations highlighting the four-topic approach. The dissertation highlighted incidences where a patient's decision-making

capacity is placed in question. For patients like Mr. J. who refused treatment, a psychiatrist should be consulted to determine decision-making capacity. In addition, a judge might be consulted to determine competency. Overall, Mr. J. and other patient's decision to reject life-saving treatment should be respected unless their cognitive capacity is under question.

Empathetic interactions between healthcare professionals and patients significantly improve patients' wellbeing and overall healthcare outcomes. At the center of any healthcare interaction is trust. However, once patients feel like their confidentiality is threatened, trust is lost and they avoid becoming forthcoming with information. Healthcare providers must, therefore, ensure that they uphold patient confidentiality at the clinical, professional and organizational level. This dissertation investigated ethical issues associated with data privacy and confidentiality and the strategies that can be adopted to improve data security. The dissertation has also highlighted situations where privacy and confidentiality can be violated legally during research and in clinical interactions. Furthermore, the dissertation presented technologies that are used in healthcare and their impact on data privacy and confidentiality.

Many healthcare providers are conflicted on how to put their personal beliefs aside and offer the best contraceptive advice to their patients. To understand the morality of contraception, it is crucial that contradicting views are investigated. Furthermore, cultural beliefs play an intricate role in the use of contraception among women from developing regions. Many still believe that contraception causes sterility, headaches, and even cancer. In other countries, governments are using sterilization as a way of controlling mother-to-child HIV transmissions. Forceful sterilization has been used in countries such as South Africa, Namibia, and Chile to control the spread of HIV. The morality of coerced sterilization of intellectually challenged women is also a hotly debated issue. When faced with such dilemmas, healthcare professionals

have an ethical responsibility to respect their patient's autonomy and provide sufficient information to ensure informed consent. Evidence also shows that many women including Catholics, are embracing different forms of contraception. When the principle of situational ethics is applied to this debate, the morality of contraception is therefore not definite. Regardless, every woman should be granted the right to make decisions about their reproductive health.

With the COVID-19 pandemic affecting every nation, Religions throughout the world are struggling with its repercussions. Drawing from the teachings of the Quran and the Sunna, Muslims are encouraged to seek medical intervention to relieve their pain. Furthermore, religious leaders are encouraging believers to implement social distancing interventions by changing how they pray and interact with other believers on a daily basis. Over the years, the world has been hit with several pandemics including the Ebola virus outbreak in West Africa. While ethical challenges exist in the management of infectious diseases, healthcare workers are expected to uphold ethical principles and maintain patients' safety.

Infectious disease outbreaks are often characterized by both scientific and social uncertainty. Policymakers and healthcare professionals are forced to prioritize competing professional and ethical principles in the face of severe resource constraints. This dissertation sought to address public health ethics with emphasis placed on individual freedoms Vs the community's wellbeing. By using the recent Ebola outbreak in West Africa, the dissertation highlighted major challenges and offered possible solutions to healthcare professionals and authorities. The values and principles of public health practice are analyzed and surveillance and outbreak response explained. Likewise, ethical principles during infectious disease outbreaks and treatment are discussed using the Ebola virus outbreak as an example. Research during outbreaks often follows unique ethical codes and professional principles. Often, healthcare providers find

themselves in the line of danger when taking care of patients with infectious diseases. The dissertation further highlighted this issue and offers possible solutions for healthcare providers who are faced with the challenge of maintaining personal care and offering the best care to their patients. This dissertation also investigated emerging trends in infectious disease control with emphasis placed on the use of computers, big data, and information-sharing software in controlling the spread of infectious diseases.

In the recent past, the outbreak of infectious disease has garnered more attention and new technologies have been developed to detect and prevent these infections, while at the same time ensure optimal public health. Improvements in DNA sequencing have led to introduction of genomic epidemiology hence enhancing traditional methods of molecular diagnostics and genotyping to aid in quick and effective epidemiologic investigations. Genomic Sequencing (GS) has enabled researchers to analyze pathogen genomes and conduct medical comparisons to identify unprecedented resolution on the spread of infectious diseases. Genome sequencing in combination with epidemiological investigation provides precision and accuracy in determining transmission pathways, revealing sources of epidemic infections, and drug resistance. Although this technology has been applied in prevention of diseases like pneumonia and malaria, the field is faced by various challenges like privacy, ethical issues, government regulations, and high costs. For instance, with the increasing need to understand the cause of diseases and health promotion techniques, sharing personal data has been identified as necessary in enabling low-risk research. However, as more genetic information is accessed, stored, and used in these fields, it is possible for privacy breaches to occur hence making it impossible to guarantee patients maximum confidentiality. Therefore, various privacy measures such as cryptographic solution, differential privacy preservation and controlled access. In addition, health regulations like the

HIPAA privacy rule and GINA have been examined to identify their importance and effectiveness in patient privacy. Various Acts and laws have been put forward to govern and limit disclosure of genetic information. Although genome sequencing proves to be significant in the provision of the outbreak investigation, its full implementation in health facilities would only be done after overcoming its barriers.

Research in Human Immunodeficiency Virus (HIV) has been developed enormously throughout the past decades. In 1987, just three years after the first HIV case was identified, the National Institutes of Health (NIH) Clinical Center opened the first HIV vaccine clinical trial. The center enrolled 138 healthy HIV negative volunteers in phase 1 trial. Recently, on November 6th, 2019, a team of scientists identified and announced a new HIV strain (HIV-1 Group M, subtype L). This discovery is considered the first of its kind since 2000 when a new strain was identified. Thus, it is expected that researchers will keep directing their hard work towards research and advancing testing and treatment options for patients with HIV. However, advancing in research is a big concern in terms of involving human subjects, especially in developing countries. Complex ethical issues may appear when conducting research on vulnerable subjects, people living with HIV (PLWH). The ethical issues revolve around informed consent, standard of care, confidentiality, discrimination, stigma, privacy, ethical review mechanisms, and community consultation. This dissertation reviewed the history of HIV research in developing countries and the reasons why developed countries conduct research in developing countries. The dissertation further investigated ethical issues involving human subjects in HIV research in developing countries and the research institutions' roles in this matter.

Public health surveillance is the systematic ongoing collection and analysis of public health data for the timely dissemination of health information to be used in assessing public

health responses. Advances in technology are increasingly transforming public health at an unprecedented rate. Currently, public health surveillance relies on technology to collect and analyze public health information faster and more efficiently. However, despite its growth over the years, public health surveillance faces several ethical challenges. For example, often times, surveillance data is collected without an individual's consent sparking debate on whether this can be classified as violation of privacy and autonomy despite the fact that it allows for the generation of a more complete data set. This dissertation provided a historical analysis of the issue of surveillance and privacy in global health research highlighting ethical principles presented in the UDBHR and their role in the maintain privacy in public health surveillance. Additionally, the dissertation compared common moral principles and religion perspectives on the issue of privacy and surveillance in global health research highlighting the four main ethical principles and religious views on the issue. The dissertation provided a critical ethical argument in support of the reduction of stringent public health regulatory policies to allow for public health surveillance and research to be conducted more effectively and efficiently.

Data availability, cheap storage capacity, and powerful data extraction tools increase the potential of improving the human condition. However, with the discovery of big data and surveillance technologies, the risk of data misuse has exponentially increased. Ethical issues involving data use have the potential of impacting all aspects of life. In line with this, this dissertation highlighted ethical issues associated with big data. Additionally, the dissertation defined big data and the technologies used to facilitate big data analytics. Surveillance technologies are also explored and the real-life use of the same provided. Internationally-accepted data privacy protection laws and regulations are also highlighted.

Advances in science and technology have allowed for incredible improvements in healthcare. Additionally, the digital revolution in healthcare provides new ways of collecting and storing large volumes of patient data referred to as big healthcare data. As a result, healthcare providers are now able to use data to gain a deeper understanding of how to treat an individual in what is referred to as personalized healthcare. Regardless, there are several ethical challenges associated with big healthcare data that affect how personalized healthcare is delivered. The transformation from the traditional medical model of healthcare to a more individualized and personalized model promises to reduce the burden of healthcare costs and to improve the healthcare system in general. However, with the increasing promise of improving healthcare, comes several ethical challenges that have affected the implementation of these technologies. There is also an increased risk of unauthorized access and data breaches that threaten the privacy and safety of patient data. Data privacy refers to the collection of data in a way that upholds an individual's legal right to their information. Data privacy prevents the inappropriate use of data while also monitoring the availability of data content and ensuring that the test subject's rights are protected. Overall, there is an urgent need for the development of data privacy protection standards that protect individual's data from access by unauthorized individuals.

The overall discussion of this dissertation accounted for many theories, frameworks, standards, procedures, and advancements widely contextual to a common borderline of global health ethics, public health surveillance, and big data analytics.

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