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THE ETHICS OF GOVERNANCE OF DATA ANALYTICS IN HEALTHCARE

A Dissertation

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By

Andrew Harrington

May 2023

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ABSTRACT

THE ETHICS OF GOVERNANCE OF DATA ANALYTICS IN HEALTHCARE

By

Andrew Harrington

May 2023

Dissertation supervised by Joris Gielen, Ph.D.

Recent literature and studies on data governance usually focus on data ethics and governance from a specific country or industry, which has been mostly business, without considering the larger global impact that is affected. Data is a worldwide asset; thus, its implications and considerations should be viewed as such. Hence, this dissertation attempts to incorporate this view by weaving together topics in healthcare, such as the blending of finance and delivery, data governance at the micro and macro levels, data analytics in healthcare, ethics of AI and information management, and technology's impact on end-of-life practices. Through highlighting these areas of healthcare, the dissertation explores characteristics of the healthcare landscape nationally and globally. As the use of data analytics in healthcare increases, the outcomes and their derivatives from these technologies increase proportionally.

Ethical governance of data analytics is focused on applying ethics to all aspects of data analytics, from beginning concepts to ending enforcement stages. This approach aims to take data governance throughout the “three P’s” of an organization: policies, processes, and procedures. This type of governance is crucial since it ensures that data analytics is safe and secure to utilize but also takes ethical principles into the foundation of the whole cycle of data. By reprioritizing ethics at the forefront of governance, those involved with these technologies will be able to produce and maintain ethical data analytics. Thus, each chapter will attempt to look at the past, present, and future issues surrounding the governance of data analytics. Understanding the ethical concerns within these issues will provide a forum for those issues that have yet to be addressed by data experts. Further, by locating the commonalities between these ethical implications, it becomes more feasible to formulate and recommend solutions. This dissertation identifies many ethical concerns and provides recommended solutions through frameworks for data governance. While these global issues are often significant, usually a concrete solution will not always work practically in all countries. Therefore, a framework for ethical data governance will help organizations and systems worldwide to build and utilize a more ethical data governance for its stakeholders.

DEDICATION

To my family ~ thank you for all your unconditional love, support, prayers, and encouragement. Your actions and words have given me the strength to persevere.

To the memory of my father ~ Timothy J. Harrington ~ thank you for your heavenly support, I know you saw this process through to its completion. Love and miss you every day.

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First and foremost, I must thank God for granting me the wisdom and knowledge to finish this dissertation – many prayers have been said by numerous people that this day would come. Praise God!

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Finally, I want to acknowledge with abundant gratitude the love, support, and prayers of my family.

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CHAPTER 1: INTRODUCTION

The success of practically all enterprises, big and small, depends so heavily on data now that it is treated as an asset, and this is where the phrase “data-driven” has resulted. The literature shows that the healthcare industry is no stranger to this fact as the technologies it uses, from data analytics, artificial intelligence/machine learning, and electronic information management, all use data to bring about many benefits, such as faster and more accurate results for all involved in healthcare including patients, professionals, and managers. Data must be controlled since it is a vital resource. Without proper management, data often becomes duplicated, of low quality, and is unable to support the insightful conclusions that come from excellent data. Moreover, improper management and governance of data can cause numerous ethical concerns regarding privacy, confidentiality, and trust. Adverse outcomes will ensue without proper management and governance, causing patient harm, financial woes, and endless legal paperwork. Therefore, ethical governance of data analytics in healthcare is essential. This dissertation aims to explain the ethics of data analytics governance in healthcare and the challenges and opportunities accompanying this management.

What makes this research different from other studies is that this dissertation focuses on multiple areas of healthcare while demonstrating how all these areas come together to reveal the need for ethical data governance across the global healthcare industry. Recent literature and studies on data governance only focus on data ethics and governance from a specific industry or country, mostly business, without considering the more significant global impact. Data is a worldwide asset, and its implications and considerations should be viewed as such. In the literature and studies centered around data governance, the authors tend to keep narrow views on the effect of data governance, or lack thereof, within the specific country – never implicating the raging global battle of health data. While both perspectives are necessary and feasible, one cannot ignore the global, interwoven nature of healthcare and society. Hence, this dissertation will attempt to reconcile these approaches by weaving together topics in healthcare, such as the blending of finance and delivery, data governance at the micro and macro levels, data analytics in healthcare, and technology's impact on end-of-life practices. By highlighting these healthcare areas, the dissertation explores characteristics of the healthcare landscape both nationally and globally. Whether these areas affect patients, professionals, or managers directly or indirectly – each of these areas has a significant impact on the healthcare landscape. As the use of data analytics in healthcare increases, the outcomes and their derivatives from these technologies increase proportionally.

Ethical governance of data analytics focuses on applying ethics to all aspects of data analytics, from beginning concepts to ending enforcement stages. This approach will aim to take data governance throughout an organization's "three P's:" policies, processes, and procedures. This kind of governance is crucial since it ensures that data analytics is safe and secure to utilize and takes ethical principles into the foundation of the whole data cycle. By reprioritizing ethics at the forefront of governance, instead of having it as merely a component of data analytics governance, all those involved with these technologies will be able to produce and maintain ethical data analytics. Since the field of data analytics is not groundbreakingly new, this dissertation does both a retrospective and prospective view on the ethics of governance of data analytics in healthcare. This dynamic view will allow for a thorough analysis of the ethics of data analytics governance in healthcare. One of the first steps to ethical data governance is identifying current and future issues in the field. Thus, each chapter in the dissertation will examine the past, present, and future issues surrounding data analytics governance. Understanding the ethical concerns within these issues will provide a forum for those issues that have yet to be addressed within the field by data experts. Further, it becomes much more feasible to formulate and recommend solutions by locating the commonalities between these ethical implications.

Ethical data governance is not a single instance fix but an involved and ongoing process. As previously noted, ethical data governance covers a wide array of the data analytics cycle and hence involves multiple stakeholders. These stakeholders include but are not limited to developers, government agencies, healthcare professionals, patients, and researchers. All of these stakeholders play some part in the ethical data governance process. For example, developers have a moral responsibility to create and design artificial intelligence and information systems that will not harm their users via improper use, storage, or acquisition of private healthcare data. This can be achieved through fostering an ethical workforce and culture in the office. By encouraging and promoting ethics in these environments, the data analytics products and services in a research and development phase will consider ethical principles and outcomes throughout the entire product or service design. This goal can be achieved in various ways, such as consulting an ethicist specialized in data analytics governance to provide oversight or to teach ethics and its practical applications to developers – who often lack proper training and experience in that area.

Government agencies are also significant stakeholders because they have the authority to pass and enact legislation that can directly or indirectly affect the artificial intelligence/machine learning algorithms being developed or released, in addition to regulating healthcare data that affects nearly all its consumers. The responsibilities of the healthcare professionals and patients' stakeholders differ from that of the developers and government agencies. They usually advocate for change in the technology itself as they spend the most time utilizing the product or service due to data analytics. This point can be further highlighted by the fact that healthcare professionals are becoming more legally liable for the consequences of unethical use of healthcare data products and services – most notably a privacy breach – which negatively impacts the patient. The researcher is a unique stakeholder because the role of the researcher perseveres throughout the previous stakeholder categories as well – developers, government agencies, healthcare professionals, and patients – all of whom contain and utilize the services of researchers. Acknowledging the significant stakeholders and their roles will raise awareness of the need for ethics of data analytics governance in healthcare.

Numerous ethical principles addressed in this dissertation align with much of the current research and literature surrounding the topic. Ethical issues in data governance, such as privacy and confidentiality, accountability, transparency, justice/fairness, autonomy, and more, are highlighted throughout this dissertation. Where the literature fails in comparison is taking the application of these ethical issues into various areas of healthcare, nor does it attempt to offer any sector-specific solutions to these issues. Fortunately, this dissertation identifies these ethical concerns and provides several recommendations for answers in the form of frameworks for data governance. While these issues are often significant in scope, globally even, usually a concrete solution will not always work practically in all countries. Therefore, a framework for an ethical data governance system will help organizations and systems worldwide to build and utilize a more ethical data governance for all its stakeholders.

The technological revolution has been around for a long time. However, the technology of data analytics is much more recent, over the past decade bringing tremendous changes in science, society, culture, and daily life, including health care. The technologies related to data analytics cover a large terrain, including artificial intelligence, big data, and electronic information management, each with accompanying ethical challenges. Data ethics refers to the accumulation of these ethical challenges in a shorthand manner.

Clinical and health leaders and organizations must engage these challenges of data ethics by fostering more effective governance oversight of ongoing reform in health care. This governance oversight includes a vast array of ever-expanding medical capabilities, constrained resources and staff shortages, fast-emerging new diseases (including pandemics), and an increasingly diverse mix of patients and consumers whose needs only grow. This dissertation addresses these challenges of data ethics in this fast-developing environment as governance oversight develops effective policies organizationally, nationally, and globally. Hence, the thesis focuses explicitly on the ethics of data analytics governance in health care.

After an introduction in the first chapter, chapters two and three establish the context for the dissertation. Chapter two explains the significance of the blending of finance and delivery in health care today. Chapter three specifies this context further by discussing the widespread tension between individual data privacy and public health surveillance from a global health perspective. Chapter four presents my approach to data ethics, focusing on the key ethical challenges of data analytics from a technological perspective that guides the applied analysis in the subsequent chapters. The applied chapters engage widespread and illustrative topics dealing with data ethics. Chapter five discusses the ethical challenges of artificial intelligence and data science in health care. Chapter 6 discusses technological opportunities and ethical challenges in end-of-life practice. Finally, chapter 7 presents a brief conclusion to the dissertation.

Chapter 2 will describe how data analytics effectively blends the finance and delivery of healthcare and can be used to assist in healthcare reform within the United States. This analysis will begin by looking back to the past in order to understand what worked and what failed in healthcare reform and why. U.S. healthcare reform began in the late 1800s and stretches to the present day. This section will detail how during this reform period, important social movements have spurred certain meaningful changes in legislation, while also critically reflecting on the Catholic Church's viewpoints of these changes due to the fact that the Catholic Church is a leader in hospitals around the country. The analysis will then focus on one of the ethical principles behind healthcare reform, distributive justice, and its foundational theories, basic concerns, and resource allocation issues. In the last section, this analysis will address some implementation considerations of a new healthcare system such as a popular reform effort of universal access to basic care.

The second half of Chapter 2 concerns the ethics of data analytics within the healthcare landscape. A brief overview of what big data is and why it matters including ethical challenges of security, privacy, and informed consent will be explored. As with any invention, data analytics poses both opportunities and challenges that must be met as society progresses. Furthermore, data analytics provides an expansion in personalized care through predictive modeling and integrative sequencing opening new realms to the possibilities of medicine. This chapter will show how data analytics has organizational implications for health systems such that it has altered and will continue to drastically alter the delivery and finance of healthcare at the same time as needing to respect an obligation for security, privacy, and confidentiality with patient population data. This turn towards patient population data sets the stage for Chapter 3 that focuses on the global health data battle – with data governance on the micro and macro levels.

The extent to which policymakers are able to strike a balance between the need to protect genuine patient and clinician preferences on the one hand and the significance of healthcare data to general public on the other will determine whether additional data access is permitted to produce more robust data about how the health care system operates.[1] The ability to manage research-related data, such as that from the Federal Coordinating Council for Comparative Effectiveness Research, securely and effectively will play a role in determining how to strike a balance that will allow for the production of evidence without jeopardizing these ethical obligations.[2]

The third chapter moves on to the public health data battle in which individual autonomy and rights are pitted against population health and the 'Common Good.' Concluding the section at the heart of the argument will be the debate between individual data privacy and public health surveillance – with ethical arguments made on both sides. This section will detail the imperative to influence policy as technology rapidly changes the norms of everyday life. Changes in policy in the form of ethical governance frameworks that enable regulation and monitoring of the technologies that are a double-edged sword are crucial. Policy at not only a national, but global level will be conveyed, using examples such as the European Union and UNESCO.

The second half of Chapter 3 will focus on biometrics. Biometrics have passed the prototype phase and are now being used and implemented in all technology and computer science areas. Biometrics are being used for personal recognition, authentication, health systems, government security, and border control - just to name a few. The potential ethical ramifications of every program using novel technology must be continuously investigated. At the municipal, national, and international levels, biometrics may be essential to guaranteeing more dependable identification systems. Humanity must, however, carefully weigh the advantages against the moral and societal concerns. A number of concerns, such as the preservation of privacy, secrecy, individual freedoms, and the interaction between personal rights and the common good are related to individual identities. Biometrics and their associated data (fingerprints, retina/facial scans, voice recognition) very closely relate to data analytics governance because biometrics are the unique personal identifiers that help data analytics and artificial intelligence/machine learning to differentiate one individual from another. Biometric ethics place a premium on the identification and subsequent de-identification steps that safeguard an individual's personal data's security and privacy.

The central question to be addressed in this section is: Are current biometric practices – such as a lack of privacy and data protection, over-surveillance, and large-scale applications – harmful towards human dignity? This question will be investigated by first explaining what biometrics are and why they matter, then the section will investigate ethical challenges associated with biometrics, and finally describe the need for creating a biometrics governance framework. While data analytics can assist in creating a biometrics governance framework, there are some concerns regarding the use and misuse of data analytics itself that must be addressed. The next chapter describes some of those concerns in two senses: one practical, within genomics, and another theoretical, within the future of digital technologies themselves.

Chapter 4 takes a different look at data analytics and focuses on the ethical concerns and challenges that this technology can display. The social policy of genomic data such as genetic discrimination, common heritage, and more concerns with distributive justice will be detailed. The section goes on to detail challenges in data analytics with the autonomy paradigm and cloud computing respectively. These issues pose a challenge to data analytics due to the cloud computing's de-centralization of data storage. A key factor in respecting the privacy and autonomy of the individual is having a secured, centralized data storage that can easily be maintained and traced back to in the event of a data breach. The rest of the chapter will lay a philosophical/theoretical foundation discussing the impact of technology in healthcare via the digital revolution and its relationship to society while looking at the future of this dynamic relationship and how data analytics could vastly alter this relationship down a slippery slope of a dehumanized world and human enhancement. A cautionary approach is taken in which concepts like technological determinism and the Precautionary Principle will be explored. An applied analysis of these concepts will be used within the topic of human enhancement citing ethical concerns and providing a foundation to advance the debate.

The fifth chapter begins by looking at a few capabilities of artificial intelligence (AI) and its potential for revolutionizing healthcare. Since AI acts as the interpreter of all the data it receives using machine learning and algorithms, AI helps scientists, researchers, and healthcare data stewards among many others to understand and adapt to the clinical outcomes that the data forecasts. Philosophical concepts such as free will, moral disagreement, and moral agency will be explored in light of AI. The chapter will conclude with an analysis of the challenges and opportunities AI has on the delivery of healthcare. The second half of the chapter continues describing the foundations of health information management and its legal and ethical aspects. An applied analysis will be detailed within systematic reviews and risk management. Finally, the chapter concludes with a call for health information technology governance – defining its need and core components highlighting concepts such as information stewardship and data quality.

The end of Chapter 4 looked at an example of how data analytics could be applied in a negative or dystopian way if humanity is not careful of the slippery slope that human enhancement can lead down. In contrast, the sixth chapter focuses on an overall positive or utopian application of various data analytics-driven technologies within the specific context of the elderly population and end of life practices such as palliative care and hospice. A historical and cultural background of death and dying will be detailed outlining systematic changes towards death over time. Opportunities of technologies in end-of-life practices will be explored such as telemedicine and electronic learning. Challenges will be described as well such as the digital-divide, professional-patient relationship via technology and fundamental issues such as the technological imperative vs humanizing. The second half of the chapter continues with ethical considerations of using care robots in aging populations using care ethics. Concepts like artificial morality, relational autonomy, and dignity will be described within this applied chapter of data analytics in healthcare.

CHAPTER 2: DATA ANALYTICS BLENDING FINANCE & DELIVERY IN HEALTHCARE

2. Introduction

The second chapter describes how data analytics can be used in a broader system context to initiate healthcare reform within the United States. Invoking its authority to tax, spend, and regulate trade, the federal government of the United States has regularly approved the gathering and use of health information to inform its activities since the 1950s.[3] However, somewhat recently, in 2009, the government created a Federal Coordinating Council for Comparative Effectiveness Research, which established a data steward under health reform.[4] The enormous volumes of healthcare data submitted to government agencies under Medicare, Medicaid, and countless other federal health programs are collected by this data steward. This council may "enable the research and investigation on a reformed health system, while in common purpose to enable advances in population health" by operating under open policy guidelines and having the power to gather, aggregate, manage, and safeguard data.[5]

Beginning with a background of healthcare reform in America, in the first section of the chapter, the chapter highlights one of the critical ethical concepts that data analytics assists in exercising – distributive justice. In this section, the foundational theories of distributive justice are explored through an array of literature indicating the basic concerns of need and contribution within allocation problems. Implementation considerations of a new healthcare system are described by listing criteria for a better system, four conditions that must be met, and universal access to basic care that technology will help achieve. The second half of the chapter concerns the ethics of data analytics within the healthcare landscape. A brief overview of what big data is and why it matters, including ethical challenges of security, privacy, and informed consent, is explored. Social policies of genomic information are discussed in length, including issues of genetic discrimination, common heritage, and distributive justice. In the chapter, possibilities and difficulties in data analytics related to the autonomy paradigm and cloud computing are discussed. Personalized care using predictive modeling and integrative sequencing are described in their effect on the finance and delivery of healthcare.

2.A. The Ethics Behind Healthcare Reform: Saving Private America

2.A. Introduction

For the last half-century, healthcare reform in America has been and will continue to be an essential topic that arises among family dinner tables and the rooms of Capitol Hill. It is no secret that the United States healthcare system is far from being a world leader and, to this day, contains numerous disadvantages, nuances, and funding issues that keep it from becoming the most robust healthcare system in the world. This analysis begins by looking back to the past to understand what worked and failed in healthcare reform and why. US healthcare reform started in the late 1800s and stretches to the present day. To understand this history of reform in the US, it is essential to mention the critical social movements that have spurred certain parts of reform with an emphasis on the Catholic Church’s viewpoints since they are a leader in hospitals around the country. The analysis then focuses on one of the ethical principles behind healthcare reform, distributive justice, and its foundational theories, basic concerns, and resource allocation issues. The last section addresses some implementation considerations of a new healthcare system, such as a widespread reform effort for universal access to basic care. Competition exists among the world's leading nations to have the most robust healthcare system. However, it is only by ethically reforming the healthcare system that the heroic act of 'Saving Private America' can be accomplished.

2.A.i. Background of Healthcare Reform in America

While healthcare reform is a complicated and essential topic, to properly understand where the future of healthcare reform in America may lie, it is imperative to know how it started and became what the current healthcare landscape is today. Highlighting a synopsis of American healthcare reform's history from the late 1800s to today helps us understand what has worked and why or why not. Then, by examining the social and grassroots movements that have helped spur certain pieces of legislation, future movements can be predicted and their outcomes forecasted. Finally, by reviewing the history of healthcare reform in light of the efforts and responses by the Catholic Church, it becomes apparent that there is an observable moral difference between what has been proposed by the most recent reform legislation in the Affordable Care Act (ACA) and what the United States Conference of Catholic Bishops (USCCB) stand for.

This is crucial to the dissertation because the USCCB fights to preserve immigrants' historical countrywide availability of health care and eliminate any potential future hurdles to access that the ACA could construct. With the U.S. immigrant population of roughly 46.2 million people as of late 2021[6], this accounts for a vast population of healthcare data that would be unusable in the government's Federal Coordinating Council for Comparative Effectiveness

Research if the immigrant population lost access to healthcare. Yet, the matter becomes more complicated as it is not as simple as Catholic social justice principles teaching the importance of the right to healthcare for the individual, as long as it is equally distributed.

2.A.i.a. Brief History of Healthcare Reform in the United States

The evolution of healthcare in America is unique compared to other developed nations worldwide. Because of the country's deep-seated commitment to capitalism, healthcare reform in America has historically taken a different course than in the UK, France, or Canada, countries that have established some universal healthcare.[7] While America’s system has diverged from the rest, it has changed dramatically over the past century to fit the needs of its citizens better. However, the healthcare landscape still requires a significant amount of amending.

Late 1800’s to Medicare/Medicaid

Healthcare originally consisted of patients receiving treatment and then working out some form of payment to doctors directly. This worked during simpler times, but as the population and industry grew, this was no longer feasible. The industrial revolution brought many steel mill jobs, economic booms, and dangerous work environments, leading to more workplace injuries. A big drive for organized medicine under the direction of the American Medical Association (AMA) began as the 20th century arrived.[8] As progressivism advanced across Europe, several countries approved their first social welfare legislation and created the foundation for required government-run healthcare.[9] Kant Patel explains, "A unique American history of decentralization in government, limited government, and a tradition of classical liberalism are all possible explanations for the suspicion around the idea of compulsory government-run insurance.”[10] A draft bill requiring all workers to have health insurance was issued by the American Association for Labor Legislation (AALL), and some states saw increased support for the initiative. As the United States entered World War I, a few states expressed interest but did not pass it. The AMA first endorsed the concept, but by 1920 it had changed its mind.[11]

Healthcare became a pressing problem that required attention after World War I as a result of the expense of treatment continuing to climb and becoming more expensive than the typical person could bear. As a result, a cohort of educators established a system through Baylor University Hospital where they would “agree to pre-pay for future medical services.”[12] This non-profit corporation, which solely offered coverage for hospital services, served as a precursor to what would eventually develop into the well-known Blue Cross insurance. The problems of unemployment and retirement or "old age" benefits captured the public's attention after the Great Depression wreaked havoc on society in the 1930s. Thus, the Social Security Act was passed into law by President Franklin Delano Roosevelt (FDR) in 1935. This legislation created a system of "old age" benefits and "allowed states to create provisions for people who were either unemployed or disabled (or both)."[13]

After American involvement in World War II, national attention shifted to the war and away from healthcare reform. In order to retain existing workers and recruit new ones at this period, employer-sponsored health insurance evolved. This excluded many Americans at the time, including those who were jobless, had impairments, or worked for a company that did not provide such insurance. The Wagner-Murray-Dingell Bill, which advocated for universal healthcare supported by a payroll tax, was launched in 1943 as a response to this gap. However, the bill faced strong opposition from the AMA and others; thus, it eventually died in committee review.[14] Healthcare reform was put on hold in the 1950s while the American administration concentrated on the Korean Conflict, which was third conflict in 40 years, and as expenses continued to climb as a result of new medical advancements like the first organ transplant and the polio vaccination.[15]

Medicare to Present Day

The American government started keeping track of National Health Expenditures (NHE) in the 1960s and calculating them as a proportion of Gross Domestic Product (GDP). During that period, "NHE accounted for 5% of GDP."[16] President John F. Kennedy pushed for healthcare reform, especially for senior citizens, but failed again due to fear tactics of an overwhelming government-run universal healthcare program spread by the AMA.[17] Following Kennedy's death in 1963, Lyndon B. Johnson gained office and expanded the Hill-Burton Program and the Social Security Act of 1935. With the help of doctors and hospitals, this initiative sought to ensure that older residents and those with disabilities had access to cheap healthcare. The Social Security Act of 1965 was approved with this concept, establishing the framework for Medicare and Medicaid. President Richard Nixon made a less comprehensive health insurance reform in the 1970s than previous single-payer system plans.[18] He proposed federalizing Medicaid for low-income people with small children in their care, requiring employers to provide private health insurance if their workers agreed to pay 25% of the expenses, and supporting health maintenance organizations (HMOs).[19]

NHE made for 8.9% of GDP in the 1980s, and healthcare privatization was widely practiced under the Reagan Administration. With this privatization, health insurance was a requirement for all companies with at least 5,000 workers.[20] States would create health insurance alliances to buy individual health insurance policies for people unable to receive health insurance via their place of employment. Subsidies would be made available for those who could not afford insurance. Flint Wainess notes, "In 1986, the Consolidated Omnibus Budget Reconciliation Act

(COBRA) was signed into law by President Ronald Reagan, enabling former employees to continue to be covered by their previous employer's group health plan as long as they agreed to pay the entire premium (employer portion plus employee contribution)."[21] In the 1990s, NHE now represented 12.1% of GDP, and during his administration, President Bill Clinton immediately took steps to address this. He suggested the Health Security Act of 1993, which combined universal protection with consideration for the market for private insurance. In 1993, after considerable debate, the legislation was quietly killed as Congress adjourned for the holiday break.

Later, in 1996, Clinton enacted the Health Insurance Portability and Accountability Act (HIPAA), establishing stricter guidelines for individual privacy. Wainess continues, "Furthermore, it set restrictions on how pre-existing conditions were handled by group health insurance and made sure that a person's health records will be available if needed."[22] The Clinton Administration also launched the Children's Health Insurance Program (CHIP), which extended Medicaid coverage to adolescents up to age 19 who lack health insurance. The intended market for CHIP was those with earnings that were too high to qualify for Medicaid coverage. Every state still manages CHIP, which is still in operation. According to 2022 data from the Centers for Medicare & Medicaid, CHIP provides low-cost health insurance to approximately 7 million children and adolescents.[23]

In order to include prescription pharmaceuticals, George W. Bush wanted to update Medicare after he was elected since, by 2000, NHE amounted for 13.3 percent of GDP. Millions of Americans still participate in the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 (often known as Medicare Part D). The next several years saw little healthcare reform as the U.S. focused on terrorism and the Iraq War. By 2010, the Patient

Protection and Affordable Care Act had been enacted, and NHE accounted for 17.4% of GDP. According to the legislation, "Americans earning less than 400 percent of the poverty level would qualify for subsidies to help cover the cost and more," and insurance providers may not deny coverage due to pre-existing conditions.[24] While this brief history of healthcare reform highlights some of the significant changes and shows the direction for US healthcare policy going forward, one must note the social movements that helped to drive all these changes, whose effects are still seen to the present day.

2.A.i.b. Social Movements

The 20th century was a prime example of the strength of social movements in reforming healthcare policy. Several different "cohorts" of people, such as women, workers, seniors, physicians, and welfare recipients, all organized themselves to induce some form of change in the several modifications to America's healthcare policy over the century. The major social movements that will be discussed are the Civil Rights Movement and grassroots movements, specifically women's and the AIDS movement. Each movement, despite having leaders, was composed of regular people who demanded change.

Civil Rights Movement

Racial prejudice kept African Americans from receiving essential medical treatment for a large portion of the 20th century. They were compelled to focus on creating their institutions, such as fraternal clubs, life insurance firms, and neighborhood public health initiatives.[25] Rightfully, civil rights campaigners disregarded reform plans that either upheld segregation or indirectly assured inequity, such as granting states authority over health care. Because the Wagner-Murray-Dingell plan lacked "safeguards to ensure equitable distribution of funds in the states where Negroes and Whites [were] forced to use separate hospitals, clinics, and other health services," the NAACP, for example, only grudgingly backed the legislation.[26] After some time, civil rights organizations expressed concern that several features of Clinton's Health Security proposal, comprising of its stress on employer-sponsored insurance and the existence of individual private insurers with a longstanding record of discrimination and predatory lending practices, may be harmful to African Americans.[27]

Desegregation has not been enough by itself to establish racial equality in healthcare, according to civil rights activists. The Medical Committee on Human Rights was established in 1964 by activist physicians to provide medical aid to civil rights campaigners in the southern United States. Nevertheless, they quickly became engaged in the northern American campaign against "inadequacies in health care."[28] However, they persisted in tackling the major barriers that low-income African Americans still had to overcome in order to get medical treatment. In the middle of the 1960s, civil rights activists succeeded in their tough campaign for hospital integration. Hospital policies on treating the poor and many medical facilities' and doctors' refusal to accept Medicaid made the connection between racial and financial obstacles to access very evident. Organizations for civil rights requested, via many class-action lawsuits, hospitals with government funding take additional residents who were struggling financially and remain in inner-city neighborhoods instead of relocating to the suburban areas.[29]

Grassroots Movements

Reforms in the medical field has been demanded by and inspired by a variety of grassroots groups, including those for women's rights, civil rights, and those with particular diseases like AIDS. However, their healthcare demands were for particular reforms on behalf of their groups, such as the availability of experimental AIDS medications and the racial desegregation of hospitals.[30] Despite these modifications, a movement for universal healthcare has not developed from these grassroots demands. Small-scale advancements in the delivery of healthcare have been viewed as obstacles to or deterrents to more thorough transformation by certain academics and reformers.[31]

Grassroots calls for healthcare have also been discovered to represent the start of a more thorough criticism of the American healthcare system. Advocates for quick and specific reforms discovered that they had a new and urgent awareness of the need for fundamental transformation as a result of their experiences with health care.[32] Eventually, requests for universal access were incorporated in the platforms of various social movements. We may be able to better understand how these two types of movements have indeed been kept separate and how they can come together by fusing the history of healthcare reform attempts with grassroots action for healthcare system improvements.[33] Perhaps the modern-day link between national and grassroots campaigns comes from the power of data analytics. Since data analytics has the scope and capability to reduce healthcare costs, financing a universal healthcare system in America could become one step closer to reality – giving these campaigns some much-needed rejuvenation and a more robust platform to advocate change.

2.A.i.c. Catholic Efforts

Catholic social theory advocates for an inclusive society where everyone has access to basic healthcare and for seeing people as subjects rather than just objects.[34] Although understanding the "body as an object", distinct from other bodies, and composed of several parts or systems has greatly increased our capacity to treat illness, it has also negatively impacted patient care and human dignity.[35] Healthcare expenses in the US prevent easy access to care, which causes financial ruin for millions of people every year. This is essentially a generational phenomenon brought on by growing geriatric longevity aspirations (discussed in Chapter 6), where practices are based on the assumption that health is a product of human inventiveness and care. Catholic social thinking recognizes God as the ultimate source of healing and believes love is necessary for good health care.[36] A viewpoint like this could show how to (re)humanize the hospital experience and address the social disparities in contemporary health care.[37]

The United States Conference of Catholic Bishops (USCCB) has long emphasized the need of having access to the highest medical treatment in order to protect human life and advance human rights from conception to old age.[38] According to the USCCB, legislative and administrative efforts to achieve health care reform should be supported which "1) ensures access to quality, affordable, life giving health care for all; 2) retains longstanding requirements that federal funds not be used for elective abortions or plans that include them, and effectively protects conscience rights; and 3) protects the access to health care that immigrants currently have and removes current barriers to access."[39] In the USCCB article, *A Framework for Comprehensive Health Care Reform: Protecting Human Life, Promoting Human Dignity, Pursuing the Common Good*, The bishops support providing the economically disadvantaged and vulnerable with accessible health care, bringing our nation one step closer to the goal of universal health coverage. Similar clarity is provided by the USCCB when it emphasizes that this must be done in a manner that respects each person's dignity and their livelihood, wellbeing, and consciousness.[40]

As Pope Benedict XVI stated, within the healthcare industry, "it is important to establish a real distributive justice which, on the basis of objective needs, guarantees adequate care to all."[41] Moreover, "if it is not to become inhuman, the world of health care cannot disregard the moral rules that must govern it. We wholeheartedly commit ourselves to healthcare reform that achieves these worthy goals. We will advocate for addressing the current problems in the Patient

Protection and Affordable Care Act, as well as others that may become apparent in the course of its implementation."[42]

The U.S. bishops claim in the introduction to Part One of the Ethical & Religious Directives (ERDs) that "the first right of the human person, the right to life, entails a right to the means for the proper development of life, such as adequate health care" citing Pope John XXIII's encyclical *Pacem in Terris*.[43] A core human right necessary for human flourishing is health care. People may be less able to thrive and experience spiritual, temporal, and financial deterioration if they are not in excellent health—their capacity to pursue fulfilling relationships declines. Life itself, together with human dignity, may be lost. Due to the fact that one's health (or lack thereof) directly affects their potential to grow, the Catholic social teaching tradition considers having access to quality healthcare a universal human right.[44] The tradition views fair access to basic healthcare as a right and sees denying that right as a breach of distributive justice.[45]

As a result of our social nature, humanity is accountable for fostering social conditions that enable individuals, families, and communities to find fulfillment in a relatively thorough and quick manner.[46] Regardless of color or ethnicity, the Catholic health ministry respects every individual with the same unalienable dignity and respect. The Catholic health ministry stands apart because of this exhortation to adopt a Christian sense of justice and mercy. It is thus perfect for taking the lead in the fight against healthcare inequities. The Catholic health ministry is pushed into the public sphere, where healthcare discrepancies find their roots and continue to maintain ailing populations at an unfair level of disease and decline, in addition to being required to serve each individual in a just and equitable manner.[47]

The history of healthcare reform and the social movements accompanying it are crucial to understanding the future of reform in America. The United States' long and difficult journey toward healthcare reform has distinguished the country from the other industrialized nations in the globe, but not always for the better. There are still numerous problems that are in place in the current system; however, many of these issues can be remedied by looking at distributive justice principles & applying them in future legislation.

2A.ii. Distributive Justice

Should everyone have government-funded access to reasonably priced healthcare that can assist in maintaining life? In the US, society is beginning to endorse the concept that all citizens should have equal access to healthcare, including insurance coverage.[48] However, there needs to be more agreement on how the government should function, how to pay for insurance, how to provide healthcare, and what it means to have fair access.[49] It is still being determined if such a weak agreement can lead to a further agreement on implementing a fair access system. This problem centers on the concept of distributive justice. This section aims to break it down by examining its foundational theories, main concerns, and allocation problems on a micro and macro level.

2.A.ii.a. Background of Foundational Theories

To understand what distributive justice is and how it works, it is critical to know how it has logically evolved through history to apply it today. Therefore, it is essential to focus on a brief history of critical theories contributing to the concept of distributive justice. While not a comprehensive list, the traditional and recent theories of justice provide a starting point for an understanding. Utilitarian, Libertarian, Communitarian, and Egalitarian views of justice have traditionally prevailed, although Capability and Well-Being theories have emerged more recently.

Traditional Theories

Utilitarian theory was founded in the nineteenth century by John Stuart Mill and Jeremy Bentham in England.[50] The central part of Utilitarian theory concerning distributive justice is the Greatest Happiness Principle, which states: “do that which delivers up the most pleasure and least pain.”[51] To maximize utility wherever feasible, or to act in a way that benefits the largest number of people, is how this expression is often translated. This theory expressly focuses on maximizing (or the right distribution of) welfare when applied to distributive justice. This notion, however, lacks precision and has raised questions about whether particular welfare tasks need to be prioritized.[52] A utilitarian with a realistic view of justice must be able to describe how welfare works in society and how to balance welfare circumstances within the framework.[53]

Libertarian beliefs are often linked to John Locke's fair and natural rights to liberty philosophies. According to a libertarian, justice focuses on "the autonomous operation of fair procedures and transactions under conditions of law and order" rather than on utility or acting to satisfy individuals' health and welfare requirements.[54] According to this theory, there is no just distribution pattern independent of free-market processes for acquiring property, lawfully transferring that property, and offering reparations to people whose property was lawfully taken or who were otherwise illegally prevented from participating in the free market.[55] In this system, medical professionals and investors enjoy property rights, and society is not ethically obligated to provide healthcare. Beauchamp & Childress emphasize that in a libertarian sense of justice, “Health care is not a right, the ideal system of health insurance is privatized, and charitable care institutions are nonprofit and untaxed.”[56] According to this view, a fair society upholds the rights to property and liberty, allowing each individual to take independent action to better their situation and safeguard their health.[57]

Aristotle, Hegel, and many other influential philosophers were the foundation for various communitarian beliefs.[58] These ideas are founded on distributive principles from moral societies' notions of the good. An approach to justice that prioritizes the common good above individual rights rejects all conceptions of justice that are based on contracts and individual rights.[59] According to communitarians, there are many distinct perceptions of what is just or moral in the world, and so there are many different principles of justice.[60] These ideas contend that society should be allowed to apply a substantive definition of the good and aim to loosen liberal norms about the impartiality of the government.[61]

Compared to other core distributive justice theories, egalitarian views have the longest history. These beliefs are based on the theological idea that because all men are born equal, they all possess the same moral standing.[62] Although these theories support equality in terms of treating individuals fairly in certain situations, none of them include a direct distributive principle requiring that all individuals get an equal share of all societal advantages.[63] These beliefs are founded on the idea that everyone should have equal freedom and access to the things in life that are important to every sensible person. Every individual would have equal access to sufficient, albeit not optimal, levels of healthcare in an egalitarian society; the precise amount of access would depend on the availability of social resources and public decision-making procedures.[64]

Recent Theories

Amartya Sen and Martha Nussbaum are credited with giving rise to capabilities theory in the twenty-first century. They claim that the freedom to attain these states should be evaluated in terms of capabilities and that the chance to do so is of basic moral relevance.[65] According to the theory, a person's ability to attain goals determines the quality of their life, and a life well-lived is one in which people maintain and use a set of fundamental talents. These talents include, but are not limited to, control over one's surroundings, emotions, physical well-being, and body integrity.[66] To maintain this justness, society must ensure that people's ability to develop their basic competencies is not hampered and that their ability to participate in politics is not hindered or damaged.[67]

Despite their apparent similarities, the capabilities and well-being theories are essentially different. The primary distinction between the two theories is that capability theory emphasizes the capacities and possibilities for well-being, while well-being theory emphasizes well-being itself. The well-being theory's co-authors, Madison Powers and Ruth Faden claim that justice is concerned with achieving well-being rather than simply having the capacity to do so.[68] They list six fundamental components of well-being, including health, personal security, rationality, respect, attachment, and self-determination. According to these authors, justice ensures that each individual has a sufficient amount of each of these components.[69]

2.A.ii.b. The Basic Concerns

Other ideas have been put out in addition to those already stated to address the distribution issue. Since they ignore one or more of distributive justice's fundamental concerns, most of these theories fall short in some manner. In reality, the significant elements that influence what is just in distribution are need and contribution.[70] A fair distribution of commodities is something that allocation, in and of itself, deals with. Distribution of these resources among the needy is seen as allocation since it leverages an individual's contribution to society and their resources to meet the needs of others. Therefore, a lack of anything deemed essential or obligatory may be used to define a need. You may have needs that are socially generated, subjective, or inherent.[71] Regardless of a person's belief, there remains an inherent need. For instance, everyone naturally needs a certain quantity of nutrients and hydration. An organism will weaken and finally perish if this inherent need is not met. In contrast to inherent needs, subjective needs arise from the thoughts and aspirations of the person.[72] These wants may be unique to each person, as in the case of two star-crossed lovers who claim to "need" one another. Subjective requirements are often socially generated demands, where society decides what is required to establish a given social standing. For instance, when a teenager feels the urge to "need" the newest iPhone to fit in with their classmates.[73]

People agree that certain goods are required for enjoyment, social interaction, or other objectives, which results in socially induced needs. This consensus is the product of the historical evolution of material and social circumstances.[74] It is evident that historically, socially induced needs have grown and have led to ever-increasing demands on people in society. Only under the real conditions of a specific society can the existence of these socially induced needs and their link to human dignity be recognized fully.[75] In other words, not everything that is required in one civilization is always required in another. As a result, there can never be a complete list of what is required since it is dynamic and ever-changing.[76]

The next concept analyzed is contribution, which can be a bit confusing. However, the fundamental tenet of the concern for contribution is that, in the absence of contributions to society, there would be nothing to share since society cannot generate anything without the labor of its members.[77] This is why it has become vital for all communities to depend at least a portion of the distribution of commodities, including healthcare, on contributions from both organizations and individuals. Contribution is motivated by recognition, hence it is crucial to the operation of society.[78]

It should be recognized that not all contributions are financial in nature, and not all rewards are monetary. People provide a wide range of political and social benefits that benefit society. For example, a family that raises good children makes a contribution of good citizens.[79] With its hospitals, health plans, educational perks, and other programs, the U.S. Department of Veterans Affairs honors people who have served in the armed forces. The continuing contributions in important societal sectors significantly affect a society's political and social health.[80] A fair and responsible distribution theory should consider all of these contributions.[81]

2.A.ii.c. Allocation

The allocation of scarce resources is an enormous and complex problem within the realm of distributive justice, and by no means does this analysis attempt to solve this huge issue. This section's main goal is to establish the idea of allocation before highlighting some of the major issues with doing so on both a micro and macro scale. David Kelly, Gerard Magill, and Henk ten Have summarized the idea in the following form: “it is morally wrong to spend X money on A while situation B exists, on which the X money ought to be spent instead.”[82] Analysis of this kind of argument reveals that it is mostly ineffective without supporting data about the advantages or futility of initially investing X dollars on A.[83]

As with any allocation or economics discussion, concepts can be detailed on micro and macro levels (further detailed in Chapter 3), with each having its own set of nuanced problems that each present with the goal of just distribution. The consequence of society's efforts alone does not result in a balanced distribution.[84] The conversation must include the patient, healthcare professionals, and institutions. In other words, microallocation also impacts how health care is distributed and political and social considerations. Although society has authority over macro allocation, lay and professional people and organizations like nursing homes and hospitals actively participate in micro allocation every day. For instance, the patient and the healthcare provider are doing triage or, at the very least, allocating their time and resources. Hospitals and other healthcare facilities must restrict treatment based on their resources and the patient's capacity to pay. Although the macroeconomic distribution of the society restricts their power, all of these groups substantially impact the health care options available to each person.[85]

The allocation argument discussed earlier has a number of issues, one of which is that it is too loose and has to be more specific. To be clear, objective A (for which the funds should be redistributed) is open-ended. Everything is seen as subjectively less important than purpose B.[86] Americans, for instance, would agree to spend more on preventive care than we do today but cannot explain where those dollars should come from.[87]

The shame associated with transferring money from purpose A to purpose B may lead to sentiments of desertion and guilt, which is another issue with the allocation argument.[88] Just like in palliative care, ceasing treatment does not mean stopping care – and similarly, just because some resources are reallocated away from A does not mean no care or attention should be paid to A. When resources are redistributed, the blame may recur like an open wound, creating an endless cycle of shame.[89]

The moral significance of the divide between identifiable persons and ambiguous unidentified groupings is a third issue.[90] Is it ethically acceptable to divert funds from a specific identifiable group of orphan kids to a bigger, unnamed group that is in just as much need? The allocation argument has to be strengthened in order to make a stronger case that it may establish universal ethical rules of behavior. This is another complicated problem, like the ones before it, without a logical answer.[91]

While distributive justice has had a long history stretching back hundreds or even thousands of years, humanity has built a background for theories that provide a starting structure for understanding what distributive justice is and how it can work. Two main concerns are apparent in analyzing these theories: need and contribution. A large portion of distributive justice is concerned with allocating resources within a micro and macro level – while more problems continue to arise, fewer rational solutions exist.

2A.iii. Implementation Considerations

While the Affordable Care Act has significantly improved health care coverage in America, 31.1 million Americans remain uninsured as of mid-2021.[92] This results from myriad problems with the current healthcare system, including inadequate access to healthcare, insufficient health insurance protection, rising costs, and an overall burdensome system for patients, their families, and physicians. This section explores alternative proposals for extending health insurance coverage while highlighting criteria that must be met for a better system and the four conditions that must be present. Following a European model, the probable answer to healthcare reform in the United States lies within a universal health insurance program. The advantages and disadvantages of this type of program are described while looking at other international healthcare program examples.

2.A.iii.a. Problems in the Present System

The United States' existing healthcare system has many issues; otherwise, the last several presidential administrations would not have made it a major part of their agendas. The Affordable Care Act, sometimes known as "Obamacare," has decreased the number of Americans without health insurance. However, it does not address many other healthcare issues that plague America. America still struggles with providing adequate access to healthcare to its citizens, adequate insurance protection, suppressing rising costs of healthcare, and implementing a less burdensome system for all.

Access will be the first issue that has to be resolved since a lack of enough funding to provide almost universal access to necessary health care, along with a lack of resources like facilities and staff, leads to medical problems, unjustified suffering, and unnecessary agony.[93] If a diagnosis and treatment are not received in a timely manner, costs may be incurred.[94] As the expense of uncompensated treatment rises, this insufficient finance mechanism threatens a national system of providing healthcare. Lack of insurance has a large and direct impact on access to healthcare, with those who lack insurance far more likely than those who do to delay or forego medical treatments.[95] These unintended repercussions may have devastating effects, particularly when they include avoidable disorders or undiagnosed chronic diseases.[96]

Studies show time and time again that people with insurance are more likely to get preventative treatment and assistance for serious health issues and chronic illnesses than those without insurance.[97] The Henry J. Kaiser Family Foundation states in their annual economic report “One in five (20%) nonelderly adults without coverage say that they went without care in the past year because of the cost compared to 3% of adults with private coverage and 8% of adults with public coverage.”[98] Nearly half of those without insurance do not have a regular location to go when they are ill or in need of medical guidance, which is one of the causes of the poor access among the uninsured.[99]

The next problem to be addressed is costs and quality, in which the US outpaces numerous countries in healthcare expenditures with no signs of slowing down. Unfortunately, these costs are not justified as the US population has poorer health than multiple countries that spend considerably less on healthcare.[100] After years of growth in life expectancy, certain communities have seen a decline recently, a trend made worse by the opioid epidemic. Furthermore, as the baby-boomer generation ages, more individuals worldwide and in the United States are experiencing age-related diseases and disabilities, putting strain on healthcare infrastructure to deal with this growing population (further detailed in Chapter 6).[101]

The expenditures associated with documenting, invoicing, evaluating, processing, auditing, and justifying medical charges are among those of the health care costs that are growing the quickest.[102] These costs include the price of insurance marketing, the earnings and cash on hand of public and private insurance providers, as well as additional overhead costs brought on by the way we now pay for healthcare.[103] The medical liability system and doctors' attempts to reduce their exposure to allegations of professional negligence result in significant extra expenditures. It is not unexpected that the quantity of professional liability claims, the magnitude of malpractice judgments, and the price of malpractice insurance are increasing.[104]

The current systems for paying for healthcare, which include several public and commercial insurers as well as third-party payers, are difficult to understand, expensive, inefficient, and invasive.[105] A complicated system of documenting, invoicing, auditing, evaluating, and processing claims is required for health insurance coverage under commercial insurance plans and state programs like Medicare and Medicaid.[106] Most everyone engaged in US healthcare, including patients and physicians, are aware of the time- and money-consuming, tedious paperwork that goes along with it. People do not want to deal with stressful financial issues or paperwork during a private and delicate procedure.[107]

2.A.iii.b. Considerations of Implementing a New System

It is crucial to take into account a number of factors while proposing or trying to adopt a new healthcare system in the United States in light of some of the issues with the country's present healthcare system. It is unethical and unwise to implement any new system without having a set of standard criteria for evaluating proposals as well as the vote of the people. In addition to the criteria, the four conditions outlined by Norman Daniels must be present within the new system for accountability in distributive justice.

To evaluate proposals for a better health care system, it is imperative to identify and use a standard set of criteria to assess any proposals. The following criteria are not meant to be all-inclusive but serve as a beginning guideline for evaluative purposes. These criteria are broken down into four categories (benefits, financing, organization & delivery, satisfaction) and are not in any particular order of priority.

In terms of benefits, a method for figuring out the extent of benefits that would be gained by putting a new system into place should exist.[108] With this, there should be a standard minimum package of benefits for everyone — not just the really poor or wealthy. Clinical efficacy should be the basis for coverage choices; if a treatment is ineffective or just marginally beneficial, a more compelling argument and proportionality will be needed to justify coverage. Benefits and coverage need to be permanent and unaffected by where you live or work.[109]

Financially, adequate money must be available to remove obstacles to receiving necessary treatment.[110] Additionally, processes should be kept to a minimum, and measures for limiting costs, particularly administrative expenditures, should be in place. Any new finance structure should consider current income streams and aim to reduce professional liability expenses. Patients, doctors, and other healthcare workers should all feel satisfied regarding their work.[111]

Facilities and staff must have the necessary infrastructure in terms of organization and delivery for optimal healthcare services to be provided quickly and effectively.[112] Additionally, systems should be in place to guarantee quality in every element of healthcare. The system should be adaptable, and innovation and improvement should be encouraged rather than stifled. Finally, rewards should motivate people to take control of their health, seek preventive treatment, and engage in health promotion activities.[113]

Norman Daniels & James E. Sabin outline four critical conditions for implementing any new healthcare system in the US. They state, "Justice requires limits to care, and the lack of consensus on distribution principles means that society must develop a fair process for setting limits and learn how to apply that process in real-world situations."[114] For such a method to successfully handle the legitimacy issue, they list four requirements. Decision-makers are responsible for the rationality of their judgments if these requirements are met.[115]

Limit-setting decisions must first be made public. Judgments must be made publicly, and so must the justifications for those decisions.[116] Transparency is guaranteed by this publicity requirement. It is important to emphasize that it does not need that all decision-making factors be determined upon or openly agreed upon in advance. The proper institutions and authorities can create such measures as they encounter issues over time.[117]

Second, the justifications for the choices must be ones that realistic resource restrictions and fair-minded individuals think are relevant to equitably providing health care demands.[118] This relevance requirement is essential because it centers the discussion of constraints on a common objective or benefit. In the American system and many governments in developing countries, a privatized, for-profit industry raises fundamental questions about what explanations shareholders may see as relevant and what data would be necessary to prove that relevance.[119]

Along with the first two conditions, limit-setting decisions must also be open to review and appeal.[120] Generally, judgments must be subject to revision in the face of new information, arguments, and debate. Lastly, there must be some regulation to fulfill the other conditions.[121]

2.A.iii.c. Universal Access to Basic Care

There are numerous proposals for extending health insurance protection among Americans, such as mandating employer coverage, creating health insurance risk pools, and expanding charity care. However, the most widely accepted proposal is establishing universal health insurance program access. Thus, the next section will be dedicated to showing how the rest of the world works in this type of program and some significant advantages and disadvantages of the system.

International Examples

Except for the United States, almost every industrialized country has national healthcare systems to provide universal access.[122] These initiatives come in various formats, but they all have the same goal: enabling all individuals to access healthcare services without financial limitations. Coverage is generally consistent and universal (everyone is eligible regardless of health condition) (everyone is entitled to the same benefits). Costs may be covered entirely by tax revenues or by a combination of employer and individual premiums and public assistance.[123]

A single, consistent program implemented nationwide, like in Sweden and France, is one format.[124] Another version, used in countries like Canada and Switzerland, establishes minimum benefits at the federal level while allowing programs to vary at the provincial or state level.[125] Allowing eligible, non-governmental programs to run locally, as is done in Germany, is another variant.[126] Another alternative is to have local councils manage a national program, as in Belgium and the Netherlands.[127]

Advantages & Disadvantages

With any new healthcare system comes a series of advantages and disadvantages; thus, all things must be considered when evaluating whether to adopt a new approach. The way some of the main advantages and disadvantages will be presented are in a coupled form – as in the advantage (or pro) with its accompanying disadvantage (or con) will be listed together. In no way does this mean to be an exhaustive list, but some of the main points and positions to consider in a universal health insurance program.

All people would have access to specified health insurance benefits that, at the very least, cover basic medical services, which is the first major benefit. Private insurance might act as a safety net to augment coverage, giving people access to conventional medical treatment.[128] The associated drawback is that significant change, including reorganization of healthcare finance methods and programs, would be necessary. Due to increased access through universal coverage and benefit extension, healthcare expenses may grow, adding to the need to keep prices down.[129]

The ability to receive consistent benefits at cheaper premium rates per dollar of coverage than is achievable under a variety of plans with different benefits and coverage is another major benefit.[130] Costs for invoicing, processing claims, marketing, reserves, and earnings might be decreased or eliminated to provide further savings. However, more governmental engagement in healthcare and tighter restrictions on volume, usage, expenditures, and quality assessments might lead to additional erosions of physician autonomy.[131] Additionally, limiting medical decision-making, patient autonomy, and the accessibility of these treatments would be more directly hampered by government choices to restrict or forego funding for specific operations.[132]

Ultimately, such a system's potential benefits outweigh the burdens, making the switch to universal access to basic care the key to bringing America back into the race for the best healthcare system in the world. While the transition may be rough and certainly will be met with opposition, such a system must prevail if ethical, quality and equitable care are given to the exponentially increasing population of the United States. This reform will be more significant than the change in Medicare/Medicaid and the Affordable Care Act combined – it will be the most significant change in healthcare in the history of the United States. Universal access to basic care follows the basic principles of distributive justice and allocation while focusing on the needs and contributions of society. This system can meet the four conditions that Daniels mentioned earlier, follows international examples, and all the criteria for a better system. The citizens of the United States must band together to create such a system and urge our government representatives to do the same. This is the chance to save private America.

2.A. Conclusion

The current state of healthcare in America could be summed up as sub-optimal. Millions of American citizens remain uninsured, while others can't have the proper access to basic care that is needed. Suppose the history of healthcare reform in America hints at what is to come. In that case, a more financially thorough investment of the US government in healthcare will have a tough time passing through the legislative branch. However, this does not mean that universal access to basic healthcare is impossible – as this kind of reform is possible. Taking the critical principles of distributive justice, America can turn its ugly healthcare system into something truly remarkable. By following the criteria for a better system, the four conditions previously mentioned, and the basic concerns of distributive justice – a new healthcare system can be devised that benefits all American citizens. This is the only proper way America will be able to regain a place at the top of the worldwide healthcare leadership board and is the answer to saving private America.

The healthcare problem in America remains apparent as the Affordable Care Act has left a considerable problem to be solved – how to provide healthcare to everyone. Many complications exist within the current system, such as inadequate healthcare access, insurance protection, rising costs, and an unnecessarily burdensome system for all parties involved. Looking forward to proposals for a new healthcare system, specific criteria and conditions need to be addressed if not met by implementing a new system. A universal health insurance program may be the answer, but it comes with its own set of problems that must be considered. Many of these healthcare problems can be mitigated using data analytics, which can reduce costs, provide more personalized care access, lead to more accurate diagnostics, expedite care, and provide numerous other benefits for all—the following section details data analytics' current and future impacts on the healthcare landscape.

2.B. The Ethical Impact of Data Analytics in Healthcare

2.B. Introduction

Over the last approximately 20 years, healthcare data's digitization and electronic use have exponentially increased. With the emergence of the electronic medical record (EMR), health information systems (HIS), smart devices, wearables, and so much more, healthcare data has moved into the digital world. Data analytics is the pursuit of taking all of this data (healthcare or otherwise) and converting it to some form of meaning and interpretation on a large scale through advanced computer systems. These systems transform, organize, and model the data in numerous valuable and informative ways. As with any new invention, data analytics poses opportunities and challenges that must be met as society progresses. Furthermore, data analytics expands personalized care through predictive modeling and integrative sequencing opening new realms to the possibilities of medicine. Data analytics also introduces organizational implications for health systems such that it has and will continue to drastically alter the delivery and finance of healthcare at the same time as respecting an obligation for security, privacy, and confidentiality with patient population data.

2.B.i. Challenge & Opportunity in Data Analytics

Numerous sectors have seen fast digitization during the last ten years. Mehta et al. state, “Healthcare has also undergone this digital transformation, with an increase in the use of electronic medical records (EMRs), healthcare information systems (HIS), and handheld, wearable, and smart devices.”[133] As a consequence, a vast array of health-related data, including genetic data, sociodemographic data, insurance claims, and clinical data, to mention a few, is now available in digital form.[134] The immense potential for improving healthcare delivery presented by this high-quality healthcare data necessitates transforming the raw data into information that can be used. This is where big data analytics steps in – and with it come many opportunities and challenges that need to be discussed. Some of the significant challenges posed to data analytics are currently by the General Data Protection Regulation (GDPR) and Fair Information Practices, simultaneously posing a new challenge of an autonomy paradigm that must be addressed to progress this field further. On the other hand, an opportunity is significant in data analytics with the ability to provide real-time analytics via cloud computing methods and improve healthcare treatment methods.

2.B.i.a. Challenge

GDPR/EU Charter Fundamental Rights/Fair Information Practices

When it comes to big data analytics, the challenges and opportunities are endless – as technology and industry continue to evolve, so will the problems and possibilities that come with it. Some of the most prominent challenges to expanding data analytics came with the recent implementation of the GDPR and the existing Fair Information Practices; while more control over privacy and consent isn't a bad thing, current constructors of the data analytics models and networks will have to abide by and adapt to these new protocols which in turn, slows progress.

First, a quick recap of what the European Union (EU) did when it passed the GDPR starting on May 25, 2018. It puts privacy and security requirements on all companies, regardless of location, so long as they target or gather information about individuals in the EU's 27 member nations, mostly in western Europe.[135] The project updates the Data Protection Directive 95/46/EC, a previous data privacy effort that was first established in 1995.[136] An express approval from the client is now required under GDPR before a business may use, keep, or analyze their personal information, as opposed to the previous opt-out approach. Nancy Davis Kho explains that GDPR added many types of information previously outside the scope of personal information (PI), such as genetic data, race, religion, and more, to be protected under the law.[137] According to the GDPR, businesses are only allowed to collect the information necessary to function. In this case, the concept of data minimization is at play, pushing corporations to stop gathering additional personal data for other conceivable future projects.[138] The GDPR has given consumers far more control over their data. They now have the right to request information about the specific data that businesses have gathered and saved about them. Additionally, customers have the "right to be forgotten" to ask that the corporation delete their personal information.[139]

Contrary to what many people seem to think, the GDPR does not just apply to European enterprises; it casts a broad net. As previously noted, no matter where a company is physically located, it must adhere to the GDPR if it utilizes the personal information of EU people in any manner.[140] Companies have been scrambling to catch up; a rather bleak 2015 survey from Ovum found that “63% of U.S. businesses expected the GDPR to make it harder for them to compete, while 70% felt that the GDPR would throw the competitive advantage to EU businesses.”[141] Businesses have seen greater expenses, process changes, and risk since its deployment.[142] Every employee's day-to-day responsibilities have been affected, from contact center agents who now start every interaction with a privacy warning to software developers who must now build in privacy controls.[143] The consumer is the final group to discuss. While it may seem like today's online customer journeys, involve endless website clicking in addition to the customary cookies notice, the impact on consumers has also meant that they have significantly been empowered with a better understanding of their data and rights.[144] The GDPR has consequences, which is the final significant truth about it; in accordance with the regulation, businesses that do not fully comply "can be fined up to 4% of annual global turnover or €20 million (about $24 million)—whichever is higher."[145]

The Fair Information Practice Principles (FIPPs), which were initially published in 1973 as the Code of Fair Information Practices and served as the foundation for the United States federal Privacy Act of 1974, were an earlier US effort to develop anything like GDPR.[146] The *Nationwide Privacy and Security Framework for Electronic Exchange of Individually Identifiable Health Information* was recently established by the U.S. Department of Health and Human Services (HHS) and outlined these guidelines.[147] These guidelines have been approved by the White House as part of a Consumer Privacy Bill of Rights that will serve as a standard of conduct for companies doing online commerce.[148] These guidelines provide a strong foundation for data exchange while upholding trust. The HIPAA Privacy Rule or other relevant legislation, which has prompted the establishment of governance processes to apply the concept, is part of the FIPPs included in the HHS advice.[149] Each of these guidelines has been accepted by the HHS as direction for healthcare entities sharing personally identifiable health information electronically. Each principle is followed by an explanation, a set of examples, and, if appropriate, examples of how the principle has been applied to other areas of law.[150]

The United States Fair Trade Commission issued rules for fair information practices more than 40 years ago, noting, "Computers linked together through high-speed telecommunications networks are destined to become the primary medium for storing and using records about people. Innovations now being discussed throughout government and private industry recognize that the computer-based record-keeping system if properly used, can be a powerful management tool."[151] Fair information practices include clauses requiring notification or knowledge so that data collectors, uses, and users may be pinpointed.[152] The ability to opt-in or opt-out of certain applications should thus, in theory, be available to data providers. Establishing and maintaining confidence in the individuals whose data is being gathered and utilized is the primary driver for this law and any follow-up legislation, even if it is being done for their benefit.[153] Besides, the new paradigm of autonomy within data collection and aggregation poses a severe threat – people must have explicit and informed consent to make a self-determining choice. Any attempt to confuse or overload that choice is a limit to autonomy.[154]

Autonomy Paradigm

Respecting people's right to self-determination is a critical component of autonomy. Autonomy is the indicator of how much the results of your process respect or obstruct people's right to self-determination or the capacity to make their own decisions concerning ethical information management.[155] This measure is determined by the degree to which individuals express their preferences for processing and how transparently choices are allowed or suppressed by the system or process design.[156] An information imbalance when someone "agrees" to something they are not aware they are doing limits their autonomy, invalidates their decision, and might also be seen as a flaw in the verity/non-deception dimension.[157] Similar to information overload, which makes it difficult for individuals to grasp their options, obfuscation may likewise limit autonomy.[158]

In a broader sense, processing that limits an individual's ability to choose—for instance, by withholding information about the product, service, or another benefit from them based on the processing of data about them—or that restricts their ability to exercise other rights or freedoms, would also have an effect on autonomy.[159] This quality is crucial for providing clear, transparent communication that can help individuals make decisions and comprehend the decisions that may be made on their behalf due to your information processing.[160] The conflict between this duty to preserve data (and respect the autonomy of persons to whom the data relate) and the obligation to contribute to the common good, particularly when doing so involves no effort at all, is at the very heart of our efforts to strike a balance (and so respect the positive human inclination to solidarity, to help others).[161] We all value and even rely on our autonomy, and maintaining it fosters trust. However, we also depend on public health services, which rely on cooperation. Therefore, we must exercise caution should the forceful use of a solidarity trump card undermine that confidence.[162]

Fortunately, most public health organizations in the West have the confidence of the people they serve. How else can the computational upkeep of vital statistics, illness registries, vaccination records, poison-control data sets, many health monitoring initiatives, etc., be justified without real opposition? Most of us rely on these services and think they will be there, often without moral concern about losing any of our autonomy.[163] We have no preference for creating and researching these archives utilizing information technology (as if any of them could be maintained on paper). The enormous success of the public health effort, which has enhanced, if not saved, millions, if not billions, of lives, offers a strong utilitarian justification for the kind of "presumed solidarity" being proposed here.[164] Nevertheless, an opportunity is abundant in data analytics with the more recent implementation of cloud computing services, providing efficient and manageable storage and retrieval mechanism for large amounts of data. This has to do with better treatment strategies that might profoundly change how healthcare is delivered. These techniques provide breakthroughs on all biological dimensions, including sequencing tools, health monitoring devices, imaging collections, and increasing electronic health record systems, all while bringing down the cost of data capture.[165]

2.B.i.b. Opportunity: Real-Time Analytics

Cloud Computing

Insight acquired via data analytics through the analysis of vast and complicated data sets is becoming a driving force behind advancements in biomedical research and healthcare delivery. Real-time analytics is possible in healthcare and other fields as more and more hypotheses may be created and tested utilizing high-throughput technologies. Cloud computing has recently evolved as a robust, adaptable, and highly efficient responses to a variety of computational and information-laden problems, made possible by the widespread use of the internet and its expanding capabilities and market demand.[166] The National Institute of Standards and Technology (NIST) describes cloud computing as "a model for enabling convenient, on-demand network access to a shared pool of configurable computing resources (e.g., networks, servers, storage applications, and services) that can be rapidly provisioned and released with minimal management effort or service provider interaction."[167]

Due to varying degrees of security and other operational requirements, cloud adoption, regardless of technology, has been uneven across the sector. Public and private clouds have historically been used less often by regulated businesses and more commonly in unrestrained environments, although this is starting to change.[168] Public clouds are being used to open scientific data sets financed by the government. An example provided by Navale & Bourne, "Human Microbiome Project (HMP) data, funded by the National Institutes of Health (NIH), is available on Amazon Web Services(AWS) simple storage service, and more biomedical data sets are becoming available in the cloud."[169] Research scientists may currently seek NIH clearance to retain and study restricted "genomic and associated phenotypic data obtained from NIH-designated data repositories."[170] The NIH is dedicated to requiring public accessibility to digital content for all NIH-funded studies, with the appropriate access limitations for data pertaining to people.[171]

Chaowei Yang, Yan Xu, and Douglas Nebert note that "Cloud computing has emerged as a new paradigm to provide computing as a utility service with five advantageous characteristics: a) rapid and elastic provisioning computing power; b) pooled computing power to better utilize and share resources; c) broadband access for fast communication; d) on-demand access for computing as utility services and e) pay-as-you-go for the parts used without a significant upfront cost like that of traditional computing resources."[172] In cloud computing, a service-oriented architecture is used. It makes everything as a service, possible, including "Platform as a Service (PaaS), Software as a Service (SaaS), and Infrastructure as a Service (IaaS)."[173] Cloud computing with big data opens up new opportunities for geospatial research and Digital Earth while illuminating possible answers to problems with large amounts of geographical data in several geosciences and related domains.[174]

Complicated studies of healthcare, such as predictions of protein-ligand docking and assessments of human activity, may be completed more quickly using a cloud infrastructure.[175] In order to reduce the costs of storing, accessing, and transmission, personal health data may be centrally housed in a cloud computing system. However, this also creates some new security threats for healthcare information. Typically, cloud computing-based medical systems use task scheduling and data monitoring as techniques to increase their efficiency.[176] Reducing the amount of analysis done on a portable device is a fascinating research topic that involves "offloading" the complex computing to a cloud, from mobile devices like PDAs.[177] A cloud infrastructure provides a helpful answer to preserving the energy of mobile devices, portable equipment, and smart wearable technologies, for instance, by communicating the implementation binary code of a cellphone or tablet to a cloud service at system startup.[178]

Improved Treatment Methods

One example of improved treatment methods is real-time health tracking for chronic illness patients who reside distant from their healthcare providers. Due to distance, real-time health monitoring solves the issue of physicians finding it challenging to keep track of their patient's health state. One striking example is patients with heart arrhythmias that need ongoing episode identification and surveillance.[179] Wearable sensors provide real-time electrocardiogram (ECG) monitoring, as well as the categorization and diagnosis of arrhythmia episodes.[180] Navale & Bourne provide another example, “using AWS EC2, mobile computing technologies were integrated, and ECG monitoring capabilities were demonstrated for recording, analyzing, and visually displaying data from patients at remote locations.”[181]

Additionally, cloud SaaS made software applications that tracked and analyzed ECG data accessible to the general public. Using the Microsoft Azure platform, a 12-lead ECG telemedicine service is now available.[182] To store and retrieve medical pictures, components of the Picture Archive and Communication System were put up on a public cloud. An examination of articles about cloud computing in the medical field revealed that, in contrast to the definitions of cloud computing, platforms, and applications, the terms "cloud" and "virtual machines" or "web-based tools" are often used interchangeably.[183] Through cloud computing, corporate vendors work with healthcare institutions and suppliers to provide healthcare services.[184] Another example is a system developed for ICU patients that combines static and real-time data and might alert caregivers to critical occurrences using cloud computing.[185] Similarly, a neonatal ICU-specific architecture incorporates information from several technological support systems to help with caregiver assistance in real time.[186]

When it comes to big data analytics, the challenges and opportunities are endless – as technology and industry continue to evolve, so will the problems and possibilities that come with it. Some of the most prominent challenges to expanding data analytics went with the recent implementation of the GDPR and the existing Fair Information Practices; while more control over privacy and consent isn't a bad thing, current constructors of the data analytics models and networks will have to abide by and adapt to these new protocols which in turn, slows progress. Besides, the new paradigm of autonomy within data collection and aggregation poses a severe threat – people must have explicit and informed consent to make a self-determining choice, and any attempt to confuse or overload that choice is a limit to autonomy. Nevertheless, an opportunity is abundant in data analytics with the more recent implementation of cloud computing services, providing efficient and manageable storage and retrieval mechanism for large amounts of data.

2.B.ii. Personalized Care

Data analytics opens numerous opportunities and challenges in personalized care – from predictive modeling to integrative sequencing techniques, the ability to tailor care and treatment to each individual quickly becomes a reality. Advances in predictive modeling through algorithms and machine learning will help cut medical costs, evaluate health risks, and improve the speed and delivery of healthcare. This can be implemented in clinical decision support systems that use data analytics in real-time to assist healthcare professionals and patients in making the most informed decisions possible. Integrative sequencing has taken genomic medicine to a new level with the ability to analyze the patient's genotype data, determine how the disease affects this patient specifically, and then select the therapy and/or medication based on the data. The P4 initiative takes these goals and devises ways to apply them within genomic medicine in the real world. With the full availability of direct-to-consumer genomic testing, several positive and negative occurrences are discussed in this section– everything from empowering individuals to make lifestyle changes based on their genomic profile to privacy and security concerns governing the handling and storage of genetic data.

2.B.ii.a. Predictive Modeling (Algorithms)

One particular data analytics method that forecasts future medical expenditures is predictive modeling. It functions by forecasting future health risks and issues and projecting future medical use for the patient and the hospital using a patient's current medical information.[187] Patients are given a particular risk level or score using one of the many available predictive modeling techniques.[188] Risk markers are later used to record these values for each patient in certain situations. Predictive modeling estimates projected patient expenses using personal health data from the EHR, including demographics, prior diagnoses, and other pertinent data. This information is important to physicians and insurers. As a consequence, patients who need special care and treatment are given priority.[189] A fraction of a given population may use the majority of healthcare expenses, according to certain forecasting models. These groups often need more time, resources, and attention, which raises the organization's total expenses.[190]

Algorithms & Machine Learning

Although not a new issue, it is becoming more common to improve healthcare or health programs research initiatives by using prediction models and machine learning algorithms. There is an expanding amount of research on non-hypothesis-driven analytical techniques for finding patterns in the rising mass of clinical and healthcare data.[191] Recent patient health studies have used these strategies in various diverse contexts, for example, "to identify high-cost patients, aid in the reconciliation of potentially erroneous entries in medication lists in patient's medical records, and identify patients at high risk for developing specific clinical conditions."[192]

It would be preferable if these analytical techniques were developed and used to help population health research and monitoring “identify patient cohorts and enhance our understanding of the phenotypic representation of clinical concepts in data.”[193] To more clearly comprehend and identify trends among potential determinants and response variables relating to clinical findings or health outcomes of interest (HOIs), machine learning and other data-driven predictive modeling methods are being created and used inside the distributed data network.[194] In reality, because distributed data networks are by definition made up of several distinct data sources, data-driven simulation techniques are essential in these systems.[195] At one location, an algorithm could be deemed ideal, but not necessarily at another. As a result, it is expected that academics will get a better understanding of the underlying data using predictive modeling methodologies that draw on and modify the data upon which they are based in order to learn from it.[196]

At one level, the physical infrastructure of a hospital, its personnel, its medical staff, its administrative staff, its diagnostic equipment, and its information systems are examples of relatively self-contained healthcare system components. At another level, perhaps the overall delivery of healthcare in a city or county, these components are parts of a more extensive healthcare system.[197] These things or organizations judge resource allocation and process redesign backed by simulation and predictive modeling. Due to significant improvements in computer power and other technical advancements, complex modeling is now viable for use in real-world contexts. The use of animation in modeling to enhance strategic decision-making has made it possible for decision-makers to comprehend better possibilities or less costly alternatives without having to deal with the intricacies and technical challenges of extensive calculations.[198] These predictive models and simulations are the go-to method for improving business, applications, and designs throughout the whole enterprise, and their usage and popularity are growing.[199]

Clinical Decision Support Systems

A clinical decision support system (CDSS), which a clinical computer program, enables users to connect to a level of understanding, patient-specific data, and relevant details at the point of treatment to enhance healthcare administration as well as service.[200] Clinical decision-makers, including pharmacists, medical technologists, and other health professionals and doctors and nurses, use CDSSs. A CDSS is useful because it delivers suggestions and alternatives for medicine, therapy, and diagnosis that are tailored to the particular patient. The effectiveness of care delivery, patient safety, and healthcare quality are all improved by this capacity.[201]

Additionally, CDSS enables quick access to medical data for professionals. Furthermore, CDSS helps minimize hospital admission costs and drug-related emergencies caused by interactions between various drugs and allergies.[202] To fully grasp the range of advantages offered by CDSS, more investigation is required. It is important to emphasize that these systems do not engage in healthcare decisions; instead, they offer pertinent information assessments that help decision-makers, such as physicians, patients, and healthcare organizations, make better decisions.[203]

According to Musen, Middleton, and Greenes in *Biomedical Informatics*, in an ideal world, these five appropriate activities may be used to define CDSS systems: they "provide the right information, to the right person, in the right format, through the right channel, at the right point in the workflow to improve health and health care decisions and outcomes."[204] They go on to say that there are three main types of CDSS systems: (1) "they may use information about the current clinical context to retrieve highly relevant online documents, as with so-called info buttons; (2) they may provide patient-specific, situation-specific alerts, reminders, physician order sets, or other recommendations for direct action; or (3) they may organize and present information in a way that facilitates problem-solving and decision-making, as in dashboards, graphical displays, documentation templates, structured reports, and order sets."[205] An illustration of the latter is order sets, which may improve productivity by offering a rapid way to choose a group of relevant operations and assist decision-making by serving as mnemonic devices.[206] Many observers see information sources that summarize the medical literature and allow people to choose information that is relevant to the situation as straightforward decision support systems.[207]

It is critical to remember the underlying truth that there will always be trade-offs when adopting any computer-based system while creating a system for clinical data. One side of this is the desire to employ the greatest technology available, and the other is the need for the system to take the users' information requirements into account and know how the system functions. A universal framework that applies to all circumstances does not exist either.[208] Systems must be customized to the organization's unique therapeutic goals and services and the requirements of doctors, employees, and patients. Clinical information systems are being implemented with a lot of effort and money. However, there are certain drawbacks. For many healthcare institutions, implementation costs might be a hurdle. Despite all the attention that privacy and security-related concerns are receiving right now, difficulties and challenges still exist.[209] Additionally, many physicians claim they do not have enough time to use the computer-based system during patient interactions. In general, however, the systems are working well and improving healthcare in various ways.[210]

2.B.ii.b. Integrative Sequencing

Utilizing DNA to identify genetic risk factors for illness and improve disease diagnosis is a key objective of genomic medicine.[211] Gene therapy and the development of medications based on molecular data will result from this. To create specifically tailored drugs for each patient, researchers are looking into how to connect DNA variations with those reactions. The term for this is personalized medicine. Ana & Donald Cleveland explain, “The concept of personalized medicine is to analyze the patient's genotype data, determine how the disease affects specifically this patient, and then select the therapy and/or medication based on the data.”[212] The results of the DNA study do not determine the diagnosis or course of therapy. Nevertheless, the analysis is included in the standard clinical workup, including the medical history findings, blood tests, and imaging scans.[213] Personalized medicine seeks to deliver the greatest treatment possible in a very customized manner, improve the precision of the suggested diagnosis and treatment, and provide speedy and effective care.[214]

P4 Initiative

With the capacity to examine the genotype data of the patient, ascertain how the illness specifically affects this patient, and then choose the treatment and/or medication based on the data, integrative sequencing has elevated genomic medicine to a new level. The P4 project takes these objectives and finds practical methods to use them in genomic medicine.[215] The cost of decoding the human genome, which contains 30–35,000 genes, has quickly decreased as better and more efficient sequencing technology has been developed.[216] Computational biology has a big issue in quickly producing meaningful suggestions from genomic skill data analysis, which has ramifications for existing public health policy and healthcare delivery.[217] When providing information and advice to patients and caregivers in the healthcare context, time and money are always essential. "The P4 paradigm, which is the predictive, preventative, participatory, and personalized health initiative, seeks to track these issues over 100,000 subjects in a 20–30-year time, creating personal genomics profiles for each subject."[218]

The P4 initiative aims to accomplish a number of objectives, including analyzing genomic data to identify disease conditions, making blood-based monitoring tools the standard for subjects, developing new approaches to achieving drug targets, and improving and more effective modeling for each subject.[219] Based on physiological monitoring and genome sequencing, the personal genomics profile, also known as the integrative personal omics profile or iPOP, generates thorough health and illness data for a subject.[220] Delivering practical advice in a hectic clinical atmosphere is still difficult. Big data analytics must fill the gap between the vast volumes of data and trustworthy suggestions and results.[221]

Genomic Health

Direct-to-consumer genomic testing now has a new market thanks to the development of low-cost single nucleotide polymorphism (SNP) profiling tools. Customers may submit a saliva sample to a number of genomic testing businesses (including 23andMe, deCodeMe, Navigenics, etc.) to obtain an online report outlining their hereditary disease markers and risks.[222] Statistical methods are used to compare the patient's SNP profile with profiles of a broader cohort and then summarize the relative risk for various conditions, such as heart disease and restless leg syndrome.[223] Some studies include recommendations for preventive actions, however, it is widely believed that most risk evaluations are not actionable.[224] Few individuals in a genome analysis modified their lifestyle as a result of the testing, according to recent research.[225]

The personal health record's integration of these findings will provide a substantial informatics opportunity. Personal health record providers will have to choose whether to keep the raw genetic data in addition to the interpretations, which may be updated over time (storage intensive).[226] It will also provide difficult system design and policy concerns when deciding whether the information in the PHR should be disclosed to providers and under what conditions via interoperability efforts supported by the Meaningful Use part of the 2009 American Recovery and Reinvestment Act.[227] Patients' access to genetic information may encourage them to participate in the clinical process as co-producers by alerting them to potential health hazards that may affect them and their families.[228]

Health databases owned by the public, commercial, and governments increasingly include personal genetic data. The databases could be used for clinical work, epidemiological studies, pharmacological research, etc.[229] Guidelines for using genetic data in these databases are being developed by the World Medical Association (WMA).[230] According to the WMA Chair Anders Milton,

> The public is rightly concerned about whether their right to privacy and confidentiality is threatened by these databases and whether information about them as individuals could be misused. Centralized health databases can make a tremendous contribution to the improvement of health. But the public's right to privacy and consent are essential to the trust and integrity of the patient/physician relationship, and we must ensure that these rights are properly protected. Any guidelines must address the issues of privacy, consent, individual access, and accountability.[231]

Personalized care and medicine are being enhanced in numerous ways by data analytics. Predictive modeling through algorithms and machine learning has created new and dynamic connections in medicine that can improve healthcare delivery worldwide. The predictive models will become more advanced and able to tell healthcare more as time progress with technological advancement. The goal is that one day these models will be able to forecast and see future health needs and public healthcare trends and modify and adapt the resources to address those trends.

Clinical decision support systems are one product of predictive models and machine learning that can assist healthcare professionals and patients make real-time decisions. Integrative genome sequencing has revolutionized personal care – the cost, time of sequencing, and availability of sequencing techniques have opened new avenues for care that is tailor-made for individuals and how their genetics play a role in their diagnosis, treatment, and effectiveness of medications. Overall, data analytics may transform the forefront of personalized care and medicine for all by reducing costs making healthcare more accessible for the poor & immigrants, providing more accurate diagnostics, personalizing results, increasing service, and expediting the decision-making process.

2.B.iii. Organizational Implications for Health Systems

Organizations continue to be significantly impacted by data analytics and its unique implications for their health systems. Information systems have a long-term effect on the future of healthcare organizations, influencing everything from delivery and financing to data management and organizational changes. By lowering costs overall by decreasing labor, waste, and inefficient supply utilization, data analytics has a significant positive impact on cost and quality. Enhancing documentation accuracy and thoroughness, shortening the time spent recording, and many other factors improve the quality of healthcare delivery. Health plan membership, eligibility, benefits, claims and reporting, and payment structure have all become standardized because health information systems have developed. From a different angle, good data management and the organizational changes that follow from such control make data analytics necessary for population data. Good data management is vital to stop the slippery slope of unethical data and information storage, usage, and retrieval. The confidentiality and privacy of patients may be seriously jeopardized in the absence of a standard or code of information ethics.

2.B.iii.a. Integrated Health Systems: Finance & Delivery

Cost & Quality

Adoption of healthcare information systems has been significantly influenced by their ability to reduce data management expenses in hospitals and other businesses. To enhance departmental and administrative processes, businesses in the healthcare industry continue to make strategic partnerships in information technology.[232] Reduced labor expenses, less waste (such as out-of-date surgical supplies bought but never used or food trays delivered to the incorrect location and discarded), and more effective administration of supplies and other inventory are the main advantages that offset certain information systems costs.[233] By effectively allocating priceless resources like operating rooms and imaging equipment, significant savings may be realized. Additionally, health information systems may aid in preventing accidental duplication of tests and treatments.[234] Information technology may lower the expenses of maintaining, obtaining, and transferring charts in the medical records department if critical patient data are made accessible online.[235]

The capacity to raise the standard of care has emerged as an additional advantage as the reach of healthcare information systems has expanded to include clinical process support.[236] Clinical documentation is more accurate and thorough, doctors spend less time documenting (and therefore spend more time with patients), fewer medication mistakes and a speedier reaction to unfavorable incidents and management communications.[237] Healthcare companies may increase the delivery of specialized treatment to distant and rural locations by using telemedicine and remote links to broaden their geographic reach.[238] After converting patient data from a simple transactional model to one more appropriate for data analysis, clinical decision support systems and a health information system with a clinical focus may provide significant benefits, such as boosting treatment quality while cutting costs.[239]

Economic analyses may help healthcare decision-makers allocate limited resources more effectively to enhance health outcomes. To assess the value proposition of ground-breaking health technology, decision-makers often utilize cost-effectiveness (CE) and cost-utility (CU) analyses.[240] Health outcomes are used in CE research to allow for cost-burden analyses, while quality-adjusted life years are used in CU studies.[241] In addition to the incremental cost-effectiveness ratio (ICER), which uses a math ratio to help determine the cost-effectiveness of an intervention - very similar to risk-benefit ratios used in bioethics arguments - these are crucial when determining whether and how different HITs can be used to allocate scarce resources.[242] The ICER is often used by healthcare decision-makers to support expenses associated with adopting and implementing innovative health technologies.[243]

Health information technology (HIT) can increase the efficiency of the healthcare industry as it continues to influence medical expenses and quality. Many politicians are turning to HIT as a crucial instrument to enhance the efficiency of the healthcare sector by eliminating medical mistakes, reducing needless testing, and improving health outcomes in the face of a continually high increase in health expenditure.[244] According to the RAND Institute, HIT will lead to a $142-$371 billion annual decrease in health costs.[245] The HIT implementation may affect the level and scope of care given.[246]

First, using electronic medical records (EMRs) may reduce the time and energy needed for a doctor to advise a comprehensive check, which might lead to a more intensive course of treatment.[247] Second, EMRs may enhance provider-to-provider communication, boosting reliance on experts and decreasing the need for duplicate testing.[248] Finally, clinical decision support systems (CDSS) may improve routine care by prompting clinicians and reducing medical mistakes.[249] However, it is unclear how these three channels will ultimately affect overall medical costs, health outcomes, and the standard of treatment.[250]

Payment Reform

Healthcare funding has suffered from a lack of uniform terminology that standardizes health plan membership, eligibility, benefits, claims and reporting, and payment structure, similar to how clinical services have.[251] As a competitive tactic, the insurance sector has maintained stark discrepancies. The federal government actively promotes the health insurance sector's transition from paper to electronic transactions and has established guidelines for this.[252] For hospitals, healthcare organizations, clinics, and individual practitioners, managing reimbursement and the revenue process has proven challenging and expensive (in terms of processing claims and days in accounts receivable).[253] Patients and families have experienced a great deal of uncertainty and frustration as a result.[254]

The adoption of standardized terminology and the conversion of data to digital format provides the chance to solve a crucial financial problem that has not been well addressed: the disconnect between payers, patients, and healthcare providers.[255] The financial performance will probably be enhanced by this link, which will also align it with the clinical function. The existing business and clinical activities must be disrupted by such revolutionary change, and there is always the risk of just automating the system. This revolution will be ushered in by new business models.[256]

Medical banking has just made its way onto the scene. It is an electronic system for processing and monitoring financial activities, including payments, reconciliation of accounts, investment account balances, invoicing and collections, and making payments.[257] Medical banking aims to handle billing and receivables, ensure that billable services were successfully done, and connect financial transactions with data on patient status and treatment results. By integrating financial data, handling collections, and offering consumers a gateway for managing transactions, banks have a significant potential benefit to the healthcare system.[258]

2.B.iii.b. Integrated Health Systems' Obligation for Population Data

The obligation to protect population patient data must be tackled at the organizational level, and subsequent changes must be made and met to ensure ethical compliance. Organizational structures of industrial and service businesses have been impacted by information technology. Automating back-office tasks like payroll was a common early application of computers. This kind of computer use necessitated no organizational adjustments on the part of the business. Later, businesses started using computers in production facilities. Companies could tailor their goods and provide their clients with greater service thanks to computers. By encouraging the decentralization of sales and support services and distributing greater responsibility to line employees, this usage of computers helped organizations become less bureaucratic.[259] With the development of computer networks connecting various areas of the company, information technology inside businesses entered its third stage. For instance, businesses can now purchase replacements instantly thanks to the integration of cash registers and inventory systems.[260]

The introduction of information technology has a flattening impact on organizational hierarchies. Most information flows followed the lines on organizational charts when memos with carbon copies were the main source of information sharing. A broad range of modern technologies enables easy and inexpensive communication between any two members of an organization. As a consequence, fresh chances present themselves. Many businesses put together "tiger teams" comprising knowledgeable employees from different levels of the organizational structure.[261] To handle an urgent problem, a team will come together for a short while before disbanding. Companies may implement "just-in-time" manufacturing and distribution techniques thanks to flexible information flow, which lowers the cost of inventory.[262]

Information technology also streamlines businesses by getting rid of middlemen in transactions. Take supply chain automation as an example. Let us say firm A purchases widgets from business B. At one time, a business A employee would contact a company B employee to place an order for the widgets. Supply chain automation is becoming a common practice across many businesses. Michael J. Quinn notes, "A computer at company A is linked to a computer at company B. The computers are responsible for ordering the widgets, eliminating the need for the middlemen."[263] The number of personnel needed to write checks, make sales orders, invoicing, pay utilities, etc., may be decreased by automating these paperwork-related tasks.[264] Information technology will most certainly have a favorable effect on businesses by driving up demand for some job categories while driving down demand for others.[265]

A leader in supply-chain automation is Dell Computer, as an actual example. Dell accepts direct phone or online orders from customers for its PCs. Large enterprises account for 70% of Dell's sales.[266] These businesses have unique websites with pre-configured systems catered to the buyer's requirements. Dell keeps its inventory low, just enough for a few days' worth of manufacturing, since it only builds computers when customers purchase them.[267]

Data Management

Data quality management is described by the DAMA DMBOK as “the planning, implementation, and control activities that apply quality management techniques to data to assure it is fit for consumption and business purposes.”[268] Data quality management is the management of information using tried-and-true quality management methods. An identifiable quality or aspect of data is called a data quality dimension. These parameters might be subjective (such as usability, transactability, or reputation), objective (such as completeness), or highly contextual (accuracy, accuracy against surrogate source).[269] Organizations must determine which attributes are crucial to company operations and are also measurable. It is essential that whatever is being measured be connected to a business risk or problem. For instance, if a patient's blood type is incorrectly documented at a hospital, this might lead to treatment issues. As a result, a hospital could need data with a 99.999 percent accuracy level and a population of all blood groups.[270]

Data quality business rules include characteristics of data quality as inputs. These guidelines specify how that data must be for it to be useful. They formalize the requirements for data quality and take action to stop, catch, or fix problems when they arise.[271] Numerous data quality business rules may be found in the DAMA DMBOK and other publications.[272] This section will concentrate on what occurs once a quality measurement has been made. Here, the problem is more with the organization's quality ethics. Organizational leaders were urged by W Edwards Deming to "adopt the new philosophy" of quality.[273] That is a moral precept. Organizations that think about quality systems and methods often do three things. First, they prioritize the demands of their consumers; they ensure that they accurately identify and comprehend both the customers and their wants.[274] Second, they eliminate anxiety and promote pride in a job well done; holding individuals accountable for the system's flaws and blunders is unproductive.[275] While it may be easy to blame the individual closest to the symptom, the main cause often resides elsewhere in the organization. Third, they concentrate on continual development. The company may achieve a sustainable quality level by gradually raising the bar without taking its success for granted.[276]

Research with customers has shown the inadequacy of the "hero ethic," which involves throwing personnel at issues and trying to repair them personally.[277] Applying a quality culture across the company and emphasizing defect prevention more would be a far better strategy than just rushing to discard and redo data. This data manipulation is unethical and can potentially create structural and organizational issues. In order to prevent this, ethical personnel must concentrate on the stakeholders' requirements, desires, and worries in the data—which might include internal and external customers—so that quality is built in.[278] The organization's method of measurement and how that impacts how quality is perceived are additional ethical considerations in information quality management. When referring to quality management, this might entail gauging the effectiveness of a process rather than keeping tabs on individuals based on the number of records that are compliant with the standards set.[279] As a result, the ethics of quality improvement shift from penalizing departure from the norm to rewarding and recognizing high-quality results.[280] This relates to the more general ethical ideas of protecting and advancing human dignity. Imagine you often call attention to the company's shortcomings, those of teams within the organization, or single out specific people as being below average. Integrating ethics into the information quality process from the start would help avoid this problem, maintain strong work morale, and better promote human dignity.

2.B. Conclusion

Data analytics has had a profound effect on the current and future states of healthcare in numerous ways – from the individual level with personalized care and the ability to tailor a patient’s care based on an integrative sequencing of their genome to an organizational level impacting the way healthcare is financed, delivered, and systematically changed throughout the entire organization. While the impact of data analytics is substantial, challenges in the legislation provide suitable barriers that this raw information is kept safe, secure, and private. As long as these challenges are met, the opportunity for data analytics to revolutionize healthcare is infinite.

2. Conclusion

New advanced data management tools are rapidly becoming the norm in healthcare facilities. These technological advancements raise some intriguing concerns about how patient data is used. In the digital era, the age-old dilemma of combining patient confidentiality protection with accessibility to patient records takes on new dimensions. Information is much more readily available, and one system security breach can violate many patients' privacy. Data integrity concerns are also heightened as more data become available to more people and agencies. Finding adequate means to guarantee that electronically stored patient care information is accessible to healthcare practitioners and other parties with a valid need to know about the patient is a problem for health information management experts. The next chapter highlights this issue by describing the health data battle on the micro and macro levels and how that plays out when individual privacy and confidentiality are pitted against public health and the common good.

CHAPTER 3: THE GLOBAL HEALTH DATA BATTLE: DATA GOVERNANCE AT THE MICRO & MACRO LEVELS

3. Introduction

The extent to which policymakers are able to strike a balance between the need to protect genuine patient and clinician preferences on the one hand and the significance of healthcare data to general public on the other will determine whether additional data access is permitted to produce more robust data about how the health care system operates.[281] The ability to manage research-related data, such as that from the Federal Coordinating Council for Comparative Effectiveness Research, securely and effectively will play a role in determining how to strike a balance that will allow for the production of evidence without jeopardizing these ethical obligations.[282] The third chapter moves on to the public health data battle in which individual autonomy and rights are pitted against population health and the 'Common Good.' Concluding the section at the heart of the argument is the debate between personal data privacy and public health surveillance – with ethical arguments on both sides. The section continues by detailing the imperative to influence policy as technology rapidly changes the norms of everyday life. Changes in policy in the form of ethical governance frameworks that enable regulation and monitoring of technologies that are a double-edged sword are crucial. Policy at not only a national but global level is conveyed, using examples such as the European Union and UNESCO.

3.A. Individual Autonomy & Rights vs. Population Health & the Common Good

3.A. Introduction

Healthcare electronic data is everywhere – on computers, phones, tablets, and virtually any device that can access the internet. Patient electronic health records, medication information, genetic testing results, and so much more are out there. What is being done with all this information, and did patients consent to its use in public health interests? This section's focus will address whether it is ethically justifiable for big data banks to use personal health information without consent for public health surveillance. The answer to this question requires a deeper look at personal autonomy, human rights and limitations, population health and an individual's societal obligations, and the concept of the common good. This section will then address how these concepts are applied in the real world by describing big data, what it is, and how it can help healthcare, in addition to its ethical considerations and limitations. The section will next discuss some of the issues with data usage and provide an explanation of the ethical basis for public health surveillance, including the hazards and obligations related to this profession, before addressing the issue of personal privacy vs public health surveillance.

3.A.i. Individual Autonomy vs. Population Health

Bioethicists nowadays are often classified based on how they see the interaction between the person and society. Ethicists have been characterized by terms like "communitarian" and "liberal," among many others, in their critiques and refutations of opposing viewpoints.[283] For a long time, bioethics was dominated by liberal individualism, which was built on the philosophical pillars of liberty, dignity, and privacy. However, ideologies that promote giving the concepts of collaboration, unity, and common good a more substantial role have begun to pose an increasing threat to it.[284] It has been argued that privacy laws, informed consent laws, and individual autonomy laws significantly inhibit medical research that aims to advance society. Although acquiring and analyzing information technology has advanced quickly, stringent laws defending individual rights have made it difficult to use such information.[285]

Even while many opponents of communitarianism do not overtly reject individual rights, it is difficult to create a compromise between such rights and concerns for the greater good.[286] The autonomy of individuals is often weighed against the interest of the public or collective good when considering the recommended ethical frameworks for genetic and clinical database systems. It ultimately turns into an either-or situation. This split may have resulted from the inability to see the intimate connection between autonomy and the common good. One possibility is to draw influence from Aristotle's political theory, which seeks to link autonomy with the general good in a clear, alluring, and persuasive manner.[287] This statement alone should help to bridge the gap between communitarian and liberal bioethics since Aristotle neither supports nor reflects either position.[288]

3.A.i.a. Personal Autonomy & Human Rights

Bioethics has often been built in the West on concepts and language connected to human rights. This idea has often been centered on the rates of individual patients vs some kind of authority, such as medical paternalism, constraints on stopping treatment under the law, or the dull operations of hospital practice.[289] There is an increasing push for bioethics to move beyond discourse centered on rights. However, this term often refers to a shift toward a patient's or family's deeper narrative or values framework. Cultural values are sometimes included, but they are oriented in a way that is more unique than multiple and universal.[290] The move from a solitary mindset to a plural one is much more inclusive when bioethics and human rights are discussed.[291]

Human Rights

The quest for a bioethics concept that encompasses human rights that is broader and fuller than one that is not already acknowledged in all civilizations, older cultures that value community above individuals, would likely be the biggest barrier to this universal approach. It is clear how much cultural values influence how we see morality in biomedicine from the emphasis on independence and self-expression in Western bioethics, especially from American bioethicists.[292] Our beliefs about uniqueness and autonomy affect all medical transactions, such as consent and privacy in the patient-clinician relationship. The patient is seen as the center of decision-making competence and complete consent in the United States and other Western countries, although many other people accept the community or familial decision-making model, notably in Eastern-Asian cultures and nations.[293] In civilizations where family and community bonds are prioritized above all else, informed consent is essentially meaningless. Decision-making ability in these situations is only possible on a social level.[294] In other words, medical decisions are relational or made by numerous family members or close friends instead of just the individual receiving medical care. Populations in patriarchal or matriarchal societies may also have medical decisions made by the family's leader.

In western civilizations, it is also believed that one's confidentiality of information should be preserved. However, this idea does not necessarily imply a universal application. The importance of privacy varies widely, according to social research on attitudes and customs related to cultural conceptions of the self.[295] To further understand the ethical complexity associated with personhood, more empirical study is needed. Therefore, the importance of autonomy is not a solution for bioethics on a global scale but rather a symptom of a deeper issue for most societies.[296]

Limitations of Autonomy

However, the autonomy concept that guides bioethics and bio law has real challenges. Autonomy is an ideal term since it alludes to a person's complete self-control. However, an individual's capacity to regulate behaviors, desires, or both may have flaws.[297] Jacob Rendtorff states, “The individual’s capacity of reasoning may be limited or nonexistent, and this is not only the case for children, senile, insane persons, etc., but also for normal, intelligent people who feel themselves weak and dependent on others or who simply do not understand the scientific project in which they are asked to participate.”[298] People may also base their conclusions on unreliable or incorrect information they have learned from various sources. Additionally, the person's wants or wishes could be unclear. The individual's sense of self is not always consistent, and there are instances when they are unsure about their desires.[299]

This image of the free and independent person with the power to make their own decisions about their own life has drawn substantial criticism for being so far from the realities of the clinical environment and the specifics of bioethics and law. Reciprocal self - determination is allegedly insufficient as a conceptual framework for comprehending the relationship between patients and physicians. According to the objection, autonomy assumes a person with no social connections. Additionally, it makes an overly strong assumption about a person's ability to make their own judgments. Rendtorff continues, “In extreme situations of medical treatment, it is not likely that people can make independent and autonomous decisions. They are vulnerable, weak, and not in control of the situation.”[300] In addition, it is unlikely that individuals make independent and logical judgments during their daily lives without the assistance of others. In actuality, the need for individual autonomy is seldom met when making judgments in severe circumstances.[301]

Furthermore, others claim that diversity and freedom are not the sole unalterable principles. Sometimes having a strong sense of community based on shared values is a need for self-determination. In this setting, autonomy assumes an institutional and cultural basis built around the shared values of tolerance for variety and individual freedom. Because of this, an explanation of autonomy cannot be wholly libertarian; instead, it must acknowledge that each person is embedded in various social customs, ties, and relationships with others.[302] One loses sight of the delicate and sensitive aspects of the human situation that call for respect and care if one just concentrates on autonomy.[303]

3.A.i.b. Population Health & Societal Obligations

As Dr. Henk ten Have states in his book *Global Bioethics: An Introduction,* "Focus on the concept of individual autonomy implies a relative neglect of notions such as the common good, public interest, and community. The individualism of bioethics discourse makes it harder to examine issues such as resource allocation, technology assessment, the aims of healthcare, and justice."[304] Renée Fox, a sociology professor, argues in favor of this criticism, saying that "bioethics is centered on value complex of individual rights, self-determination, and privacy, at the expense of social responsibility and social justice."[305] The flimsy ethics of individual autonomy have historically focused on the patient issues brought on by clinical medicine and medical technology. Still, they cannot effectively handle the social and institutional framework of medical decisions.[306] Perhaps it is time to adopt a different principle and change how the West interacts with the concept of autonomy in bioethics and bio-law.

Changing Ethical Frameworks

The classic Hippocratic medical ethics were created within a framework of professional ethics based on virtue, emphasizing the obligations of beneficence and secrecy on the part of physicians.[307] The foundation of the doctor-patient relationship was the patient's confidence in and respect for the doctor's authority. However, the emancipation that was taking place in many other spheres of life led to criticism of this paternalistic attitude in the late 1960s. According to Alfred Tauber, "Medical ethics was caught up in rights movements and took the position that patients needed to be empowered against paternalistic doctors and an intimidating technology that threatened to dehumanize patients."[308] The movement in favor of the individualism approach may also be seen as a response to the repressive past of eugenics and the forced involvement of people in activities under the guise of the greater good, namely the Tuskegee case in the United States and Nazi physicians' experiments on POWs. Thus, bioethics pledged to treat each person's liberty, privacy, and equality with the utmost regard.[309]

It has been claimed more and more often since the 1990s that bioethics committed a grave error by elevating human autonomy to the status of a core ethical concept at the expense of other crucial values. A few arguments have proposed new ethical frameworks for greater communal values like reciprocity, mutuality, solidarity, citizenship, and universality.[310] As communitarian ethicists constantly point out, humans are social creatures, and "our nature is distorted if we think of ourselves only as co-existing social atoms."[311]

These objections and issues suggest that an ethics that is more contextualized is necessary. The gathering, storing, and use of personal data, including genomic and health records, cannot be controlled by the same ethical principles as clinical testing, treatment-focused clinical care, public health, or other areas.[312] The distinctions between these settings and their internal disparities are attracting increasing attention in the modern day. Invasive biomedical research involving people is where the so-called guidelines for informed consent were developed. In other circumstances, such as demographically based genomic repositories or population health, they may not be appropriate. However, some detractors are concerned about creating a risky precedent. They fear that if ethical guidelines are loosened to allow for a study on human genetic databases, this might lead to modifications in other research areas and, ultimately, result in research subjects losing protection.[313] One concept related to the push to focus new ethical frameworks on more collective values is the common good.

Common Good

The welfare of society was a priority for the ancient Greek polis. The reciprocity of such benefits is essential to the survival of the shared benefits that belong to everyone in society, including peace, stability, success, fairness, and solidarity. It was believed that the goals of the society and the individual would be compatible under normal conditions. In a dispute, the common good would be seen as superior. The core of Aristotle's political theory is his claim of, although neither is sufficient on its own, "the state is by nature clearly prior to the family and the individual since the whole is of necessity prior to the part."[314] Every citizen's well-being is intertwined with the republic, and individuals are exposed to the republic's virtue daily. The common good, for Aristotle, relates to "a good proper to, and attainable only by the community, yet individually shared by its members."[315] For Aristotle, the common good must be both collective and individual. It spans the objectives and reasons individuals seek in their social and interpersonal interactions instead of correlating with the whole of individual commodities.[316]

Both the virtue of the people and the institutional framework of the republic are recognized by Aristotle as requirements for the common good. A shared existence oriented to the common good is necessary to have collaborative pursuits, thus citizens must act fairly.[317] Unfortunately, many people lack justice and are always in conflict for things like power, money, or honor. Since there is always a shortage of outside resources, their lousy behavior causes fierce rivalry and ongoing disputes. As a result, reorienting people's moral priorities toward virtue via education is a crucial need for achieving the common good. For example, overcoming human disparities in interests, abilities, and jobs is one of the challenges to achieving the common good.[318]

According to Margit Sutrop, society is more than just a collection of different people vying for the same few resources.[319] We all have a number of common values as members of the community. Society's role extends beyond just giving individuals the resources to live fulfilling lives. It is challenging to formulate a definition of the common good that fully encapsulates and takes into account our shared interests.[320]

Suppose one views the common good in Aristotle's definition as equivalent to the public interest. People would then realize that what is required of them is careful consideration of its constraints and circumstances in addition to commitment to the common good.[321] The interesting question is, how do such limitations apply to the growing big data problem and the genetic databases that could be used for the public interest of health and wellbeing? This question will be further investigated as to whether it is ethically justified to conduct public health surveillance (via biobanks, genetic data repositories, or other means) without patient consent. This will be done by first explaining what big data is, how it can help healthcare and the ethical challenges of privacy and security that go along with it in a modern-day application of the battle between individual autonomy and rights versus public health and the common good.

3.A.ii. The Big Data Problem

Since the beginning of recorded history until 2003, there has accumulated around 5 billion gigabytes of information, making now the most data-rich time ever.[322] For comparison, in 2011, 5 billion gigabytes of data were generated every two *days*.[323] In 2013, 5 billion gigabytes were generated every ten *minutes*.[324] In 2015, 5 billion gigabytes of data were generated every ten *seconds*.[325] That is a lot of data, more than the human mind can comprehend, and it will only continue to exponentially increase over time, hence ‘big data.’ This is only the beginning when it comes to the big data problem – while it offers exciting and new avenues to healthcare by reducing costs, personalizing medicine, and predicting future health problems – many ethical challenges need to be addressed in these new developments. These obstacles include, but are not exclusive to, concerns with informed consent, privacy and security, and epistemological questions. These challenges must be addressed as the healthcare world moves forward with big data; otherwise, the system will fail to respect some of the most basic bioethical concepts of autonomy, consent, and justice.

3.A.ii.a. What is Big Data & Why Does It Matter?

The healthcare sector has generated large volumes of data for many years. They will continue to do so due to patient records, compliance, regulatory obligations, and patient care, to mention a few.[326] Although much of this data is still in paper form, digitizing this vast quantity of data has become more prevalent in recent years. This transition is driven by a few variables, the most noteworthy of which is its potential to lower costs while improving the quality of healthcare service. These enormous data volumes, or "big data," have the potential to serve a range of healthcare tasks that might be advantageous to the majority, if not all, healthcare sectors.[327]

The Four V’s of Big Data

According to academics, there is not a single, generally agreed definition of big data. Four essential characteristics—volume, variety, velocity, and veracity—are often used to characterize big data.[328] Regularly created and collected health-related data will amass to a reasonable volume of data. Raghupathi et al. describe, “The already daunting volume of existing healthcare data includes personal medical records, radiology images, clinical trial data, FDA submissions, human genetics and population data genomic sequences, etc. Newer forms of big data such as 3-D imaging, genomics, and biometric sensor readings are also fueling this exponential growth.”[329] Huge quantities of data exceed the capacities and retrieval capabilities of traditional data processing, organization, and storage and retrieval, including data warehouses, making volume a crucial component of big data.[330] Big data hence necessitates scalable and efficient information management and storage strategies.[331]

Healthcare data may be found in many different places, including electronic health records (EHRs), medical tests, smartphone apps, and social media. The application of this information to improve healthcare is, however, quite limited. Big data methodologies allow for the effective connecting and analysis of data in many formats to address specific operational, commercial, or research problems.[332] Raghupathi et al. continue, “Future applications of real-time data, such as detecting infections as early as possible, identifying them swiftly and applying the right treatments (not just broad spectrum antibiotics) could reduce patient morbidity and mortality and even prevent hospital outbreaks.”[333] For newborns in the NICU, real-time processing is already being examined to discover potentially fatal infections earlier.[334] If real-time data analysis could be applied to vast volumes of healthcare data from all specialties, adding the second "v" for variety, healthcare would experience a renaissance.[335]

Velocity is another defining characteristic of big data. Massive volumes of continuously updated, variously structured data cannot be processed and analyzed in real-time by conventional IT health infrastructures.[336] Data management may be done faster and with greater flexibility thanks to big data infrastructure. It is a blessing that improvements in data management, especially in virtualization and cloud technologies, have made it simpler to design systems for more efficient data collection, storing, and analyzing.[337] Real-time and fast data accumulation is taking place. Unprecedented issues arise from the steady influx of new data accumulated. The amount, variety, and collection of data needed for output retrieval, evaluation, comparison, and decision-making have changed along with the speed at which data is generated.[338]

According to some professionals and academics, the fourth element is veracity, sometimes referred to as data assurance. In other words, the large data, analysis, and results are accurate and reliable. Veracity is the desired outcome, but it has yet to become a reality. Data quality issues are of highest relevance in the sector because correct information is essential for making survival decisions and because the quality of medical files, particularly unstructured information, is extremely inconsistent and sometimes wrong.[339] The most notorious instance is probably incorrect translations of shoddy handwriting on prescriptions.[340]

Advantages to Healthcare

According to Roski et al., "Big data may have the potential to create approximately $300 billion annually in value in the health care sector, two-thirds of which would be generated by lowering health care expenditures."[341] Big data has so far proven useful in the therapeutic field in a number of circumstances, such as with the advent of tailored medicine (particular diagnostics and therapies predicated on a patient's thorough risk assessment) in the treatment and care of cancer patients.[342] Another example is to use decision support systems to match medications to the risk categories of specific patients. These systems are improved by automated detection of diagnostic imaging pictures, and literature mining.[343] Another example of how patient-generated data is utilized is to personalize screening and therapeutic options along with educational communications to support desired patient behaviors.[344] A fourth, though not the last, example of how big data has already established its utility is the fact that population health assessments powered by big data have shown patterns that could not have been identified had fewer quantities of regularly structured data been examined instead.[345] The Centers for Medicare and Medicaid Services' use of big data fraud prevention and detection methodologies has superseded older manual documentation techniques. Over $4 billion in expenses have been recovered thanks to these methods in only 2011 alone.[346]

Big data is helpful in healthcare research and development, which is another field. The research and development pipeline for medications and devices may be made leaner, quicker, and more focused using big data and predictive modeling.[347] Clinical research designers and participant recruiters may more effectively match medications to specific patients with the use of statistical approaches and algorithms, which lower trial failure rates and hasten the development of cutting-edge cures. Finally, before pharmaceuticals are put up for sale, big data analysis must be used to go through health records and clinical studies to uncover follow-on implications and harmful impacts.[348] Raghupathi et al. conclude, “These advantages also help areas of public health in which big data can analyze disease patterns and track disease outbreaks in transmission to improve public health surveillance and speed response. Faster development of more accurately targeted vaccines, such as choosing the annual influenza strains and turning large amounts of data into actionable information that can be used to identify needs, provide services, and protect and prevent crises, especially for the benefit of populations.”[349]

3.A.ii.b. Ethical Challenges

It should be no surprise that with all this patient information and data streaming around, this infrastructure has some ethical concerns and challenges. Many ethical issues are covered in the literature on big data, including informed consent, security (encryption and data protection), stewardship, and epistemological questions (such as those of power or control and the digital divide).[350] The scope of this section will address the two most popular themes in the literature of privacy and security and informed consent concerns with big data.

Privacy & Security

Our present and past are becoming obvious to individuals with the right access and expertise as our actions are captured and replayed in digital reality. For instance, the Rapid Information Overlay Technology (RIOT) software, created by US defense contractor Raytheon, reviews a single person and tries to make their daily activities perfectly clear using data that is freely available from social network and information systems affiliated with an IP address, among other sources.[351] This information was made public by the British newspaper *The Guardian*.[352] Data analysts use big data to assess our internet consumption habits, friendships, sleep patterns, and shopping preferences. This information is personalized only in a few circumstances, usually in intelligence circles.[353]

However, de-individualization is just one facet of anonymization, which involves taking away components that enable data to be related to a particular person.[354] Andrej Zwitter notes, “Location, gender, age, and other information relevant for the belongingness to a group and thus valuable for statistical analysis relate to the issue of group privacy.”[355] Whether or not a dataset has been normalized depends on how many and which group characteristics are still there. This would entail stripping the data of its substance if it were to be stripped of all aspects about any group. As a result, groups are continuously getting more open even if the data is anonymous because it is de-individualized.[356] Privacy and security will continue to pose an ethical challenge to big data until the anonymization problem can be tackled. Another major ethical challenge that is part of the big data problem is informed consent, as explained in the next section.

Informed Consent

The concept of consent denotes the ability and right of an individual to exert control over information about them, to limit how it is used and reused by organizations like research institutes and healthcare providers, and to revoke such use or reuse.[357] According to existing consent regulations, it is better for society to place an emphasis on personal data ownership above the social advantages that might be gained by disclosing sensitive data for a variety of reasons.[358] In contrast to rigid rules for every single conceivable use, an equilibrium between control of the person and informed disclosure in the context of public safety, environmental preservation, or other aims may be necessary for approval in order to effectively exploit the possibilities of big data.[359]

For instance, the Human Genome Project has put in place permission procedures that allow data to be used and reused for a variety of scientific purposes.[360] The project has tight guidelines for data protection. Even while the details of that use are unclear when the study asks for their consent, it also warns individuals as to how their volunteered personal data may be used and repurposed for their benefit and that of others. In order to maximize participants' chances of benefiting from the study, its permission procedures explicitly specify how participants' data may be shared with other scientific research projects and to what degree data can be safeguarded.[361] According to Tene & Polonetsky, “In examining such an approach and the potential for its wider adoption, policymakers should balance the value of data uses and potential privacy risks, assess the practicability of obtaining true and informed consent, and understand the enforceability of restrictions on future data sharing and use.”[362]

Sometimes, gene sequencing research is restricted to "information altruists," or people eager to offer their data (and occasionally their identities) in the hope that their social standing or financial resources will sufficiently protect them from future prejudice or negative effects.[363] 'Radical honesty' approaches, in which people volunteer to share their de-identified genetic information with the public, are comparable. Establishing "honest broker" and "stewardship" consent models is another strategy to safeguard the interests of data subjects by having unbiased third parties negotiate broad consent agreements.[364] By focusing on professionalism or enacting sanctions for data misuse, it is feasible to delegate a duty of researchers who have access to participants' personal information to instill emotions of accountability in them. Prohibiting unethical research practices like re-identifying anonymized data would lessen any possible harm to data subjects.[365]

By serving as a jumping-off point and a point of reference for future study and debate on the ethics of big data, the quick analysis outlined in this section aims to change widespread and excessively optimistic views. An overview of big data through the four v's (volume, variety, velocity, and veracity) and why it matters in its advantages to the healthcare system was reviewed. The ethical challenges that must be addressed with this new avenue of processing data were mentioned, precisely privacy and security issues and informed consent problems. However, these issues are just the tip of the iceberg – many other ethical and technological issues must be addressed before big data comes into full swing in healthcare, which is a rapidly approaching deadline. One of the key topics at the center of the big data discussion is the conflict between upholding individual data privacy versus deanonymizing personal data to assist in public health surveillance. The challenges in big data use and the ethical justifications for public health surveillance are detailed in the next section.

3.A.iii. Individual Data Privacy vs. Public Health Surveillance

By necessity, public health monitoring takes place without express patient agreement. The continued use of personally identifiable information for reporting communicable illnesses and other forms of public health monitoring has legitimate legal and scholarly backing. The ethical justification for monitoring without a patient's express permission is examined in this section using current medical and population health ethics topics. Lee et al. stress, “Overriding individual autonomy must be justified in terms of the obligation of public health to improve population health, reduce inequities, attend to the health of vulnerable and systematically disadvantaged persons, and prevent harm.”[366] Additionally, data components obtained without permission must only cause the absolute minimum disruption, support efficient public health action, and be kept in a secure environment.[367]

3.A.iii.a. Challenges in Data Use

Big data presents several challenges with its use – some were highlighted briefly in the previous section, such as privacy, security, and informed consent. This section will take a closer look at electronic healthcare (e-healthcare), specifically at privacy and confidentiality issues that physicians face when debating whether to disclose information such as an infectious disease to the public. In addition, additional data utilization issues will be addressed, and how those should be handled within the legal and professional ethics worlds – subject to future change as time and data changes.

Privacy & Confidentiality

The quick development of e-healthcare has significantly impacted information security for patients. Furthermore, breaches of patient confidentiality and privacy may occur quickly, in large numbers, and without being noticed in the e-healthcare setting.[368] State and professional organizations have acknowledged that safeguarding the information entrusted to health care professionals is a fundamental ethical obligation for all clinical staff in light of these e-healthcare possibilities and the populace's concerns about security and confidentiality. A key element that gives information management actions by those in charge of regulating personal health information ethical and moral dimensions is the fact that patients provide information to healthcare professionals in confidence and out of need.[369] Preserving the confidentiality of patients' individually identifiable health data is essential for e-healthcare to be successful and to live up to its promises.[370]

To get therapy and enhance their health, people must provide information to healthcare professionals. This information is provided on a confidential basis. The patients are aware that their present and future medical treatment is the primary reason for revealing, collecting, and retaining personal healthcare information. It raises serious privacy and confidentiality concerns when such private medical information is exploited for other reasons unrelated to their treatment.[371] The government claimed the common good to support additional usage of individual e-healthcare data in socially beneficial initiatives. Nevertheless, it is debatable whether financial considerations and further uses of patient data are acceptable.[372]

Calculating crucial data is necessary when planning and allocating resources over the country.[373] The sharing of sensitive medical information outside of patient care is also closely scrutinized in the national control of contagious and epidemic illnesses. To advance democracy at the national level, personal privacy and secrecy must be legally protected.[374] How is e-healthcare information used? Does one use have purpose over another? What happens if the use is ambiguous? These questions and more are answered in the next section involving e-healthcare utilization.

Utilization

Chronic difficulties with safeguarding e-healthcare information have arisen because of its many uses. Personal e-healthcare data's primary goal is to help clinical care choices for a specific identifiable individual.[375] Therefore, it is very important to identify each individual subject of healthcare information correctly and accurately for main use objectives. Additionally, the law and professional medical ethics preserve the patient's privacy and confidentiality.[376] The term "secondary uses" refers to further applications of e-healthcare data. The veil of protection effectively prohibits the secondary purposes and uses of health data that support controlling disease outbreaks.[377]

The secondary applications of clinical information might be considered as a compromise among the privacy rights of a person and society's desire to lower healthcare expenses while enhancing the quality of treatment and effectiveness within the delivery system. To evaluate the quality of treatment, plan and manage healthcare services, and conduct clinical or epidemiological research, it is essential to employ EHRs.[378] A well-managed healthcare system has thereby benefited patients more because of the secondary applications of electronic healthcare data.[379]

Every secondary utilization of health information, whether it benefits the patient or the public or not, such as utilizing it to deny a job or health insurance application, raises concerns about privacy and confidentiality as well as legal and ethical difficulties.[380] Through the many healthcare professions, ethical issues are handled. In the US, legislation like HIPAA that safeguards personal information are handled within the legal departments of hospitals or, if escalated, the courtroom.[381] The complete erasure of the subject's personally identifying information is thus required for secondary use of e-healthcare data, as is informed consent. An essential issue for e-healthcare is the elimination of personally identifying information, which is being addressed through anonymizing and pseudonymizing the data.[382]

3.A.iii.b. Ethical Justification of Public Health Surveillance

Lee & Thacker define public health surveillance as "the ongoing, systematic collection, analysis, and interpretation of health-related data with the a priori purpose of preventing or controlling disease or injury, or of identifying unusual events of public health importance, followed by the dissemination and use of information for public health action."[383] Public health monitoring differs from other forms of monitoring, such as security, in that its primary goals are the prevention or control of sickness or harm as well as the improvement of public health.[384] In certain circumstances, public health monitoring is used only to assess the severity of health issues, characterize the course of a disease, identify epidemics and outbreaks of well-known or newly discovered pathogens, and track the dispersion and progression of health events.[385] In addition to supporting epidemiological and clinical research, it also creates and tests theories, evaluates prevention and management strategies, monitors isolation activities and infectious agent changes, pinpoints alterations in medical procedures, plans population health interventions including via means of assets, and appropriates and distributes funds for treatment and control.[386]

Considerations

Public health monitoring techniques may be regarded as morally admissible and systems as ethically justifiable if they comply with the positive operational criteria and abstain from transgressing the negative ones. Building a system for monitoring public health is the first action in current best practices, which involves having explicit knowledge of the system's public health goals to guarantee that the relevant data are gathered to address the critical issues.[387] Prioritizing health outcomes depending on the scale of the impact, assessed by frequency, severity, cost, or preventability, is often necessary for determining what public health concern to address.[388] The operational principles of gathering accurate information and responding quickly to the healthcare requirements of a population are met by this prioritizing.

The requirement for adequate data to guide both the management of public health and the ability to protect the privacy of individual patients' medical records must be balanced when deciding which data categories to collect.[389] Lee et al. emphasizes the "Current recommended approach is to collect the minimum number and simplest data elements necessary to meet the goals of the system to minimize risk to individuals, thus meeting the operating principle of imposing the least possible infringement. Early engagement of partners and affected communities is recommended in developing public health surveillance systems, especially when the data are sensitive, or populations are particularly vulnerable."[390] Choosing what kind of information should be gathered in a surveillance system often involves consulting the impacted groups. In the 1990s, community involvement was successfully employed to win over objections to name-based HIV reporting, even in places like New York City and San Francisco, California, where there had been vocal early opposition.[391]

The best practices that are currently being used for the data stages, such as data gathering, aggregation, processing, and evaluation, cascade straight into a well-planned system.[392] Given the system's emphasis on public health, gathering the fewest and least sensitive data pieces is required. This is consistent with the tenets of the system, which include rationality, minimal intrusion, and attention to root causes of illness. Lee et al. states "Collecting information from all affected cases (or a representative sample) is the hallmark of population-based public health surveillance, leaving no subgroup excluded from data collection or, perhaps more importantly, from identifying the need for intervention."[393] The lack of restriction due to demographical, behavioral, or social factors operationalizes the goals of removing injustices, correcting structural inequities, and inclusion.[394]

Data gathering is crucial to the fair and equitable distribution of treatment and preventative measures in a sector like public health that is scientifically based. Consider the case when a demographic is often left out of public health monitoring, perhaps as a consequence of receiving treatment from a certain kind of practitioner who has less reporting responsibility. If so, structural discrepancies in the benefits gained for system participation will be revealed to this group, which is underrepresented in the statistics.[395] Groseclose et al. continues “Acquiring accurate data during collection and collation is a minimal requirement of a public health surveillance system. To ensure data accuracy, ongoing monitoring and periodic evaluation are recommended for all systems.”[396] By guaranteeing the use of the data gathered and giving proof that the advantages of data collection exceed the drawbacks, this approach helps satisfy the requirements of two operational principles. Complete understanding of the surveillance system is necessary for using suitable analytical methods and correctly interpreting results.[397]

The operational pillars of responsible interpretation ensure the effectiveness of the intervention, under this case, surveillance, so that advantages outweigh violations. The last component of best practices for data security is defined processes for how data are collected, transported, accessed, kept, utilized, or shared, as well as specifications for technical and physical security safeguards of data.[398] Lee et al. says “Limiting the number of printed and digital copies of case data, anonymizing and encrypting data during transport, limiting the number of users to the smallest possible, annual security training, and incorporating specific sanctions into annual confidentiality agreements signed by personnel working with surveillance data are some of the recommended best practices for maintaining confidentiality and data security."[399] These processes demonstrate how to protect confidentiality and prevent personal injury by protecting data and reducing the danger of damage. Additionally, they support little intervention.[400]

The best available procedures for information use are deduced from the core principle that data gathering must not be an end in itself but rather a means to improve the condition of the area where the information was gathered. These practices include information exchange and conversation to those who need to know it as well as implementation of the data to health promotion strategies and initiatives to achieve the best outcomes.[401] It need excellent communication techniques and understanding about the people and organizations that can utilize the data from a monitoring system to take action for public health. Furthermore Lee et al. explains "Effective communication models require assessing the quality of data, the definition of the purpose of the communication and the audience, the development of the message, selection of the channel, marketing of the information, implementation of the plan, and evaluation of the process and outcome."[402]

During this stage of the public health surveillance action, operating principles such as intervening on the data to benefit society, proving that advantages outweigh violations, and minimizing disparities by highlighting inequities and recommending initiatives to counteract them—are all applied.[403] When spreading unfavorable information about socially underdeveloped minorities, caution must be taken to guarantee that the least amount of damage is done. By engaging affected groups and community leaders on the best communication strategies and populations, the harm and heightened marginalization that may come from direct mainstream media messaging may be minimized.[404]

Risks and Responsibilities of Public Health Ethics

The public health authority is now responsible for the reported data after a reportable condition has been identified and submitted in accordance with the legal duties imposed on the healthcare practitioner.[405] It is a significant obligation to collect and store personally identifiable information. Since public trust is the cornerstone of public health monitoring, treating patients with respect and dignity is essential for the continuous operation of public health management.[406]

The public health system is aware of the consequences that individuals and communities face as a result of public health practitioners publishing name-based data about private medical matters. Potential damages have been recommended to be protected by ethical guidelines.[407] Lee et al. suggest “These include the following: a collection of individual identifiers only when essential to achieve the public health goals of the system, acquisition of the minimum amount of information needed to meet the public health objective, and engagement of affected communities and stakeholders to consult regarding the most effective way to disclose and disseminate the findings of public health surveillance data, especially when they might substantially add to the stigmatization of an already marginalized group.”[408] For classification initiatives that pose the greatest social concerns, such as HIV and other STDs, the acquisition, preservation, and use of monitoring data must adhere to strict programming criteria.[409]

The agreement between the public health sector and the general community must include the utilization of monitoring data to improve health. The fundamental ethical condition that the risk involved in obtaining and preserving the data is justified by the possibility that it will be utilized to accomplish the intended goals continues to apply to every public health dataset. In the nineteenth century, Herman Biggs, a physician from New York who helped establish surveillance, was certain that "data were collected to be used, not to keep adding machines busy."[410] This attitude remained into the twenty-first century when William Foege, the director of the Centers for Disease Control and Prevention from 1977 to 1983, indicated that gathering data was crucial for limiting sickness and that spending resources should not be permitted if no mission is completed.[411]

In fact, it is still morally required that we utilize the data we acquire to advance public health; any exceptions to this rule need to be supported. Ethics was often used as a defense for switching to personal identification tracking in public health monitoring programs that had previously used anonymized systems in order to best use the data for health optimization. As an example, the United States ended its national anonymous HIV monitoring program in 1995 among expectant mothers in pursuit of routinely checking expectant mothers and infants and sending the results to their pre-existing identity surveillance system.[412] This made it possible to share the findings with expectant moms and new mothers so they could decide whether to get chemoprophylaxis or early therapy.[413]

Overall, the United States public health sector has a proven history of handling private information responsibly. The need for rules and codes for the ethical gathering, preservation, and use of health care data is growing as more and more electronic storage makes it possible for easy accessibility, verification, and distribution.[414] Due to the diversity of authorities, public health programs confront difficulties at the municipal, state, and federal levels, but these difficulties are surmountable. Scientific and legal justifications for public health monitoring in the absence of explicit and specific patient permission, contemporary public health ethical frameworks and their guiding principles, and, at least in part, a thorough monitoring system involving disadvantaged populations, gathers the minimal amount of data necessary, stores information safely, and utilizes information for public health promotion.[415]

3.A. Conclusion

The dominant concept and practice of bioethics have been called for to change from a more individual-centered to a more global-centered emphasis throughout the last several decades. With this shift comes a move from less stress on personal autonomy and privacy to more emphasizing the community, solidarity, and the common good. Applying this shift in thought to today in America, the problem of data sharing for public surveillance comes to the forefront. The mainly Western notion of anti-paternalism and advocacy for the concept of respect for autonomy takes precedence in the medical field within the physician-patient relationship. However, there is more to bioethics than this simple relationship. Humans are interconnected and social beings and therefore are connected to a community, so the individual good should be the same and connected to the community good. This way of being connected to the community good can come through the analysis and use of electronic health records for public surveillance.

Combined with the possibilities of algorithmic computing and data sorting, much public health information is now available to be used in numerous ways. Of course, with these data use and sharing come ethical considerations such as privacy, security, informed consent, and confidentiality. These issues must be addressed to the best extent possible to use this data for research – and anonymization and pseudonymization allow these possibilities to be addressed. However, with some public health data, this is not possible. As discussed in the last section, it can be ethically and legally permissible to use such data without the individual's informed consent. Several federal statutes that regulate entry to and the potential utilization of specific categories of information, like genetic information or data on other biometrics, offer challenges since they need explicit, informed consent for data use. Some of these challenges, such as privacy, confidentiality, surveillance, and large-scale biometrics application, are detailed in this chapter's next section.

3.B. Ethical Challenges of Current Biometric Practices

3.B. Introduction

Biometrics has passed the prototype phase and is now being used and implemented in all technology and computer science areas. Biometrics are being used for personal recognition, authentication, health systems, government security, and border control - just to name a few. The potential ethical ramifications of every program using novel technology must be continuously investigated. At the municipal, national, and international levels, biometrics may be essential to guaranteeing more dependable identification systems. Humanity must, however, carefully weigh the advantages against the moral and societal concerns. A number of concerns, such as the preservation of privacy, secrecy, individual freedoms, and the interaction between personal rights and the common good are related to individual identities. Biometrics and their associated data (fingerprints, retina/facial scans, voice recognition) very closely relate to data analytics governance because biometrics are the unique personal identifiers that help data analytics and artificial intelligence/machine learning to differentiate one individual from another. Biometric ethics place a premium on the identification and subsequent de-identification steps that safeguard an individual's personal data's security and privacy. The central question to be addressed in this section is: Are current biometric practices – such as a lack of privacy and data protection, over-surveillance, and large-scale applications – harmful to human dignity? This question will be investigated by explaining what biometrics are and why they matter, exploring ethical challenges associated with biometrics, and finally, describing the need for creating a biometrics governance framework.

3.B.i. What Are Biometrics & Why They Matter

3.B.i.a. Brief Biometrics History

Biometrics is a technique that identifies and reliably authenticates an individual's identity by using physiological or behavioral attributes that are unique to that person.[416] Sutrop & Laas-Mikko explain, "Such characteristics are facial image, fingerprints, hand geometry, the structure of the retina or iris, DNA, gait, heart pulse, and voice, among others. Biometric recognition offers many advantages over the traditional personal identification number (PIN) or password and token-based (such as ID cards) approaches."[417] Since biometrics are tied to a specific human being and are difficult to replicate, they may help avoid identity theft and restrict the usage of multiple credentials by one individual.[418] Biometrics are constantly accessible and cannot be forgotten, which gives them an advantage over conventional passwords and PINs.[419] These factors have led to the adoption of biometric systems by both public and commercial entities in a variety of situations, including social security benefits, border protection, healthcare systems, banking, collection management, insurance, and business, to mention a few.[420]

Origins

When civilization had already advanced to the point that it necessitated frequent interactions between strangers, the need for biometric identification systems could be traced back to the earliest urban communities throughout the Middle East and China.[421] Military personnel, sailors, and merchants are examples of people who often went outside of their hometowns and needed to be identified. The earliest means to identify someone else and be recognized was presumably via a written description of physical characteristics. Due to the increasing frequency and complexity of human interactions, descriptions of bodily appearances alone become insufficient. Mordini & Massari say that “The first recognition schemes were probably based on artificial body modifications (such as branding, tattooing, scars, etc.) and tokens.”[422]

The first genuinely global civilization in the west was the Roman Empire. In addition, it was the first instance of a system that mainly relied on badges and written documentation for identifying individuals.[423] Individuals in medieval Europe were identifiable by permits and safe conduct granted by religious and civic authorities since most people never ventured outside their homes or communities. Substantial civilizations' growth and urbanization's ease of movement required the use of new identification procedures. The first passports were granted by King Louis XIV of France in 1669, but by the end of the 1700s, passports as well as other types of identification were widely used.[424] However, a widely used passport system did not start to control interstate travel through till turn of the nineteenth century. Around the beginning of the 20th century, passports and identity cards—which, in some cases, also included facial photographs and fingerprinting—were the major means of identifying individuals.[425]

Auto-IDs were developed by the late 1960s. However, it took some time since it was recognized that biometrics were different from previous Auto-IDs in specific important ways. For perhaps the first point in the history of the humankind, biometrics has improved the body's inborn physiological identification system order to evaluate the effectiveness of outer physiological and behavioral features, allowing individuals to identify one another more easily.[426] Mordini & Massari conclude that “Complex personal recognition schemes, tattoos, seals, passports, badges, save conducts, passes, passwords, PINs: biometrics make obsolete all these traditional identification paraphernalia and – at least in the long run – promise to replace all of them.”[427]

Present Day

Since the turn of the 20th century, biometric characteristics have been routinely employed to identify specific groups, including convicts, employees, political refugees, etc.[428] The use of fingerprints in forensics for criminal investigations became well-established in the 20th century. Personal identification, or the link of identity with a particular person, has become an urgent problem due to population increase and rising mobility, as well as the emergence of new risks, including terrorism, international crime, illegal immigration, and identity theft.[429] Airports now have body scanners, scanning software, using fingerprints and face recognition technology, biometric passports and identification cards that will help fight terrorism.[430] Simultaneously, more people realize that even these precautions cannot keep us safe from malicious intent. "We live in a globalized world of increasingly desperate and dangerous people whom we can no longer trust based on their identification documents which may have been compromised."[431] Today, there is more interest in biometrics because governmental agencies seek to control and manage inappropriate activity and criminal intent to stop terrorism and other illegal activity.[432]

The tremendous advancement of biometric technology over the last several decades is mainly attributable to digitization. Non-automatic biometrics for identification or verification, such as conventional fingerprinting, are dependent on analog models in contrast to automated biometric technologies, which rely on digital representations.[433] Mordini & Massari explain, "Digital biometrics differ from traditional biometrics both quantitatively (the digit format allows us to collect, store and process a vast amount of data electronically in a short period) and qualitatively (being numeric strings instead of icons, digital representations have different qualities from analogical representations). Current biometrics include fingerprints, ultrasound fingerprinting, iris scans, hand geometry, facial recognition, ear shape, signature dynamics, voice recognition, computer keystroke dynamics, skin patterns, and foot dynamics."[434] Upcoming (2nd gen) biometrics can probably employ methods like "improved face recognition, remote iris scanning, skin luminescence, brain wave analysis, body odor, etc."[435]

Today, the primary purposes of using biometrics are to differentiate one person from another via identification or verification processes, as well as to anticipate someone is behavior or intents.[436] According to Sutrop & Laas-Mikko, "the first aim is related to the practical identity and accountability of the person that makes them trustworthy. What must be ensured is that the person identified is the person they claim to be, thus proving their rights, entitlements, and responsibilities."[437] To get entry to a facility, for instance, the individual may need to have their fingerprints verified. Prior to this procedure, the person's fingerprint is scanned in order to provide them access rights. The second objective is more challenging; it entails automatically categorizing a person based on an automated assessment or judgment about that individual. A preset attribute that justifies include the individual in a group of people who might represent a danger or risk to society is the basis for the judgment.[438]

The knowledge of data collection is what distinguishes first gen biometrics from second gen biometrics. First-gen biometrics use physical contact for data collection and management, giving users the chance to become aware of what is going on, learn why the data is being acquired, and respond appropriately to protect their rights.[439] Second-generation biometric surveillance involves remote and covert data collection and processing that is carried out without the subject's awareness.[440] As a concluding concept for this part, what if society included a person's biometric profile with information about their beliefs, principles, and ideologies? Leavitt suggests "This, in essence, would make possible a measure (metric) of the mental aspect of one's life (bio).”[441] This could be a broader definition of the term "biometrics," but does not language development include words taking on new meanings?

3.B.i.b. Applications

The applications of biometric use are infinite – as technology, science, and society grow, there will only continue to be opportunities to use and apply biometrics within many aspects of life. From using it to log in to personal devices to medical and big data analytics, biometrics has a massive reservoir of untapped potential. Seals, tokens, documents, and other conventional forms of identity may be forged or used fraudulently.[442] Biometrics will be susceptible to attack but are much harder to commit fraud with.

Medical

Medicine will soon enter the big data age. Clinical use of genomic analysis is advancing the development of targeted molecular treatments and pathogenesis. A biobank is one way to successfully use genomic data; depending on the project design, this kind of study participant pool might include patients from the general community.[443] As a result, ethical concerns including privacy protection have grown. Due to the widespread usage of electronic medical records, a vast quantity of electronic health information has amassed in the clinical context. It is now feasible to collect health data from smart gadgets as they have spread. Its treatment becomes increasingly difficult as data from the clinical context and associated medical studies increase. Without reliable data management, it will be hard to defend the rights of study participants.[444] Additionally ongoing are patient-focused information delivery and interactive research utilizing digital platforms. Big data gathered from various sources will be examined by artificial intelligence to provide new information.[445]

Future medical care and research have been suggested to be based on precision medicine, which treats and prevents illness by taking individual patient variances in genes, environment, and lifestyle into account.[446] Any application of information and communication technology (ICT) for healthcare will be crucial in this age of customized medicine, sometimes known as "eHealth." Only a few of the issues with eHealth include security, express authorization for data exchange and future usage, standards, organization, and deidentification.[447] The development of a trusting connection between study participants and researchers will inevitably lead to such new ethical difficulties.[448]

To provide patient-centered information in research, some efforts have adopted a new methodology. Teare et al. state that "One of these is RUDY, a study in rare diseases of the bones, joints, and blood vessels organized by the research team at the University of Oxford, which uses a patient portal that allows patients to enter their information online."[449] Furthermore, it detects and gathers sporadic advanced illness or health information which, while not yet well studied, will soon be crucial data. The march toward consumer healthcare management is compatible with the transmission of information that is motivated by the requirements of the patient. This idea has already gained a lot of support in the US because of the development of technology that makes it simpler for patients to get and communicate vital health information with someone on their healthcare staff. Blue Button is an illustration of this endeavor.[450] A website with a blue button indicates that it allows users to obtain their medical records. By making the information easily accessible for viewing, this aids patients, families, and caregivers in taking greater control of their health information and assisting in the making of better-informed choices.[451]

This shift is crucial for putting any future healthcare system into place. Online patient submission of medical data, including genetic data and medical records, is predicted to increase.[452] As a result, it is anticipated that electronic techniques, such as online permission processes and health information exchanges, will alter the current landscape of medical research. Information and communication technologies may also make it easier for study participants to participate, feel empowered, and communicate with the researchers.[453] Electronic technologies may, however, raise a few ethical concerns. Some of these ethical difficulties in both fundamental and specific areas will be covered in the following portion of this chapter.

Types of Personal Recognition

When utilizing electronic healthcare systems, it is thought that several types of authentication are required during registration and login. When a registered user returns to the network, they must log in. Since others might mimic the user when they log in, there is a greater risk of information leakage consequently. As a registered participant, you must authenticate yourself upon login. This may be accomplished in one of three ways: (1) using what you know; (2) using what you have; or (3) using who you are.[454] Users are authenticated by "What you know" based on information that is personally known to them, such as a secret phrase or password. Other individuals may be able to impersonate the user if they can find out or guess this information. The risk increases if customers use a basic passcode that is easy to deduce and one that is the same between another website. However, it gets increasingly challenging to remember passwords as they grow more complex and are used more often.[455] Even a complicated password may be retrieved through keylogging by a hacker or malicious computer program, making this method of authentication less secure.

“What you have” uses a user's possession of something, such a gadget, to authenticate them. To prevent unauthorized usage, users register their gadgets in advance. Then, the person using that device is verified. The usage of a token that creates a unique password is an option. Users may only utilize preregistered devices using this approach, which poses a security risk in the event of loss or theft of the registered device.[456] Biometric authentication, sometimes known as "what you are" systems, is finally made possible by modern technologies. Users may be verified by the systems using their voice, iris, ear, face, or fingerprints. Biometrics was included as a means of authentication in the US Food and Drug Administration's guidelines for employing electronic consent.[457] Biometric data, however, is delicate and has a built-in flaw: if disclosed, it cannot be modified. As a result, it must be protected carefully. Sutrop & Laas-Mikko explain “In identification functionality 1:N, one-to-many, or N:1, a many-to-one match is performed.”[458] In the case of 1:N, a single unique identity is compared to and matched with its corresponding identity within the infinite repository of identities stored in the server. In the case of N:1, the infinite number of identities in the database are compared and matched with a single unique identity. More commonly, a 1:N match is performed when a user logs into a database. The verification process's conclusion determines whether the identification claim is accepted or rejected. In contrast, the outcome of identification is a list of identities that have a chance of being the individual. Utilizing the identifying feature, a person may be uniquely linked to any further identifying data that has been gathered or kept about them.[459]

According to the most recent recommendations made by the US National Institute of Standards and Technology, the most durable technique now is two-factor authentication.[460] Kogetsu et al. emphasize, “Sufficient security cannot be secured by single authentication, and the problems of authentication by username and password alone cannot be ignored. Combining two or more factors is more secure. Two-factor authentication combining ‘what you know’ and ‘what you have’ is currently the most viable.”[461] This procedure might be used to get people's permission to share their genetic and other health information online. However, in order to improve security or reduce the likelihood of key loss, it could be necessary to utilize graphical passwords or other methods.[462] The kind of data kept or shared in the system affects how acceptable two-factor authentication is. For arbitrary medical or health information, such as blood pressure, gathered from home or using a smartphone, ordinary two-factor verification could be suitable.[463] If data or information that might be used to identify a specific person is shared and maintained, stricter security procedures could be required. Consequently, biometric authentication will probably be highly beneficial in the future, but the process needs further debate. We believe "what you know" to have a significant role in this purpose; thus, the combination of "what you have" and "what you are" cannot be used to prove intent.[464] It is thus vital to establish an authentication method that can attain higher levels of security.

3.B.ii. Ethical Challenges

3.B.ii.a. Fundamental Issues

Several ethical challenges concern the use and implementation of biometrics. These challenges have different levels of detail, consequences, and solutions and should be separated as such. Hence, I have divided the ethical challenges into fundamental issues, or those problems that lie at the core of biometrics dealing more in the theoretical and philosophical discussions such as human dignity and liberty, and specific topics, or those that deal with real-world application and have a more practical and direct effect on the world. This separation between fundamental and specific issues should help to understand that the ethical challenges posed by biometrics are two-fold and, therefore, should have some form of a governance framework that will address the issues in both realms as the future of this technology develops.

Human Dignity & Individual Liberty

Physical traits and behavioral traits are transformed into biometric data via measurability. Only quantifiable anatomical and functional characteristics may be regarded as biometric characteristics. A human characteristic may be viewed as a physical, quantitative phenomena if it can be quantified.[465] Physical parameters including length, mass, temperature, and electric current may be used to measure this. Although medical research has long quantified human biological characteristics for therapeutic uses, the question is now whether it is ethically acceptable to use this method to identify persons.[466] As Mordini asks, “If identity and identification concern the essence of the individual, would biometric identification run the risk of reducing the richness of human identity to a sum of mere physical quantities?”[467]

The phrase "informatization of the body" relates to this idea, which describes the dispersion of a person's physical and behavioral characteristics throughout the global information network via digitization.[468] The fundamental worry with the "informatization of the body" is how the digitization of bodily characteristics may impact how we portray ourselves and lead to "disembodiment" processes.[469] While privacy experts and civil and human rights groups are concerned about the possibility of function creep, which is "defined as identification systems incorporating biometric scanning that would gradually spread to additional purposes not announced or even intended when the identification systems were initially implemented" philosophers frequently worry about "informatization of the body because it would touch our inner nature, the human essence."[470]

The ability of biometrics to extract out of any biographical details, and to concentrate primarily on "bare life" in the opinion of some academics, carries the potential of a future in which people will transform from their biological bodies into "cyborgs," where they will be free to build or merely recreate themselves and alter their individual identity as though they were changing apparel.[471] Biometrics and information technologies' self-descriptions as "technologies of immateriality" have drawn criticism from other, more critical viewpoints.[472] Dematerialization is a process that some academics have described as moving from item, commodity, symbol, to simple information.[473] An item inhabited by "us" would be created by the body via this disembodiment process, similar to those used by biometric technology.[474] Mordini & Massari state “Disembodiment occurs when a person’s identity is separated from their physical presence. This dematerialization leaves the body and its personal identifiers as objects separate from the identity of the person attached to them.”[475] This has prompted some sincere inquiries into the possibility that biometrics endangers the body's humanity and violates human dignity.

Any personal identification procedure does in fact imply that people are recognized as having rights and duties, which may be seen as restricting individual freedom.[476] Furthermore, biometric applications cannot avoid providing additional information that might be exploited and is unrelated to recognition, making them far from being a "clean" identifying method. [477] The following section will examine a few ethical and privacy problems that specific applications and systems brought up.

Universal Declaration on Bioethics and Human Rights

Biometrics are considered to be "borderland" technologies since they combine knowledge from several fields, including information, security, the life sciences, and medicine.[478] The Universal Declaration on Bioethics and Human Rights, which expressly tackles "ethical issues related to medicine, life sciences, and associated technologies as applied to human beings," is a suitable source to refer to when considering ethical issues with biometrics.[479] Mordini points out "The main principles of the Declaration that are relevant to biometrics are likely to be Article 3 (about human dignity and human rights), Article 6 (about consent), Article 8 (about respect for human vulnerability and personal integrity), Article 9 (about privacy and confidentiality), Article 10 (about equality, justice, and equity), Article 11 (about non-discrimination and non-stigmatization), and Article 12 (about respect for cultural diversity and pluralism)."[480]

Article 3 of the Universal Declaration on Bioethics and Human Rights says, "Human dignity, human rights, and fundamental freedoms are to be fully respected. The interests and welfare of the individual should have priority over the sole interest of science or society."[481] When the interests of a person and those of society collide, the individual must win ultimately. Undoubtedly, it is often viable to approach security issues from a win-win perspective. Increasing both individual rights and society security might resolve many perceived tensions between those two requirements. However, the Declaration emphasizes that when a genuine dispute arises, the only viable and moral solution is to put individual rights first.[482]

In accordance with Article 2 (Consent), "scientific research should only be carried out with the prior, free, expressed and informed consent of the person concerned."[483] Informed consent is a need for all types of scientific study, not only biomedical research, as this article demonstrates. This implies that when human subjects are involved, biometric studies should adhere to the same strict guidelines that apply to the area of full consent in healthcare. Human fragility and individual dignity are preserved according to Article 8, which states that "individuals and groups of special vulnerability should be protected, and the personal integrity of such individuals respected."[484] The article's significance for biometrics centers on the concern that these systems would not be built adequately to provide complete accessibility to poor and handicapped groups and individuals. Engineers must use universal design concepts, methodologies, and tools to create biometric devices that are usable by all people, including those with impairments, especially when it comes to extensive applications.[485]

Article 9, which is concerned with privacy and confidentiality, definitely has a place for biometrics. This clause explicitly demands that collecting personal information be compliant with "international human rights law."[486] It suggests that when adopting biometric applications, a more extensive human rights effect assessment should be necessary, including but not exclusive to a privacy impact analysis.[487] Mordini summarizes that “Article 10 (equality, justice, and equity), Article 11 (non-discrimination and non-stigmatization), and Article 12 (respect for cultural diversity and pluralism) collectively draw attention to the risk that biometric identification could favor discrimination, stigmatization, and racial and ethnic harassment.”[488] This is a genuine issue, especially for big apps and biometric databases for profiling individuals. But this does not signal the inevitable demise of biometrics. On the other hand, by facilitating civic identification and consequently increasing equity, justice, and fairness, biometrics may turn out to be an essential component of development projects in low-income countries.[489]

3.B.ii.b. Specific Issues

Privacy & Data Protection

A digital version of the biometric might be lost, stolen, or otherwise compromised. Numerous problems, not the least of which is privacy, might arise from illegal access to biometric storage systems. Because the biometric cannot be altered and, if compromised, poses a risk to the donor's life, abuse of biometric data is a severe problem. John R. Vacca notes “Even when used as intended, the biometric control captures personal information, such as fingerprints, iris scans, palm geometry, and more."[490] Even if users are informed that their biometric information is being utilized, policy restrictions prevent them from always having the option to refuse. They may need to employ biometrics to do their job or to access connected systems or services. Some people may not want to utilize it because of the "Big Brother" idea. Others, however, could really fear that the data might be used against them to monitor their activities, fake exchanges, or for other nefarious reasons.[491]

Biometric technology is expanding and will continue to pick up steam. Vacca continues, "Organizations must accept biometrics and determine the best approach to ensure that they are used appropriately, that the information stored is adequately secured, and that data collected on the user remain private."[492] Essential factors including data gathering, storage practices, and the consent of the persons from whom the information are being gathered must be carefully taken into account during an audit or review.[493] In order to decide, it is also necessary to take into account the relevant rules if the data collection, retention, and usage were lawful as well as any hazards connected with using biometrics within a business.[494]

Historically, biometric-based technology has been seen as dehumanizing and a danger to people's right to privacy. A person's location, for example, leaves a trail of unmistakable private information even as identifying technologies get more and more secure.[495] Jain et al. stress "In the case of biometric-based identification, this problem is even more severe because the biometric features may inform others about an individual's medical history or susceptibilities, e.g., retinal vasculature may divulge information about diabetes or hypertension."[496] As a result, there is a valid worry about privacy concerns related to biometric identification. It is not acceptable to use a biometric measurement's data for purposes other than those for which it was created.[497] It is challenging to guarantee that the biometric evaluations gathered will just be employed for the intended goal in just about any linked information processing model. It is challenging to assure that the biometric evaluations collected will only be utilized for the intended purpose in almost any linked information processing architecture.[498]

Surveillance

Governments and organizations, like airports or railroad associations, have a propensity to be more interested in the kind of person you are than your identity, including if you have malicious or "hostile" intents.[499] While this is happening, it is becoming more clear that even more advanced identity documents, such biometric passports that include a face picture and fingerprints, will not completely protect us all from malicious intent.[500] It is now quite evident that just knowing someone's identification will not be enough to stop a danger. These factors have led to a continual hunt for fresh surveillance techniques.[501]

Second-generation biometrics allow for the observation of every person in public areas. Since the act of monitoring suggests a lack of confidence in society as a whole and the identification of people who should not be trusted based on some trait that is assumed to indicate a specific goal, surveillance may include broad mistrust against everyone.[502] Continuous and ongoing monitoring might result in a double morality where everyone could be acting out. Some researchers worry that individuals will change how they behave as monitoring awareness increases.[503] As Ploeg et al. say, "Society is at risk of losing its innocence. Before you know it, we will all behave similarly so that we are not seen as suspicious."[504] Those who have experienced living in a totalitarian regime with its extensive monitoring system are acquainted with these effects.[505]

In addition to offering tremendous potential for conventional forms of monitoring, biometric identification technologies seem to be central to the vision of the emerging "society of control."[506] One of the critical components of globalization is the constant movement of people, which biometrics may identify, track, and monitor.[507] In theory, biometric technology could even give each person on the planet a singular, unmistakable identity by enabling identification procedures on a worldwide scale. If the world embraces a more thorough use of biometrics – the end of anonymity could be at hand. It would be feasible to compile a comprehensive record of a human's life in this imagined new world, including their whereabouts, spending patterns, interpersonal ties, connections, etc. This end to anonymity would also mean that any individual could be tracked, even without their knowledge creating an asymmetry in information.[508] Compared to other freedoms like the right to search for, get, and share information, which this kind of system aims to restrict, this amount of monitoring and accompanying breach of privacy does not stand well.[509]

Large Scale Applications

Two broad categories of issues are anticipated for a fingerprint matcher. The first category of problems deals with circumstances in which it is vital to confirm or authenticate a person's identity. As a conceptual foundation for one-to-many matching, this one-to-one matching issue is of particular importance.[510] Jain et al. describe, “The second, more challenging problem occurs when it is essential to ensure that a particular database contains only a single entry for any given individual. This happens in the case of social services wherein one wishes to prevent individuals from collecting welfare under multiple aliases or in the case of identity card issuance.”[511] For this identification issue, it is necessary to scan an extensive database of people to see whether a particular person is already present.

Criminal justice applications have received most of the attention in previous work on automated fingerprint recognition systems. It is reasonable to demand the hiring of skilled fingerprint inspectors to review a significant set of possible matches in the criminal justice application space since there is a relatively substantial cost associated with missing a possible match, such as the release of a wanted criminal.[512] Additionally, a large degree of filtering is almost always required for felony fingerprint verification searches, which reduces the size of the data that is checked. This filtering may have an impact on categorization based on the overall ridge pattern, as well as demographic screening based on factors like age, race, and region.[513] Last but not least, criminal justice fingerprinting systems save pictures of each of the 10 fingers.

Vast social service or national identity registration requests, which will need inquiries and archives holding imprints from a significant fraction of the state's or country's whole population, require the ability to examine records of millions worldwide.[514] Jain et al. continue, "An understanding of the systematic changes in the error rates of a fingerprint identification system with database size is also needed as part of a framework for extrapolating measurements from small benchmarking or sample databases. Criminal justice fingerprint systems are not characterized as allowing extrapolation of measure performance data to large database sizes."[515] Characterizing outcomes in the form of how often they occur in the top or top 10 places is given special importance. These metrics help compare results obtained on different databases but are unsuitable for estimating identification error rates on more extensive databases.[516]

3.B.iii. Creating a Biometrics Governance Framework

3.B.iii.a. Regulating Biometrics

The concept of limited conservation of data pertains to how personally identifiable information about data subjects is stored.[517] Data should only be retained for as long as is required to fulfill the reasons for which it was obtained. Additionally, the subsequent processing of personal data is subject to this regulation. If the administrator wishes to maintain the data after it has expired and lost its usefulness, it should be anonymized.[518] If no identifying components remain in a single collection of personal data, the data are considered anonymous. Any information that may be used to re-identify a specific person should not be included in the data. Successful data anonymization removes any traces of personal information.[519]

National Level

There appears to be a legitimate conflict between personal and communal values when it comes to biometrics. The problems that remain unresolved primarily concern who will determine that biometric data will now be gathered to safeguard domestic security, the process used to make this choice, if appropriate discussion is allowed, and whether key individuals in society are to be considered, and whether or not the utilization of biometric technology as a protective measure is appropriate despite the dangers involved.[520] The "risk society" concept's creator, Ulrich Beck, has noted that the debate on risk starts where our confidence in our safety and our faith in development stops.[521] The idea of risk thus alludes to a "peculiar, intermediate state between security and destruction, where the perception of threatening risks determines thought and action."[522] Whenever people talk about risk, people are worried about anything that could happen if they do not do anything to alter the way things turn out. Risk measures one's exposure to risk and the possibility of suffering loss.[523] Risks are hence estimates of potential occurrences; they happen in the context of uncertainty. As a result, we have limited capacity to assess hazards, take precautions against them, and modify the proportionality of these precautions.[524]

Ethics training and applying relevant laws and regulations are crucial first steps in ensuring privacy. The scientific community has had to balance open data access with genetic privacy. Technology improvements are accompanied with worries, discussions and conflicts on a range of subjects, such as ethics, rules, and legislation pertaining to the safeguarding of genomic privacy.[525] Although many of these rules and regulations have been slow to take effect, they nonetheless significantly influence personal genomics research, teaching, and clinical practice. Shi & Wu point out, “As indicated by recent privacy and identity infringement work, protecting genomic anonymity becomes next to impossible because researchers increasingly combine patient data with many types of data from social media posts to entries in genealogy databases.”[526] In order to educate students, investigators, medical professionals, and society concerning these mechanisms for safeguarding genomic security, it is crucial to develop and extend educational activities.[527]

The Health Insurance Portability and Accountability Act of 1996's (HIPAA) Standards for Privacy of Individually Identifiable Health Information, or the "Privacy Rule," is a crucial piece of health information protection legislation.[528] The Privacy Rule was created to control how covered firms used and disclosed customers' health information. It lays forth standards for people's rights to know how their health data is used and to exercise that control.[529] It should be noted that business partners, insurers, data clearinghouses, and health providers are all protected organizations under the privacy regulation. HIPAA does not protect health and medical information from these listed organizations. As a result, recently founded, for-profit sequencing and genetic testing businesses (like 23andMe) produce a lot of healthcare data that is sensitive and identifiable yet is exempt from HIPAA rules.[530] The recently emerging user personal health information from social networks, activity trackers, digital healthcare apps, and home paternity testing is not protected by HIPAA.[531] Shi & Wu conclude, “Additionally, the privacy rule only protects identifiable health information, and there are no restrictions on the use or disclosure of de-identified health information. Metadata, such as age, race, and geographical regions, can be publicly accessible.”[532] The potential risks to genetic privacy are one illustration of how such non-identifiable data and documents may be utilized to reveal private information about particular people.[533]

Global Level

Currently, certain countries—like Finland, Sweden, and Norway—have established national biometric systems; other countries—like France and the United Kingdom—have not, but plan to.[534] Germany deserves special attention because the parliament previously disallowed the creation of a national biometric database. The German parliament claims that a national biometric registry does not include one of the fundamental rights protected by German law, which is the ability to decide what information is publicly available.[535] The Fourth Amendment's ban on unwarranted searches and seizures is the main impediment to collecting biometric data in the USA.[536]

Although there are several reasons to share biometric data with other parties and organizations, the most common one is to facilitate international law enforcement and security. The "Prüm Treaty" and the "Five Country Conference Protocol" are the international agreements pertaining to the exchange of biometric data that are better known.[537] 13 EU members have signed the Prüm Treaty, which permits them to share internet access to their respective countries' databases for DNA and fingerprints.[538] The Five Country Conference Protocol authorizes the sharing of fingerprints or other biometric information for the purposes of intelligence and law enforcement.[539] The United States of America, Canada, the United Kingdom, and New Zealand are all parties to the protocol. The Association of Southeast Asian Nations (ASEAN) nations are also working on a comparable multinational endeavor.[540] Additionally, several bilateral agreements exist enabling the exchange of biometric data between specific nations.

Data sharing raises substantial political and ethical challenges in addition to several technical issues, the main ones of which are related to standards and technological compatibility.[541] Reciprocity is most likely the fundamental problem. Mordini explains "Provided that all actors and principals agree with the need to ensure a basic level of data protection and respect for informational privacy in these databases, the international community has widely divergent views about acceptable levels of data protection. To date, there is no agreement on common international privacy principles that could provide a framework for using biometric data."[542] For instance, the EU forbids the transmission of peoples' personal information to an area or nation outside the EU unless that region or nation guarantees a comparable degree of data protection as the EU.[543] As has been the case, for example, with the never-ending argument between the United States as well as the EU over the sharing of passenger data, such official views will always lead to deadlocks.[544] In the worldwide and interconnected world of today, while it is difficult to restrict the flow of data to a select few nations, it is also unrealistic to think that all nations would agree with the EU's stance on the protection of personal data.[545] This brings up the major, and arguably more troubling, ethical problem with the exchange of biometric data internationally.

3.B.iii.b. Global Examples

There are numerous global examples of biometrics governance frameworks – but few are more robust than the EU since the implementation of the GDPR. It is *the* standard, right now, for the most comprehensive biometric data privacy and security. Therefore, the analysis will begin with the European Union and then move to look at UNESCO's example to further what a global biometrics framework should aim for.

European Union

Since the passing and implementation of the GDPR, the EU has been one of the global leaders in data privacy, security, and surveillance – biometrics included. However, many essential legal documents were implemented before the GDPR that set the stage for its arrival, including the Data Protection Directive, the Charter of Fundamental Rights of the European Union, and the Treaty on the Functioning of the European Union – all of which will be touched on in this section. The Data Protection Directive governs how personal data is processed in Europe. “It affirms that the processing of personal data is subject to principles of purpose, specification, and proportionality: personal information may be collected only for specified and legitimate purposes and not further processed in a way incompatible with those purposes”; in addition, such information needs “adequate, relevant and not excessive and about the purposes for which they are collected and/or processed.”[546] According to the proportionality principle, there should be a proper balance seen between quantity of information gathered, documented, and given weight or worth of the goals being pursued.[547] Data volume might relate to the amount of processing being done. However, because even a small quantity of sensitive material entails a great deal of danger, it may also relate to the type of data being handled. [548]

Securing proportionality may be challenging since many variables need to be considered, many of which are context dependent.[549] In theory, only extreme instances may be resolved in a way that is undisputed. In most real-life situations, no proportionality decision can be made without carefully considering contextual elements. These considerations encompass both the processing's purpose and its overall context, such as the national security, educational, healthcare, or workplace contexts; the need for the handling and the existence of workable or less threatening solutions; the type of data is being generated and its vulnerability, such as whether the data reveal personal health information.[550]

A basic human right that applies to the usage of biometric information is the right to privacy when processing personal information. The Charter of Fundamental Rights of the European Union and the Treaty on the Functioning of the European Union both include provisions that are fundamental to this right.[551] Deliversky & Deliverska state, “According to legal instruments, the right to personal data protection is a universal right provided to everyone, as this protection must comply with a person's fundamental rights and freedom. The European Convention on Human Rights proclaims the right to personal data protection. Through this mechanism, the right to respect private life has been guaranteed, as well as the right to home and correspondence, and it lays down the conditions under which restrictions of the right are permitted.”[552] The primary piece of law protecting persons against the release of information at the level of the European Union is Directive 95/46/EC. The free interchange of personal data is addressed by this piece of law, sometimes referred to as the data protection directive. The European Commission advocated for updating data protection laws at the EU level at the beginning of 2012 since ensuring security is the main goal of all laws governing the protection of personal data.[553]

Article 7 of the EU Data Protection Directive states that "no data collection can go unnoticed by the subject being monitored."[554] The goal should be for the subject to be conscious of the many types of information being collected on them. However, precisely this is what integrated biometrics would stop. Article 7, paragraph 2 stipulates that paragraph 1 is not applicable in the event of "processing of data relating to offenses, criminal convictions, or security measures," provides the escape hatch from this legal predicament.[555] However, is it proper to apply the idea of security precautions to every technology used in any situation? A never-ending expansion of an ambiguous security area cannot be used to justify the increasing prevalence of embedded biometrics.[556] Additionally, it does not appear that visitors' privacy rights will be honored even if they are informed that they will be inside a biometrically monitored location. Once individuals are accustomed to warning labels, they are less likely to be seen. Since the EU is part of the United Nations (UN), looking at a more significant part of the world through the lens of UNESCO – a specialized agency within the UN – seems to be a logical next place to look for how to create a biometrics governance framework.

UNESCO

Emerging technologies provide UNESCO and its partners with a wide range of new possibilities and channels for action, allowing them to actively participate with the rise of the information society and demonstrate the UNESCO guidelines below while still carrying out their responsibilities. An advisory board is created in the first suggestion.[557] International research on the moral consequences of cutting-edge technology should regularly benefit from advice from an advisory board. Top technology specialists are sought after by policymakers and the public, and UNESCO's mission and certain university institutions' technology-focused programs are complementary since both organizations support principles such as information availability and observance of human rights. As a result, by establishing a specialist advisory committee on information ethics, UNESCO would be able to benefit from the expertise of leading technologists and win the recognition they deserve.[558]

One such group might help UNESCO maintain the kind of collaboration that were discussed during the World Summit on the Information Society while avoiding the issues that impede important, rising conferences.[559] This advisory board should consist of youngsters and young people from all around the globe as well as technology and info ethics professionals to guarantee that the group's results are adaptable and forward-thinking. Additionally, UNESCO might work with academic institutions to organize brainstorming sessions to address essential concerns in the future.[560]

The establishment of a technological community to safeguard personal data is the second suggestion.[561] Controlling the flow of personal data will be essential for ensuring that people can access information and exercise their human rights in the information age. The poll on the "Ethical Implications of Emerging Technologies" recognized this as one of the most significant factors since technology would likely be utilized more and more to exert control over people's lives.[562] Here, it is suggested that the issue of digital identity management be the focus of an uncommon cooperation since it will be the cornerstone for subsequent developments involving the transfer of personal data and because the market is preparing to introduce new products in the upcoming years.[563]

A hole in the global system would be filled by significant efforts in the security of personal data. Personal data protection is urgently needed right now. The Montreux Declaration, issued in September 2005 and calls for multilateral norms in this field, was endorsed by the International Group of Data Protection and Privacy Commissioners in recognition of this need.[564] The need is also recognized by computer scientists, notably well-known members of the identity game business group and the World Wide Web Consortium (W3C), who believe their effort has immense potential, both for good and bad. Nevertheless, a lot of nations look for guidance on the moral principles their laws should uphold.[565]

Since the Council of Europe (COE) and the Organization for Economic Cooperation and Development (OECD) both enacted legislations well over 20 years ago to address the issue of incorrect treatment of personal information in the digital era, the idea of safeguarding personal data is not a new one.[566] These measures make up a robust set of safeguards when taken simultaneously. These OECD principles include transparency, accountability, openness, individual engagement, purpose specificity, usage restriction, and limited collection.[567] An anti-discrimination clause is included in Article 6 of the COE Convention.[568] The COE regulations, on the other hand, only apply to signatories, while the OECD guidelines are not legally obligatory. These instruments are purely legal in character, even if they were founded with international force. Without adequate worldwide enforcement, their contents are likely to be disregarded, particularly by non-signatory countries. They are unrealistic for ensuring the appropriate global handling of personal data by machines. UNESCO might assist the technology sector in creating instruments to enforce personal data safeguards when the legislation is deficient by collaborating with W3C and academic institutions.[569]

3.B. Conclusion

Individuals fall prey to the delusion that personal identification in and of itself endangers fundamental rights and invades the private realm. Any technique for determining a person's identity indicates that they are recognized with rights and duties, which may be seen as restricting their freedom. Nevertheless, without personal identities, there would be no rights and freedom. No one's civil, political, or social rights can be imposed on them since they are nameless. Only an identifiable person and someone with a public identity may assert their rights, including the right to remain anonymous. There is currently a lack of public knowledge of the types of data gathered and their intended uses. Since humanity's ability to cooperate with security protocols varies depending on their perception of risks as real and the effectiveness of security protocols in relation to those risks, it would be a serious mistake to ignore the public's behavior and physical attributes when conducting planned covert monitoring.

Many nations are working on second-generation biometrics systems, but there has not been much public debate about the benefits and drawbacks to employing this new technology. Imagine there is a risk of confidentiality being violated or data being misused after being gathered without permission or, in some instances, even with the subject's knowledge. In such events, individuals can feel duped and distrust governments more generally. The future reaction might be severe since it is hard to rebuild public confidence after misuse. Data should thus only be retained if it is required to fulfill the goals for which it was obtained to prevent this possible public reaction. Additionally, the subsequent processing of personal information is governed by this regulation. If the administrator wishes to maintain the data after it has expired and lost its usefulness, it should be anonymized. A collection of personal data becomes anonymous when all aspects that may be used to identify a person are taken out. The data should not include any elements that might lead to the re-identification of specific persons. Successful data anonymization removes any traces of personal information. This governance framework is then detailed at the national and global levels with specific examples of the European Union & UNESCO to show examples of existing early biometrics frameworks.

3. Conclusion

This chapter summarized the data battle between the individual’s autonomy and rights versus population health and advancing the common good. Recall that the key challenge is whether decision-makers can strike a balance between the need to protect real patient and clinician concerns and the need to place value on health records for humanity. To provide proof without jeopardizing these legitimate interests, it will be necessary to consider whether data used for research, like that by the Federal Coordinating Council for Comparative Effectiveness Research, can be handled properly and securely. Regulation and control of biometrics are essential since they are one of the main types of data utilized in public health statistics. While data analytics may help with the development of a framework for biometric governance, various issues with the use and abuse of data analytics itself need to be addressed. The next chapter describes some of those concerns in two senses: one practical, within genomics, and another theoretical, within the future of digital technologies themselves.

CHAPTER 4: ETHICAL CHALLENGES OF DATA ANALYTICS IN HEALTHCARE

4. Introduction

The earlier chapters focused on the benefits and opportunities that data analytics governance can provide the healthcare landscape through its finance and delivery, as described in Chapter 2. In Chapter 3, data analytics governance assistance is detailed at the micro level, with the individual's autonomy and rights paralleled against the governance at the macro level with population health and the Common Good. The fourth chapter takes a different look at data analytics and focuses on the ethical concerns and challenges this technology can display. The social policy of genomic data, such as genetic discrimination, common heritage, and more concerns with distributive justice, are detailed. The section details challenges in data analytics with the autonomy paradigm and cloud computing, respectively. These issues pose a challenge to data analytics due to cloud computing's de-centralization of data storage. A critical factor in respecting the privacy and autonomy of the individual is having secured, centralized data storage that can easily be maintained and traced back in the case of a data hack.

The rest of the chapter will lay a philosophical/theoretical foundation discussing the impact of technology in healthcare via the digital revolution and its relationship to society while looking at the future of this dynamic relationship and how data analytics could vastly alter this relationship down a slippery slope of a dehumanized world and human enhancement. A cautionary approach is taken in which concepts like technological determinism and the Precautionary Principle are explored while using these concepts to assist in repositioning a medical ethos for the future. An applied analysis of these concepts is used within the topic of human enhancement citing ethical concerns and providing a foundation to advance the debate.

4.A. The Ethical Challenge of Data Analytics in Genomics

4.A. Introduction

The twenty-first century has, without a doubt, thrown humanity into the informational technology age stemming from famous and influential inventions in the digital world. Innovations such as the smartphone, social networking, high definition, commercial GPS, and cloud computing –to name a few are some of the reasons why society lives in a digital world. Big data is one term used in describing all this digital information, and its potential uses for the world and the healthcare industry are limitless. However, with all this informational data comes a big data problem, and it, like many other technological ethical issues, must be addressed. Issues surrounding privacy, security, and consent concerning your personal data (especially genetic data, as discussed in this chapter) are of the utmost importance to keep the updated policy. The social policy of genomics highlights genetic discrimination, common heritage concept, and distributive justice in genomics and insurance companies. The section concludes by giving a global privacy governance framework that will help set the policies in the right direction to address the ethical loopholes in the big data dilemma.

4.A.i. Social Policy of Genomic Data

Big data, while providing numerous benefits to healthcare described in the previous section, obviously has several ethical implications that must be monitored and maintained as time progresses. Security, privacy, and informed consent are some of the most significant areas of moral concern. However, there is reason to argue that the social policy of genomic data has the most potential cause for concern. This area involves all three previously mentioned concerns and adds new situations, such as genetic discrimination and problems with distributive insurance justice. Genetic discrimination can occur and affect life and health insurance as well as the workplace despite the current policies to fight it. Then, a different view is expressed by looking at genomic data as a common heritage of humanity. Any findings should benefit society, as declared by UNESCO. This section concludes with a look at genetic data regarding life insurance informational symmetry and how other nations handle genetic testing and insurance.

4.A.i.a Genetic Discrimination in Health Insurance

While it may seem evident that discrimination of any kind – including genetic as described here – is wrong, it is not always that simple to prevent. As technology and big data continue to advance rapidly, so do the availability and accuracy of genetic testing. While no one can choose their genetic makeup or predispositions, insurance companies still use this information to charge higher premiums to those who are genetically disadvantaged. While policies have been passed to reduce this discrimination against insurers as well as employers, these current policies are not complete and provide loopholes that insurers and employers can exploit. The ethical course of action would be to continue passing legislation that will patch these loopholes while maintaining a free and stable market.

Genetic Testing Concerns

Genetic testing has numerous benefits. For example, "Ashkenazi Jewish women who test positive for a mutation in the BRCA1 or BRCA2 tumor suppressor gene have a lifetime breast cancer incidence of 82 percent, compared to less than 20 percent for the female population at large."[570] Even though a negative test result cannot guarantee that an individual will remain cancer-free, partly because many instances of breast cancer have causes other than genetics, having a positive test result can lead to better proactive outcomes such as routine screening, more effective treatments, and lives saved.[571] In the same sense, for example, a young child without symptoms of Huntington's disease but with a family history of the condition, may think that only a genetic test will give them the capacity to make future-oriented responsible decisions such as whether to raise a family or the type of career to achieve. The knowledge that a genetic test could give this individual, especially in the case of Huntington's disease, which does not have a treatment or cure, may not be seen as a blessing to some, who would rather have the peace of mind that ignorance can bring them.[572] However, for numerous people, the availability and accessibility of genetic testing have been a blessing of priceless information.

At the same time, the widespread use and availability of genetic testing have revealed fears of discrimination in various areas: employment, health, life, and disability insurance, with the underlying motive of creating a "genetic underclass."[573] Further, it is precisely these kinds of fears that are cause for public alarm and concern in the genomic revolution.[574] While many may disagree about the extent of genetic discrimination that takes place, a general consensus exists that opposes genetic discrimination of any kind. As with many public opinions, views range from "no amount of such discrimination is acceptable" to more detail-laden ideas.[575] Regardless, the consensus against genetic discrimination is remarkable, as governments in both North America and Europe have implemented actions to outlaw various parts of it.[576] The following subsection will focus on some legislation enacted in the United States to prohibit various forms of genetic discrimination.

GINA & ADA

The Genetic Information Nondiscrimination Act (GINA), which had been the subject of a lengthy 13-year congressional debate, was finally approved on May 21, 2008, and it went into effect.[577] Adding to the federal and state protections already in place for genetic discrimination, such as employer-sponsored group plans in HIPAA, GINA acts to outlaw employment and health insurance genetic discrimination[578]

The Americans with Disabilities Act (ADA), like GINA, prohibits discrimination in the workplace based on a person's impairment. The ADA's scope of which individuals considered to have a disability is somewhat limited. Therefore, it does not outlaw all forms of discrimination in employment. Disability is described under the ADA as "a physical or mental impairment that substantially limits one or more of the major life activities of an individual, a record of such an impairment, or being regarded as having such an impairment."[579]

The ADA and GINA cover individuals in an opposite parallel manner in the most severe cases. When it comes to genetic discrimination in employment, GINA covers the individual, even when asymptomatic; however, the ADA does not. Conversely, the ADA will cover the symptomatic individual, which is not specifically covered in GINA. The lack of coverage and problem for most lies in the middle of these extremes. Within the ADA, people with "mild, temporary, or pre-symptomatic conditions" do not meet the criteria for a disability as previously mentioned.[580] Likewise, under GINA, people with a genetically-based anomaly but not physically symptomatic are not going to be covered.[581] This is one narrow way to view how genetic data should be seen and handled, resulting in confusion, discrimination, and misunderstandings. A different way to look at genetic data without prejudice is the view that it is the common heritage of humanity. Any breakthrough findings regarding genetic data should benefit humanity as a whole, as declared by UNESCO.

4.A.i.b. Common Heritage

The idea of a 'common heritage of humankind' was used in international law as far back as the 1960s to manage universal resources like outer space and the ocean floor.[582] The argument was that these "things" are a common heritage of mankind, they need to be utilized for goals that advance the interests of all people.[583] Interestingly, this concept dates back even further to traditional Roman law, which distinguishes a "category of *res extra commercium*, or things outside of commerce; property that cannot be exchanged."[584] A few examples of this common property were considered to be the seas and rivers. This common property category made a law that these things could not be traded or owned by anyone or any nation.[585]

Initially, this concept only applied to those resources like the moon, the ocean floor, and the Antarctic. Still, this notion quickly added vital resources that were of benefit to humanity, even if they resided within a specific country, such as the rainforests. As Henk ten Have explained, "labeling areas as common heritage means that they are vital for the survival of humankind. It also means defining global responsibilities."[586] The concept of common heritage was first labeled regarding the human genome by the HUGO Ethics Committee. It was followed by UNESCO in its Universal Declaration on the Human Genome and Human Rights (UDHGHR) in 1997, declaring that "the human genome is the heritage of humanity."[587]

Universal Declaration on the Human Genome and Human Rights (UDHGHR)

The UDHGHR, which was approved by the UN General Assembly and UNESCO in 1998, is recognized as the pioneering effort for international bioethics governance.[588] This legislation sparked an international moral debate regarding the human body and life with financial considerations. The discussion produced two notable aspects of global bioethics governance. The first aspect regards that the field of science is seen as a global commons requiring shared principles. Starting in 1990, The Human Genome Project created knowledge that should be available to all globally, even though specific applications of the project can be privatized for various reasons. The new understanding should benefit humanity. It should be widely disseminated and available to countries not involved in the research endeavor. There is, therefore, a need to go beyond a strictly economic perspective since the "genome is the heritage of humanity."[589]

The other aspect of global bioethics governance is a greater emphasis on human rights. Genetic technologies can limit reproductive freedom and promote sex selection, thus introducing new forms of discrimination and stigmatization. Access to genetic services and potential new treatments can also be limited for various reasons in different countries. The new knowledge will only benefit humanity if special attention is paid to ethical concerns, particularly the human rights implications. Article 1 of the UDHGHR states, "The human genome underlies the fundamental unity of all members of the human family, as well as the recognition of their inherent dignity and diversity. In a symbolic sense, it is the heritage of humanity."[590] This introductory statement has several practical implications: the genome cannot be appropriated as someone's property and finically exploited (Art 4); benefits from scientific advances should be available to all (Art 12); research results should be used for peaceful purposes (Art 15); scientific knowledge and information should be freely exchanged and publicly accessible (Art 19).[591]

The UDHGHR was intended as an incentive for national legislation. Since important federal legislation is lacking, and global human rights regulations are too vague and unspecific in this area, there is an opportunity for a global initiative, not to impose a framework on all countries but to start a global dialogue on how human genetics can develop for the benefit of everyone. But even this modest objective requires subtle processes and practices of deliberation and interaction to defuse controversies that otherwise result in ineffective statements.[592]

Global Public Goods

Global public goods are a notion in international law that resembles common heritage in certain ways. In the 18th century, the concept was conceived by David Hume and Adam Smith. However, it lost much popularity until the widespread debate by economically challenged countries for global public access to AIDS drugs in the twentieth century.[593] Benefits from an item must not be exclusive for it to qualify as a global public good, and its use should not deplete the available supply for others or cause its use to be restricted.[594] Additionally, a global public good should provide advantages that are accessible to individuals from various backgrounds, ages, and cultures.[595] For example, knowledge about the human genome could count, given that it satisfies each of the aforementioned requirements, as a global public good.[596]

In designing and implementing genomic databases, a key idea has been the idea of global public goods. To illustrate further, a HUGO declaration from 2002 about human genetic databases said: “population genomic databases and the primary sequence data contained therein to be global public goods.”[597] HUGO declares that these goods [human genomic databases] are to be shared by all with no restrictions. Their statement continues that “Human genomic databases are global public goods. (a) Knowledge useful to human health belongs to humanity. (b) Human genomic databases are a public resource. (c) All humans should share and have access to the benefits of databases.”[598] The terminology surrounding the idea of global public goods is useful for ushering international agreement in genomic analysis and the dissemination of its findings specifically to contribute to health equity in the socioeconomically challenged nations.[599]

4.A.i.c. Distributive Justice in Genomics

Everyone has an equal right to the products made possible by the results of the human genome's study and testing since they are a global public good and a part of humanity's common heritage. Distributive justice aims to ensure this is precisely what happens. The most obvious area that this can be monitored is in the insurance arena, specifically life insurance, as will be discussed. To manage this justice, it is essential to look at other countries worldwide and how they have handled this matter.

Allocation of Life Insurance with Genomic Data

Currently, it is legal for life insurance firms to inquire about an insured person's medical background, way of life, and family history, all of which are relevant to the person's genetic information.[600] The insurance company can use this information for underwriting the insurance contract; notable examples include a family history of a disease, pre-existing conditions, and high-risk hobbies (such as mountain rock climbing or parachuting).[601] A paradigm international life insurance example is the U.K., which uses a universal voluntary mutual insurance model instead of a solidaristic insurance model.[602] These are the two main types of insurance models, and the subsequent analysis comparing these two models follows. A mutual insurance market functions by pooling the collective risk of all the insured together and then requires payment based on an estimate of how much risk the insured brings to the collective pool.[603] The quantity of coverage supplied is closely associated with the amount of insurance bought, and these transactions are often confidential.[604] In addition, these transactions are voluntary, which means U.K. citizens have a choice as to the level of coverage they prefer.

The other insurance model is solidaristic insurance or sometimes called social insurance. This model is similar to mutual insurance as the risks are also pooled, and payment is based on a prior agreement (like an individual's ability to pay or requiring an equal contribution from everyone in the market). However, the solidaristic model differs as the payment required is unaffected by the degree of risk added to the pool, which means that insurance coverage is separate from the payment amount and is more correlated with the level of need of the individual.[605] These transactions are usually government-run and required by all government citizens. This model limits the amount of coverage an individual can choose. International examples of this model are health insurance services in the majority of EU nations and the UK, supplying coverage to all citizens and funded by general taxation.[606]

Given the compulsory nature of solidaristic insurance, it can still operate with vastly differing degrees of knowledge regarding a person's risk.[607] Given that the cost of insurance is unrelated to the recognized risk that was added to the pool, as well as the lack of control the person has over the extent of coverage, The provision of more information will not be beneficial to a high-risk person for more coverage just as low-risk individuals cannot skip out on contributing to the payment pool in a true solidaristic fashion.[608] On the other hand, mutual insurance requires informational symmetry to function correctly.[609] Martin O'Neill highlights this importance in mutual markets: "systems of mutual insurance markets are stable only under conditions of informational symmetry whose need can be explained by virtue of an instability that mutual insurance markets undergo in the face of informational *asymmetry.*"[610] This informational asymmetry is why insurance companies inquire about personal medical history, high-risk hobbies, and family medical history and precisely why the insurance agreements are only validly enforced when all relevant information is fully disclosed.[611] Thus, informational symmetry is a fundamental part of mutual insurance contracts. However, our understanding and awareness of genetic information that could be risk-relevant are increasing with no signs of slowing down. With contemporary biomedical advances in genetics happening every day, a look into how these advances change the nature of the life insurance marketplace is critical in shaping the future of the legal and ethical fields.

Most medical conditions have a genetic component that can assess the risk of developing the disease, thanks to advances in genetic technologies. The availability of genetic testing and subsequent knowledge of one's genetic risk can allow a person to mold their future to reduce that risk (via behavioral changes or preventative medicine) and come to peace with what may lie ahead.[612] Due to the significance, overall usefulness, and especially sensitivity surrounding genetic testing and information, it is reasonable to assume that people should be able to keep this information private if they choose. One powerful way of achieving this privacy would be dismantling the mutual life insurance market to be replaced with a solidaristic model. This model allows for preserving people's interests in maintaining privacy while accessing genetic information and avoids genetic discrimination by the life insurance company.[613] This "one-sided" form of information gives the individual full access to their genetic data without the requirement to convey that to insurers. This choice has the drawback that individuals will be forced to sacrifice their choice in the level of coverage that the life insurance can provide as customary with solidaristic insurance models.[614]

While this is a rather extreme option for solving the problem, social justice demands will help create a consensus to forward this cause. This can be explained if you think about which issues the theories of social justice part from and what is similar about these theories. Martin O'Neill gives this example: "many disputes among theories of distributive justice involve thinking about the degree to which *choices* made by individual agents out to affect their economic prospects."[615] However, one glaring problem with that is genetic endowment is not something you can choose, nor is it related to individual effort and is wholly outside one's agency to control. Given that genetic endowment has no regard for personal preference, there is little room for argument over responsibility, choice, or desert issues.[616] In a similar spirit, ideologies of justice often vary on how much outcome equality should be valued versus economic sufficiency, giving precedence to the weak and vulnerable, or any other distributive goal.[617] However, if life insurance is a "gateway social good," as O'Neill describes, which means it is otherwise "essential for delivering basic economic opportunities, securing fundamental rights, and for avoiding social exclusion, then all these sorts of theories should agree that it is an essential matter of justice to ensure access to life insurance."[618]

Insurance and Genetic Testing in the International Context

In the Netherlands, France, Switzerland, Austria, and the United Kingdom, policies do not exist that monitor the use of genetic tests as a precondition for the end of a life and/or health insurance contract.[619] In countries like the Netherlands and the UK, insurance companies differentiate the agreements with their users by the sum insured.[620] Judit Sándor notes, "If a specific limit is exceeded, there is at least the possibility of requiring the insurance applicant to disclose the results of previous genetic tests. In Austria, Switzerland, and France, the disclosure of test results is neither a right nor a duty."[621]

In most European countries, laws require the insurance applicant to divulge any and all information concerning the insured risk, such as diseases. The insurer may end the contract if the insurance applicant does not reveal any of this information. However, it is only in the United Kingdom that this disclosure duty applies to life insurance contracts.[622] Another example in the Netherlands is a disclosure obligation if the applicant has any information referring to diseases that have already presented symptoms. In this sense, genetic information is not a predictor of future health events but rather a diagnostic tool similar to the results of a typical medical examination.[623] Regarding procedural law, there are two sides. On the one side, there is Austria, with a very robust and widespread legal basis, while on the other side is the United Kingdom, which does not have a robust legal basis but numerous reports and codes that guide practices.[624] To add to the differences, Switzerland takes more of an Austrian approach, while France maintains a strict outlaw of any kind of genetic testing for procedural purposes.[625] Despite these differences, most countries display some sort of effort to protect private genetic information in health insurance.

Many, if not all, other European nations have passed legislation regulating the use of genetic screening in insurance agreements and other legal contexts. Further examples include the unlimited utilization of results from genetic testing in Spain, Japan, and Canada.[626] Also, in Canada, the insurance applicant must disclose genetic testing information; to the applicant's detriment, results can be used to terminate a contract. Japan may lag a bit behind as it allows genetic testing without many ordinances to regulate the practice. However, due to a few aspects of the Japanese healthcare system, genetic test results can only be used in life insurance contracts and nothing else.[627] In addition, any negative results of previous testing or investigations of the applicant must be disclosed.

In Denmark, disclosure is obligatory if the genetic results concern the applicant's current or former health condition, prohibiting any discrimination based on potential future health conditions when negotiating insurance contracts.[628] In Sweden, there is an underlying agreement between the state and national insurance associations that control the country's usage of genetic testing. The insurance applicant must agree to add to the genetic database and add any information related to themselves.[629] The harmonization of legal regulations on an international level is crucial if you were to consider the potential of massive multi-national insurance companies competing with each other in smaller domestic markets and could bypass other national laws and regulations by contracting individuals in other countries where the law may not apply in the same way. The European Union, however, has thought of this potential and has enacted laws to respect other European regulations, even if they are not signed into law yet.[630]

This is but a brief introduction to the social policy of genetic big data and focuses on highlighting the importance of genetic discrimination in insurance, the flaws of the current policies in place to combat discrimination, a presentation of the view that mankind shares a genome as a common heritage and is a public good that all should benefit, and finally the problems that genomic data faces with distributive justice and some international examples of how it is handled. With this in mind, it is imperative to create a global privacy governance framework that will help address all of the above issues ethically. Tighter regulation of these genomic data banks, or biobanks, is necessary as a part of this framework, in addition to the global harmonization of laws regarding genetic privacy.

4.A.ii. Creating a Genomics Governance Framework

With an understanding of the big data problem and its ethical issues, including the social policy of related genetic data, the need for data governance and regulation is clear. Genetic testing companies, biobanks, and other data infrastructure facilities must be regulated on what they can and cannot do regarding personal privacy and security of our personal, genetic, and other forms of data. Therefore, this section aims to give a starting point for the need and framework for such governance to be enacted into future policy.

4.A.ii.a. Regulating Biobanks and Privacy

A well-rounded idea of privacy as a foundational principle can help sort between the multiple stakeholders and get to the root of the problem with biobanks. Most places, especially in bioethics, hold the right to privacy as a long-standing and widespread ideal to be achieved.[631] Numerous texts from laws, ethical manuscripts, and regulations worldwide have all pointed to the essential nature of the private life or the right to privacy and maintaining confidentiality in professional relationships, contracts, and most laboratory testing.[632]

Graeme Laurie et al. describe four dimensions of privacy issues in biobanking:

> (1) physical privacy (e.g., gathering and storing biospecimens and testing them without consent); (2) informational privacy (e.g., possible misuse of information); (3) decisional privacy (e.g., control or influence over what is done with data and biospecimens); and (4) proprietary privacy (e.g., ownership of biospecimens and the control of identity as it relates to one's genes).[633]

A critical question arising from these four dimensions of privacy related to biobanking is how can scientific advancement and research promotion effectively take place with so much privacy around the biobanking industry. This question and more will be answered in the following subsection.

Scientific Advancement & Research Promotion

The risks of a privacy breach, especially data misuse in biobanks, can be prevented or mitigated by protecting and promoting privacy at all costs. Unfortunately, even with an active stance on security, breaches of confidentiality and data misuse can still happen. Violations in privacy breaches can span a wide range of harms, such as "group discrimination following a scientific publication containing group associations (e.g., cancer and Ashkenazi Jews), individual insurance or employment discrimination, and reusing DNA collected for research for criminal profiling."[634] The risks to these examples are real. Still, fortunately, there is a low incidence rate, and there are laws and regulations in place (or soon to be) to even further reduce the risk and manage any harm resulting from a privacy violation or misuse of data.[635] The danger still exists, which begs the issue of how the biobanking sector can continue to provide adequate privacy protection, support for research, and scientific development.[636]

One response suggests that an assessment should occur of the restrictions on biobank clients' privacy rights under different legal systems. This should be done with a mindset that privacy is seldom an absolute in law or ethics while simultaneously clarifying the research improves public interest in biomedicine.[637] Edward Dove states that "indeed, most legal systems recognize that privacy must yield in certain circumstances or that the level of protection might be calibrated relative to other social values and interests."[638] This next paragraph is only a short description of the extent of biobank customers' privacy with a critical look at the decisional and informational privacy dimensions.

Protecting biobank users' genomic and related data, including biospecimens, is an obligation of researchers and healthcare professionals. There are numerous ways that this objective can be achieved, but most commonly is accomplished by the biobank's data stewards who are "(1) seeking the explicit (although not necessarily specific) consent of participants to share their data with other researchers, (2) replacing personal identifiers in a dataset with at least one code (also known as reversible de-identification or key-coding), or (3) anonymizing a dataset (i.e., permanently removing direct identifiers, hence the synonymous term irreversible de-identification) before making it available to other researchers."[639] Laurie et al. add that "each method has value in the protection of privacy interests but also inherent limitations."[640]

A Fallacy of Sufficiency

There has been an ongoing discussion in the literature for quite some time that the traditional concept of consent is particularly questioned in biobanking. In the biobanking industry, many institutions are designed to focus on the future of research. Within these institutions, however, a research subject cannot be fully disclosed the entire range of possibilities of projects that will make use of their information and samples for the duration of the study and institution– certainly not if the subject's data is transferred to another biobank.[641] Therefore, leaning on the traditional sense of consent in a specific context lends itself to a fallacy of sufficiency: "no participant can be sufficiently informed at the initial stage about the range of unknown actors and uncertain events to follow, and therefore to set up specific consent as the requisite criterion for participation means that most biobank initiatives will lack a sufficient ethical or legal basis on which to recruit and operate the resource."[642]

In addition, the traditional sense of consent usually involves an all-or-nothing approach, with it rarely, if ever, contributing to any control over privacy. Many people mistakenly believe that more control means more privacy. Biobank users have their consent summed up into two options: to participate or not to participate, with the ability to withdraw later but to a variable/unknown extent. For those users who value privacy as a significant dimension of autonomy, unfortunately, the ability to negotiate over the terms of data access is near impossible.[643] Further, participants' consent does not release data stewards from their ethical and legal obligations to use data securely and responsibly.[644]

4.A.ii.b. The Need for Privacy & Security Law Harmonization

Bottlenecks of Global Data Sharing

This subsection will highlight two bottlenecks of global data sharing caused by the lack of a worldwide privacy governance framework. The first bottleneck occurs when ethics committees and similar regulatory bodies (such as IRBs) are out of sync with the current data privacy policies and laws – which becomes a difficult challenge to overcome since new laws and policies are being frequently implemented worldwide.[645] However, ethics committees often hold a stricter level of privacy protection than the current laws require, eliminating any ethical-legal equilibrium. These entities are generally meant to act as safeguards, so this creates a bottleneck when ethics and the law are not in-sync. Many research ethics committees have a severe deficit of any privacy-related training or certification among the members. [646] The types of consent that many of these research ethics committees reviews are traditional, with the research involving a direct action on a human body. In the case of biobanks, an influential research committee would have expertise in data involving "the nature of the population and longitudinal studies and the security and changing nature of data collected and linked over time."[647]

Instead of using actual people, research in biobanks uses big databases and samples of human tissue. Within the various kinds of biobank research, more nuanced considerations must occur, creating the second bottleneck. Unfortunately, while different institutions have various requirements for their research ethics committees, most are comprised of people with expertise in bioethics and law but not data privacy or governance law which can be seen in the current practices of biobanks.[648] These data privacy and governance laws require any entity that collects, uses, or discloses health information to uphold high levels of security to prevent any breaches or hacks. While current practices require research ethics committees to determine whether or not sufficient safeguards exist to maintain the data's confidentiality, in order to achieve this goal, someone must be on the committee who has unique training and wisdom with relation to information systems and de-identification methods that accompany the data.[649]

Establishing Privacy Laws for Biobanking

While, currently, a global data privacy standard is yet to be developed, the European Union, for example, has produced some legislation regarding data privacy harmonization with plans to make it more robust over time.[650] Regardless, progress is being made on the data privacy front. Another small step was made with the passing of the Madrid Resolution of 2009. However, it failed to include any privacy stipulations regarding biomedical research.[651] In the same vein, a call for harmonization of data privacy in the biobanking field has been requested several times.[652]

What has ultimately been missing between the domains of privacy law and biomedical practice is a thorough international and comparative legal review of biobanking procedures throughout the globe and how each country's privacy laws impact biobanking activities. These fields are in a hybrid nature of inquiry, drawing professional advice from numerous areas such as life and social sciences, policy, and law.[653] Due to this fact, more thorough and widespread research is needed in the privacy law and biobanking fields that will help identify problem areas and overlapping areas in the respective fields. The goal of this research would be to lead to deeper discussions and subsequent analyses that could give direction to a future policy that could pave the way for much more accessible and ethical biobanking.[654]

Moving forward, it is no surprise that it will be a tremendous challenge to write a robust worldwide law or regulation concerning research on biobanking and privacy. Still, nonetheless, it does provide a starting point. While creating any sort of global framework will be a difficult and time-consuming task, it should be achievable if created with principle-based law.[655] Edward Dove notes that “principles are compatible with harmonization, providing an embodiment of the core values and interests at stake within a common language and framework for action that clearly and determinedly promotes data sharing and use.”[656] For some countries and peoples, principles allow for too much flexibility while sacrificing certainty, however, it remains crucial to retain some flexibility at the local level. Regardless of one’s view of principles, they are able to give a common starting point to allow for discussion on how they can be utilized in regulation.[657] It should be understood that the primary use of principles is to create a kind of harmonization that is useful, easy to apply, and supportive of the diverse cultures and peoples around the world.[658]

One could say it is in the realm of possibilities and desirable to pursue stronger and more robust harmonization of the currently very segregated and siloed data privacy laws around the world, as this goal would ultimately permit more ethical and efficient sharing and use of data that will most certainly contribute to advances in healthcare and biomedical research for the benefit of humanity.[659] On the other hand, one must be aware that any notable breakthrough in data privacy harmonization will be a monumental challenge to implement due to various cultural, social, or technological differences amongst nations.[660] Thus, the way forward should not aim to achieve a common data privacy framework with particular rules and regulations but rather seek to create a set of universal data-sharing principles that can be set to a larger governance framework.[661]

4.A. Conclusion

The effects of big data on the technological world are apparent – it affects humanity in innumerable ways, most notably in healthcare. These effects have numerous benefits and can significantly reduce expenditures. However, several ethical implications come with this data, specifically genetic data. The social policy aspects highlight the current genetic discrimination in GINA and the ADA and the concept of the common heritage. The UNESCO declarations show that any research and testing should benefit all of humanity, not factor in discrimination. Therefore, a global privacy governance framework is suggested and should be used to enact future legislation to protect society against the current forms of genetic discrimination that it faces.

4.B. A Cautionary Approach to Digital Technologies in Healthcare

4.B. Introduction

Globally important social and cultural transformations have always been led by technologies. The latest societal change technology has caused has been termed the digital revolution. With the ever-growing intertwining relationship between technology and society, it becomes increasingly important to take a cautionary approach to these digital technologies. Hence, ethics and philosophy have a chance to question and analyze technological developments that could save humanity from a dystopian future run more by machines than by man. This is argued by first describing the digital revolution, its close relationship to society, and how information communication technology is explicitly a large part of that relationship.

The analysis then proceeds with a philosophy of technology and an explanation of technological determinism and strategies to avoid it. A medical sociologist’s perspective is used while the Precautionary Principle's close relationship to Technology Assessment is defined, which bases the reasoning for this section on why taking a cautionary approach to digital technologies is crucial. This section concludes with repositioning the medical ethos for the future, one that values ethics education in light of the numerous technological developments. The analysis applies this reasoning to human enhancement – one of the largest areas of contention with digital technologies – and a detailed account of what it is and what progress has been made thus far. The distinction between radical and moderate enhancement is described, and the analysis concludes with ethical concerns about enhancement. Overall, the ethical challenges displayed by digital technologies must be dealt with to avoid a dystopian future of technological determinism.

4.B.i. The Digital Revolution

4.B.i.a. Technology & Society Relationship

It should be of little surprise, but the digital revolution is transforming human lives. As technology continues to impact various aspects of life, such as communication, healthcare, and entertainment – to name a few – society is becoming exponentially more integrated with these technologies and their impact on daily life.[662] The digital revolution can be defined in many ways. Still, one such definition by philosopher Nicholas Agar can be described as "the widespread and rapid replacement of mechanical and analog electronic technologies by digital technologies...Digital technologies are radically changing the ways that we share information, travel, treat disease, and party."[663]

Notable technology advancements have routinely been used to mark points in history before and after the upgrade. For example, in 1958, Hannah Arendt used specific technological objects to categorize civilizations (such as the bronze age and now the digital age).[664] More recently, Sally Wyatt advocated that cultural factors influence these divisions.[665] Further, Lewis Mumford proposed that we take a clue from anthropology and archeology fields and link specific artifacts to periods of time as we attempt to learn about the society and culture of human beings through their use of particular objects in certain time periods.[666] In these different ways, Information and Communication Technologies (ICTs) have clearly designated the kind of change brought about by notable technological advancements, specifically how information is transmitted and processed.[667]

Newer and more advanced developments in the manufacturing world have started a worldwide change in the world of work, such as the Fourth Industrial Revolution.[668] Shou-Yan Chou notes, "The fourth stage in any industry has become synonymous with state-of-the-art status, digitization, and smart automation."[669] While a consensus is absent regarding the optimal way to use these developments, numerous industries and countries have ideas and plans to gain a competitive advantage in the global race to become the most technologically advanced society.[670] Many of these countries' plans involve transforming industries to be "smart" or utilizing more digital software technologies instead of physical hardware.[671]

The emergence of the Internet of Things (IoT), which may be characterized as an expansion of the Internet to incorporate physical items and systems, served as the impetus for the numerous changes that the Fourth Industrial Revolution brought about.[672] Chou notes, "IoT comprises a collection of digital technologies, including sensors, communication modules, and various software applications that can digitally integrate analog physical systems with the digital world, providing constant and readily available information about those systems."[673] IoT enables quick, accurate, coordinated, and collaborative choices and actions, which makes the physical system intelligent.[674] This combination of the digital realm with physical systems produces a synergistic effect that can be applied beyond the world of manufacturing to society.

It is no surprise that ethical problems can arise out of the use of technologies. A general consensus exists that early identification of the issues could provide a way to mitigate them with appropriate legal and regulatory action.[675] One of the main ethical issues that arises is the struggle between technology's normative and empirical aspects. The Collingridge Dilemma, which claims that, among other things, "it is impossible to know with certainty the consequences of an emerging technology at an early stage when it would be comparatively simple to change the technology's trajectory."[676] When the technology has been around for some time, and it becomes more apparent what the ethical and social implications are, it also becomes much harder to change its outcomes and social contexts. Even though the Collingridge dilemma poses some severe problems for the future of technology, it attempts to anticipate the social and ethical problems that might arise through design choices and legal regulations.[677]

4.B.i.b. An Information Society

The relationship between society and technology is furthered with the use of Information and Communication Technologies (ICTs), specifically with ICTs have impacted how information is transmitted and processed. Oxford University's Luciano Floridi, a professor of philosophy and information ethics, "reconstructs these changes by identifying three macro-periods: pre-history, history, and hyper-history."[678] He notes that the information cycle, defined as the "occurrence, transmission, process and management, use of information," has significantly changed over time.[679] In the time before ICTs, known as pre-history, society had no way of recording information and thus was only processed orally.[680] Then, with the invention of writing, however primitive it may have been, society entered the information age or history. Now, with the use of ICTs, society has entered the period of hyper-history. The notable difference between these periods "is not only in the quantity and speed of information transmitted but especially in *how* it is transmitted and processed."[681]

Therefore, Pierre Lévy, a philosopher and professor of communications at the University of Ottawa, touches on "a speed of evolution of knowledge and of a collective intelligence formed by the social existences of the subjects who participate in it, which can continually reshape itself."[682] Federica Russo attempts to take this notion and relate it to the idea of connective intelligence, which describes how things are based upon how they connect to each other instead of what we have been told they are.[683] With ICTs making connections like this, they are able to push boundaries and change the world around them by creating a different way of viewing the field of ontology.[684]Spaces like this allow for technologies to interact amongst themselves, often times even without human input. ICTs such as e-health technologies, social media, and data analytics are just a few examples of technologies that have the power to cause new ethical and ontological problems in this period of hyper-history that we are living in.[685]

This ICT-powered hyper-history period can also be called the Information Society and has turned out to be extremely transformative to the contemporary way of living. Increasing every day, the role of ICTs in society's development is constantly changing and in need of assessment. Previously there have been numerous ideas to test and attempt to understand ICT's role in development better. The various ideas have been disseminated from a wide variety of fields, including organizations, corporations, government agencies as well as non-governmental organizations (NGOs).[686]

These various fields have deduced that "ICT is a core catalyst or key strategic resource for economic and social development."[687] This notion of ICT is generally positive. However, it fails to keep in mind the various interactions of ICT in the subsequent social and material spaces it occupies. Philosopher Natascia Boeri describes the problem that "development projects frame ICT as a tool to create a more equitable place but ignore that it is within an unequal society that these technologies are created, and it is through an unequal society that these technologies will be used."[688] It is no surprise that society has different, yet no less important, roles in the ICT world. Therefore, it is not safe to assume technology is the sole source of significant social change, but rather a 'socio-technical product.'[689] In a related notion, Saskia Sassen, a professor of sociology at Columbia University, gives us a framework that precisely details what technology and society have in common, “allowing humanity to recognize the embeddedness and the variable outcomes of these technologies for different social orders.”[690]

Viewing ICT in a different frame like this has a meaningful impact on how someone would comprehend the ICT's function in society's growth. For example, Boeri attempts to better apply Sassen’s technology and society’s integration framework to comprehend this reinterpretation of ICTs function in development, a case study involving ICT centers in rural India was used.[691] Boeri strives to avoid making the same assumptions about technology that are made in many other evaluations of ICT centers: “a technological determinism that camouflages real social divisions.”[692] Her assessment aims to question the assumption that development projects offer only positive results without noting the underlying or unrealized changes that happen from technological developments that can be summarized in the digital divide problem.[693]

4.B.i.c. Forward to a Social-Digital Future

This connection between society and digital technologies has been a popular topic amongst contemporary philosophers as the digital revolution significantly influences human affairs. Nicholas Agar writes, “the digital revolution poses a threat to humans as doers, as authors of our own destinies. We make significant choices about ourselves and the world, in large part because we reason in certain ways.”[694] Agar claims that one can predict that the digital revolution will radically remake work and redirect human agency.[695] This is something that society cannot change. However, humanity will nonetheless fundamentally alter the world of work and where human agency can be sourced to. This will require careful consideration of the domains of human activity that society surrenders to the machines.[696]

In Agar's view, societies that advance to the digital revolution ought to be disseminated into "social-digital economies."[697] These kinds of economies emphasize two completely divergent types of activity, each focusing on two completely divergent types of value. The digital economy focuses its activity on maintaining the value of efficiency. This kind of economy values outcomes above all else and the means only when they are impacting the results in a negative way. It is completely possible that one manufacturing process may be valued over another due to factors such as efficiency, costs, or using fewer materials. On the other hand, the social economy prioritizes humanness. This kind of economy prefers entities with minds akin to humans, with preferences to subsequently interact with entities that espouse feelings akin to humans. Society enjoys the company of other members of "the mind club," a phrase Agar takes from psychologists Daniel Wegner and Kurt Gray.[698] Wegner and Gray this exclusive club as "that special collection of entities who can think and feel."[699]

Humanity's preference for alike members of the mind club takes particular interest in the personal aspects of our lives by leading our selection of friends, lovers, and even in the domain of work. Agar describes, "if we think about it, we want our baristas and nurses to have minds like ours too. We will rightly reject the inefficiencies of humans when they stray into parts of the economy that emphasize the skills of the computer. But we should have the courage to reject digital technologies when they trespass on distinctively human activities."[700] Society should be asking the more important questions that progress of AI may lead to machines that contain human-like thoughts and emotions. Society's contract with the machines should be one in which people can complete the tasks where feelings are important and play a role, and machines can complete the numerous data-driven jobs where feelings do not matter.[701]

As time progresses, it will become more apparent that humans will be substituted from areas of work that focus on pure efficiency, and humans will become more available to do types of work that fulfill social interaction needs. In today's technologically advanced societies, "social worker" is the name of a job that addresses the most extreme harms caused by social isolation and indifference.[702] Social work should be vastly diverse in a social-digital economy that resides within a mostly now digital age. With that being said, human social needs are quite dynamic and often complex. Unfortunately, "jobs placing humans into direct contact with other humans are foremost amongst those that our current emphasis on efficiency is causing us to seek to do without."[703] For example, in automated checkouts and customer service, AIs are taking the place of workers who deal directly with other human beings.[704]

Agar notes that "machines will always be poor substitutes for humans in roles that involve direct contact with other humans."[705] In this case, humans, prefer connections, no matter how small or insignificant, to other humans. People often want to know what is happening in the thought processes of those in the service industry in this kind of economy. While efficiency remains important, it is not the only factor to consider in these interactions. Of course, people would like the barista with whom they placed an order for a coffee not to forget about it. At the same time, people value, even subconsciously, the human interaction as the coffee gets delivered to the customer. "When a drive for increased efficiency causes us to do without human workers, we leave ourselves ill-prepared for the kinds of digital future that we should be seeking."[706] If humanity would like to continue down the path of the social-digital economy, then these are the kinds of jobs it should maintain and preserve for humans. It should aim for a future in which machines do much of the heavy lifting and complicated calculating, but humans find work meeting the many social needs of other humans.[707]

4.B.ii. Philosophy of Technology

4.B.ii.a. Technological Determinism

Even in 2022, it is impossible to know which innovations will be remembered long after they were invented, and which ones won't. Regardless, the custom of using technologies to associate places and periods of history remains commonplace, even though technologies' cause-and-effect relationship may not always be apparent. Considering how often people ponder about how technology and society interact, it never required a formal name.[708] Nonetheless, researchers and scholars have labeled it technological determinism, which comprises two main aspects. According to Robert Scharff and Val Dusek in their book *Philosophy of Technology: The Technological Condition: An Anthology,* "The first part is that technological developments take place outside society, independently of social, economic, and political forces."[709] As history has shown us, advanced manufacturing processes spark from people with a knack for inventing or designing and are absent of anything to do in respect to interpersonal relationships. The second, more crucial claim made by technological determinism asserts "that technological change causes or determines social change."[710]

A strong connection exists within technological determinism that social and technological progress are equal. Scharff and Dusek note that Vladimir Lenin shared this view he said "Communism is Soviet power plus the electrification of the whole country," and interestingly, this view stays popular among a wide variety of politicians today.[711] In another example of a politician holding this view, In his 2006 State of the Union speech, George W. Bush said that he believed technology to be the answer to the impending energy issue in the United States.[712] In the past, technological determinism has had the understanding that every generation comprises a handful of inventors and inventions that actually turn out to forward the progress of human development. On the other hand, unsuccessful inventions are quickly forgotten and swept up in history. Noteworthy inventions are able to quickly and easily prove their usefulness and speedily make their way into the everyday lives of individuals and society, thus transforming them. Through this route, technological breakthroughs can have meaningful social impacts.[713]

It is often the case that the invention of new technologies invokes completely opposite reviews. Some view certain technological advances as groundbreaking improvements, while others view them as a potential slippery slope to a disaster. Regardless of the side one takes, the fact cannot be ignored that information and communication technologies have put humanity on a "predefined path, which we cannot move away from."[714] This causes digital technologies to become either positively or negatively normative. Russo explains that "this normative dimension of technology, and a fortiori of ICTs, makes the link between digital technologies and ethics explicit: technology is closely related to the sphere of action and of decision."[715] In a similar sense, Hans Radder notes that technologies are tied to the place in which they operate, which has social and cultural aspects in addition to the material ones.[716] It would seem that technologies are somehow related to the norms observing how humans interact, such as which people can interact with certain people and what the technologies ought to do or ought not to do in those situations. Imagining how social interactions could be impacted by digital technologies, how they might be advantageously employed in politics, or how they might be the focal point of important political platforms, might be useful.[717]

There are two notable tactics to remove oneself from the psychological trap of technological determinism, the first tactic involves thinking about possibilities. This tactic originally comes from M.I.T. mathematician Norbert Wiener in his book, *Cybernetics: Or, Control and Communication in the Animal and the Machine,* where he states that cybernetics gives humanity these possibilities to escape the mindset of technological determinism – and it's up to us which possibilities we choose to advance or not.[718] What exactly is cybernetics, though? Heather Love details, "Cybernetics emerged around World War II as a techno-scientific field of study that employed statistics and probability to develop machines capable of high-speed, high-volume data processing."[719] She continues that "The basic goal of the machines was to enable the transmission of useful information or to facilitate communication and the ability to incorporate feedback, at rates that exceeded the scope of human cognitive processing."[720] In other words, cybernetics uses positive and negative feedback loops to further the ethical inquiry – similar to that of the Socratic method which continually asks the "why" question in order to get to the root of the problem. Wiener went further to say that technology is more like applied social and moral philosophy than applied science.[721] He also talked of hesitations regarding the use of cybernetics in military operations. He argued that cybernetics should be a service to humanity, not used as potential weapons or for exploitation. On the other hand, technologies such as cybernetics can also provide massive opportunities such that the digitization of society has the opportunity to control and regulate the free market.[722] Society need not fall to the potentially harmful effects of digitization but can proactively turn them into opportunities to improve its current condition. Similarly, computerization can pave the way to developing the discussion of certain norms.[723] Russo concludes that "instead of being passive victims of (digital) technology, we *create* technology and the material, conceptual, or ethical environments, possibilities, or affordances for its production or use; this makes us also *responsible* for the space of possibilities that we create."[724]

The link between knowledge, or science, and its applications, or technology, might be reformulated as a second strategy to escape the technological determinism trap.[725] Technologies, specifically those of the digital variety as been discussed, cause ethical questions to be raised for how it is applied in certain situations. For example, in science, you study physics and nuclear reactions, whereas, in technology applications, you learn to build a nuclear bomb.[726] Hence, science itself is not intrinsically moral or immoral. These conclusions are only applicable to the use of technology or science. It is crucial to remember that the border separating science from technology is often hazy and imprecise. Heather Douglas adds, "This distinction, as well as the one between pure and applied science, is a product of our historical, philosophical, sociological reflection on techno-scientific practices."[727]

These two strategies lead us down the same road: either the issue of normativity arises because digital technologies are inherently moral or immoral, or because they are a branch of hard science.[728] This question forms because science and technology are related to action. People take action almost every moment, from the smallest decisions, like drinking a cup of coffee in the morning, to larger ones, such as testing a nuclear fusion reactor or giving consent to a life-threatening procedure. Humanity, specifically in groups such as institutions, and digital technologies, are constantly a part of the decision-making process.[729]

4.B.ii.b. A Medical Sociologist's Perspective

This section takes a bit of a break from the philosophical views regarding technological determinism and the like and looks at the topic through the lens of a couple of medical sociologists. Sociologists have always been fascinated with information communication technologies (ICTs) and their impacts on society's relationships with each other and towards technology itself. Medical technologies are of particular note here as they are simply intrinsic to the healthcare landscape today, whether it has direct or indirect effects on patient care. Sociologists Stefan Timmermans and Marc Berg have provided a detailed look at both medical and sociological research-related technologies. According to Timmermans and Berg, there are three primary areas of sociological study on medical technologies, each with a specific emphasis on a distinct technology.[730] The first area, of course, is technical determinism, which holds that technology is indeed a "driving political force in late modern societies, or as a political tool in itself."[731] Additionally, they provide an illustration of how radical feminist discourse that labels every new reproductive technology as a means for maintaining patriarchal control over women would fall under this classification.[732]

Any kind of literature on "new genetics" and a large portion of political economics study on the pharmaceutical sector might be said to fall under this first group. New genetics here refers to individuals who undergo the consequences of geneticization.[733] Geneticization here refers to "the increasing tendency to define differences between individuals as largely or entirely due to genetics."[734] Dr. Henk ten Have defined geneticization as "a heuristic tool that can help to re-focus the moral debate on the implication of new genetic knowledge towards interpersonal relations, the power of medicine, the cultural context and social constraints, rather than emphasizing issues as personal autonomy and individual rights."[735] Timmermans and Berg conclude this category by noting that this more theoretical part of medical sociology only looks at the decisive and generally newer technologies that take medicine to a new level by revealing more robust social and ethical problems to be solved.[736]

They continue to denote the second category as social essentialism. This category details that technologies are "blank slates to be interpreted and rendered meaningful by culture."[737] This area of sociological study focuses on medical technology, such as radiology equipment, which may be very beneficial to the sociological research community. For instance, the investigative research by Strauss et al. outlines the structure of the work in technology-heavy hospitals, how the staff works with complex technology and patients simultaneously, and how patients experience technologically invasive treatments.[738]

Timmerman and Berg's third and most current classification of sociological studies of medical technology combines ideas and strategies from both science and medical sociology.[739] This category is based on the conviction that "technologies are not regarded as isolated inanimate objects with fixed characteristics, but as, at least metaphorically, actors."[740] This does not imply that any technology is conscious of itself or has its own thinking. This concept should focus your attention on how these technologies can assume the norm of new practices due to their particular characteristics. Simultaneously, technologies can adapt to their interactions with society and their environment. According to Bruno Latour, "technologies are regarded as members of networks in the sense that they can be involved, when in use, in relationships with a whole range of persons, other technologies, practices, and so on."[741] Therefore, instead of assuming that technologies are great influencers of society or carriers of various indirect cultural and social meanings, technologies, at least in practice, must deal with these questions in an empirical manner.[742] However, in attempting to answer these questions empirically, it is essential not to forget to use the Precautionary Principle and Technology Assessment, which will prevent any harm technology may cause in the empirical investigation. These notions are explained in further detail in the following section.

4.B.ii.c. The Precautionary Principle & Technology Assessment

In 1992, with the ratification of the Rio Declaration, the Precautionary Principle (PP) came to light despite disagreement on a standardized definition of what exactly it is.[743] Nonetheless, the majority of the meaning of the PP can be found in the Wingspread Conference Statement: "When an activity raises threats of harm to human health or the environment, precautionary measures should be taken even if some cause and effect relationships are not fully established scientifically."[744] The PP's philosophical base has been somewhat flimsy from its founding, but numerous attempts have been made to change that fact. The main point of the principle comes from what has been termed the "paradox of precaution," which states that according to the PP, mankind must refrain developing dangerous but possibly useful technology in order to avoid harm.[745] Jonathan Hughes explains that in this view, "harm occurs since the benefits of adopting the technologies are foregone with, for example...lost opportunities to prevent disease and death, resulting in a precautionary principle that would instruct society to refrain from implementing itself."[746] Further, even supporters of this view have admitted that the principle is not well-defined and does not translate well into rules of behavior regarding technology.[747]

Progress has been made since 2006 to create more clear and sound philosophical renditions of the PP, whose goal is to provide actionable guidelines regarding technology in unique instances. Political philosopher Stephen Gardiner's products have helped establish specifications for the PP to be used realistically.[748] A significant advancement according to Gardiner is that the PP "applies in conditions of uncertainty, but not when ignorance exists of the range of outcomes over which there is probabilistic uncertainty."[749] At that time in 2006, the PP did not have a way to find and normatively assess any possible results of developing technology. An avenue to give the PP a way to make these assessments can be supported through empirical research that can be used to find various uncertain outcomes of the technologies and then use that information to provide a basis to make a normative claim.[750] Different ways to ethically assess emerging technologies need a route that uses cross-referencing technology with various moral values and ethical principles.[751] By locating the results inside previously established moral theories and notions, these identification procedures do more than just identify a possible range of ethical outcomes; they also give the outcomes a normative character. The blending of facts and standards is compatible with one another in this manner. Hence, without this identification process, the PP is “of little use in evidence-based policymaking and does not explore the relationship between facts and norms in future-oriented ethical assessment.”[752]

Now it is necessary that, relating to the outcomes of technology, both prescriptive and descriptive kinds of information are necessary to use the PP in the decision-making process. As previously mentioned, this information should be collected in empirical ethics research to identify the outcomes and then use those outcomes to give insight into normative claims on emerging technologies. The most popular approach is called Technology Assessment (TA), which is used to gather this kind of information in an uncertain environment.[753] “TA is a field that studies and evaluates the interaction between new technologies and the environment, industry, and society.”[754] There are numerous similarities between TA and other approaches that can be used to assess emerging technologies, such as value-sensitive design, participative design, and various socio-technical methods.[755] Research and studies in TA typically focus on forecasting studies and/or foreseen applications of emerging technology.[756] Most importantly, TA has a built-in form of identification of outcomes, a relatively normative perspective in emerging tech, and a wide array of empirical tactics to research this perspective.[757]

It is no surprise that TA has been born out of many of these emerging technologies' adverse or undesirable side effects. Technology Assessment is composed of “a family of approaches that combine empirical research on likely consequences of technologies with normative insights.”[758] TA has several parts, such as participative TA and constructive TA, both of which use a wide variety of methods, notably the participation of numerous stakeholders, specifically people who could be seen as future users of the emerging technology. By carefully guiding technological development and oversight, TA research aims to anticipate and address the myriad problems that evolving technologies present. Armin Grunwald, a professor of philosophy of technology, recognizes a few obstacles that TA replies:

> that of integrating at an early stage in decision-making processes any available knowledge on the side effects, that of supporting the evaluation of the value of technologies and their impact, that of elaborating strategies to deal with the knowledge uncertainties that inevitably arise, and that of contributing to the constructive solving of societal conflicts on technology and problems concerning technological legitimization.[759]

Therefore, TA becomes a stronger untied field of study that focuses on disseminating and evaluating knowledge regarding environmental, social, and economic outcomes to give a framework to navigate the subsequent social response to the future of emerging technologies.[760] These future emerging technologies can be assessed with the use of the Precautionary Principle and Technology Assessment as described in this subsection, however, if the moral ideals and ethical standards we associate them with have not advanced in line with technological advancement, the evaluation may not be accurate. Society's ethos must be repositioned to be ready for the future that emerging technologies will most certainly bring.

4.B.ii.d. Repositioning the Medical Ethos for the Future

Recently, there has been a lack of ethical discussion and questioning in this more modern culture. Little public ethical discourse is ever seriously entertained philosophically; morality is strictly privatized, individualized, and compartmentalized in personalized spaces and other venues such as private residences, political offices, and in breakout-rooms at conferences.[761] The hostility of political culture supports the idea that any lack of passion in public debate can show disinterest in the cause no matter which side of the spectrum the candidate resides on. It is difficult to see how society can address the challenges of organizing medical care in this epoch without improving the level of discourse on social values and ethical matters. This conceivably could be done by enhancing the education of all citizens about philosophical concerns and methods in debating issues of great importance. However, education alone may not accomplish this goal. As author Thomas McCollough notes, “in contemporary America, the emphasis is on efficiency, organization, technology, and profit, leaves little room for serious moral deliberation on difficult subjects.”[762] The general public is overwhelmed by advertisements, distractions, entertainment, ruthless politics, and celebrity rumors that are absent of any legitimate, ethical discourse. Author Henry Giroux has noted that schools in the twenty-first century have become venues for selling products instead of creating deliberative citizens.[763] “Society has ceded the *polis* to advertising in various electronic formats.”[764] This means that society has sacrificed what is good for its citizens to exploit them for the lucrative business of personalized advertising across multiple electronics such as mobile device ads (via apps or web browsers), tv, radio, and many other e-formats. It is precisely this slippery slope of tech capitalism exploitation that must be avoided with the use of the digital age tools that big tech companies provide.

How is humanity going to rationally discuss complex healthcare issues concerning resource allocations, the privacy of medical information, genomics, the impact of technology, and cost-effectiveness if it does not learn the underlying philosophical and mathematical principles and the structural facts that impact these issues? There is a need to seek a higher level of public discourse and a greater understanding of the implications of ethical and statistical analysis in solving societal healthcare problems. Roy Poses, in his article, *A Cautionary Tale: The Dysfunction of American Healthcare,* noted that large bureaucratic organizations, including the regulatory agencies, “act in accordance with their own agendas and threaten to undermine the core values of medical practice, as the physician turns into a technocrat controlled by various interlocking bureaucracies."[765]

The growth of medical technology and the corporate control of medical practice create a further challenge to the practice of medicine as a holistic healing art. However, these technologies uphold a standard of efficiency that relies heavily on clinical data and regulation by bureaucracies at the internal and external levels. The assessment of quality, safety, computerization, and mechanization of processes have accelerated affecting the character of medical practice in both good and bad ways.[766] Despite rising healthcare costs, federal and private policies mandate that computerization and mechanization must be better than the status quo and worth pursuing despite the substantial added costs and relatively little evidence of benefit. Serious deliberation on the cost of computerization of healthcare delivery has been deferred and is yet to be fully addressed.[767] If the priority of healthcare institutions continues with data, healthcare will sacrifice humanness and further separate patients and doctors who need more than just another statistic to the institution.

Professor of philosophy at the University of Montana and expert in the philosophy of technology, Albert Borgmann encourages consideration of the nature of technology interactions instead of focusing solely on the power of technology. He notes: "Technology...promises to bring the forces of nature and culture under control to liberate us from misery and toil...there is a promise that this approach to reality will yield liberation and enrichment by way of domination of nature."[768] Borgmann further posits that this vision led contemporary society to believe technology is the key to the good life.[769] His ideas assist in shedding light on the myth that unregulated technological growth is the solution to the problems that plague healthcare. The healthcare bureaucracy appears to subscribe to the dominant myth of the twenty-first century that more advanced technology inevitably leads to better outcomes as it implements "meaningful use of electronic medical records and orders."[770] The Leapfrog Group, a consortium of large employers, has taken a more cautious approach, concerned that the electronic health record (EHR) may introduce new types of medical errors and views the matter with greater discernment.[771]

Could raising the knowledge of ethical discourse, starting with more ethics education in colleges and high schools, help? Several authors contend that good public deliberation is possible, but structure and process must be developed and followed diligently.[772] Today's culture has made such discussions more challenging to have, let alone try. Robert Sternberg, an American psychologist and psychometrician, has studied and advocated for the role of wisdom development in education.[773] His theories of wisdom education that balance self-interest with other-directed concerns and tacit and formal knowledge were applied in a New Jersey school district with very positive results for these students.[774] The question is, why isn't this catching on and becoming more popular? The reason most likely relates to "the pervasive consumerist ethos that eschews contemplating the selfless, the deliberate, and the unexciting."[775] The chapter will now turn towards an applied analysis of how taking a cautionary approach to technologies may be of real ethical consideration when it comes to human enhancement. If society is not careful, the perceived benefits of human enhancement can lead down a slippery slope to creating a new host of issues described in the final section of this chapter.

4.B.iii. Applied Ethics Analysis to Human Enhancement

4.B.iii.a. Benefits Beyond the Biological

It is not hard to imagine a future in which science fiction cyborgs take another step closer to becoming a reality, with human beings more often becoming implanted with bioelectronic devices. Advancements in numerous technologies such as “semiconductor devices, cognitive science, bioelectronics, nanotechnology, and applied neural control technologies are facilitating breakthroughs in the hybrids of humans and machines.”[776] For example, every day, we see increased instances of computing power, breakthroughs in prosthetics, artificial implants, and the like that facilitate the combination of man and machine. This fusion of the organic and inorganic is becoming much more normal and available as bioelectronic and mechanical parts are replacing or enhancing current body parts. It is crucial to understand that the improvements mentioned in this section do not have curative functionality, giving those with disabilities such as amputees, the paralyzed, or the blind a chance to overcome their condition. The curative devices that help these people with sensory, motor, cognitive, or other disabilities are generally not provocative of a debate of the ethical nature of these devices. The ethical issues lie when these technologies are used to enhance human capabilities beyond that threshold to where it could be considered a step in the evolution of humankind.[777]

Gifting humans with abilities such as x-ray vision, smelling sensitivity for carbon monoxide and mercury, night vision, extended range vision capabilities, and glow-in-the-dark pigmentation without a doubt change the natural human ability.[778] Even more noteworthy and radical are the enhancements that could become possible through brain-machine interfaces. Within the realm of possibilities, brain-machine interfaces replace the capacity for thought and memory.[779] These technologies will make it possible for people to maintain a continuous internet connection and instantly retrieve encyclopedic information levels. Ellen Mc Gee notes that “Building in these interfaces, surgically implanting them in the brain, will allow for greater energy and efficiency and will eventually enable humans to operate without radios, TVs, printed newspapers, cameras, GPS units, credit cards, computer workstations, ATMs, wireless, corded or mobile phones, and other separate devices."[780]

Brain-machine interfaces use technology that can externalize data already in the brain and give the user the ability to access data from external sources.[781] This should raise huge ethical red flags concerning privacy and autonomy to have this data input-output flow outside of one's control – in a way, stripping ourselves of human dignity. Hypothetically, in the future, if human cloning ever does reach reality, this brain-machine interface would be able to take the memories, emotions, and essentially life and personality of its source and upload it into the clone – thus creating a sense of immortality.[782] Another way that could be achieved would be uploading one's consciousness into a computer or the cloud. This would enable ageless minds that could travel at lightspeed and communicate telepathically.[783] In this hypothetical future, every person may face the choice of what kind of reality they want to live in: "a natural, an immortal with a body, or an entity that exists in virtual reality."[784] Due to the possibility that these technologies could one day make this choice a reality, ethical and legal guidance should be written and enforced to usher humanity along the way.[785]

Unlike the enhancements talked about with genetic technologies or with drugs, brain-machine interfaces have had little to no ethical limelight from the scientific, government, or international communities. McGee argues, "Neither of these future enhancements – genetic or pharmaceutical – will alter future humanity, as will bioelectronic systems that mix electronic and biological components."[786] She reasons that biology limits how far genetic enhancements can go – whereas human-machine cyborgs are not restricted in the same way. In addition, drug enhancements merely increase standard human memory and performance by just a bit, these enhancements don't even come close to the abilities of a brain-machine interface to share and retrieve data at lightspeeds. Editing genes can only enhance the optimum for a biologically based human.[787] Splicing a gene from another biological system into the human genome would surely augment human abilities. McGee gives an example of inserting the gene that gives dogs their superior smelling ability to humans. However, since the human intellect is already superior to animals, these genetic enhancements would only be able to go as far as the greatest degree of intelligence determined by genetics.[788] The human being may undergo significant change thanks to bioelectronic devices, implants, and prostheses, augmenting benefits that are simply beyond the biological.[789]

4.B.iii.b. Radical & Moderate Enhancement

Numerous technologies have promised human enhancements beyond the imagination that could be provided by the more conventional means such as via injection, pill, or genetic modification currently available now. These are exciting prospects – but are they genuinely desirable? In his book, *Truly Human Enhancement: A Philosophical Defense of Limits*, Nicholas Agar argues that "some ways of enhancing cognitive powers or extending life spans are undesirable specifically because they enhance these attributes to a great degree."[790] This happens to be the case even when more minor variations of cognitive enhancing or life-extending developments are considered good. Hence, it becomes necessary to differentiate between moderate and radical types of enhancement. Agar claims that "radical enhancement improves significant attributes and abilities to levels that greatly exceed what is currently possible for human beings."[791] On the other hand, Agar continues, "moderate enhancement improves significant attributes and abilities to levels within or close to what is currently possible for human beings."[792] Agar's overall view endorses some moderate enhancements but rejects radical enhancement, which he calls the "ideal of truly human enhancement."[793] This view takes humanity's desires and uses them as directors to give way to advances that improve humans. [794]

The differentiation between radical and moderate enhancement is quite vague. Consider enhancing our cognitive powers – the futurist and inventor Ray Kurzweil envisages "adorning human brains with increasingly powerful electronic implants, soon generating an intelligence about one billion times more powerful than all human intelligence today."[795] This is radical. This kind of power in a mind would have intellectual abilities greater than any human in history. It also becomes possible to imagine cognitive enhancements that are more vague. The world's highest IQ has been measured at an intimidating 210.[796] Suppose that IQ is an accurate measure of intelligence. Would an education program that boosted students' IQs to 250 moderately or radically enhance intelligence? Should a human being with an IQ of 250, on the assumption that IQ is an accurate measure of human intelligence, be recognized with intellectual abilities that far transcend what humans are now capable of?[797] Maybe the best way to classify it would be in the realm of vagueness between that of radical and moderate enhancement. It sometimes seems that vagueness poses a hurdle to settling into one camp or the other. Yet, it does not by any means diminish the separation of radical and moderate enhancement. For example, there are hairy and bald people on earth who still exist despite a formal boundary between the two. Understanding what constitutes a radical enhancement and what constitutes a moderate enhancement may be done despite some degree of ambiguity.[798] Once society knows how to determine the clear cases of radical or moderate enhancement, it should have the intellectual tools needed to tackle vague topics.[799]

So, how could more robust enhancements be of less value than weaker enhancements? Agar makes significant points in a few rebuttals regarding the radical enhancement of human capabilities. Agar offers “moral criticisms of some radical enhancements – they impose significant, unjustified costs on others.”[800] The arguments tend to support legal bans on “technologies or uses of technologies that lead to certain varieties of radical enhancement.”[801] Agar is principally concerned about enhancements that alter our sense of moral being to different benefits and our ethical safeguards against various potential harm.[802] Any kind of modifications that would jeopardize our morals should be prohibited since they reveal unenhanced humans to potential harm.[803]

Agar criticizes various radical enhancements in an efficiently rational manner. The advocates of radical enhancement display it as being cost-effective and valuable in the long term. Hence, to the proponents, it vastly improves the overall well-being and interests of people who have the procedure completed. Agar argues that radical enhancement will disappoint. Humans tend to value memories or experiences that are just outside the normal range of events due to the fact that they can properly engage them.[804] Any memories or experiences that are extremely distant to the normal range of human events are less impactful because we engage with them significantly less. These times and memories are of less worth than the memories they would instead replace. Humans do not prioritize wisdom gained through radical cognitive enhancement because they view knowledge inefficiently without radical cognitive enhancement, which extends to a more existential understanding of humanity’s place in the universe.[805] These barriers either are non-existent in regard to lesser cognitive enhancements or are critically reduced. Agar claims that both his points about radical cognitive enhancement need an account of what it means to engage with the experiences and knowledge brought by enhancement and a theory about why successes or failures of engagement should be significant.[806]

4.B.iii.c. Ethical Concerns

The general ethical consensus as stated previously in the benefits beyond the biological section is that enhancements, whether bioelectronics or implanted chips, when used for therapeutic purposes, is not ethically concerning. However, concerns that are present with curative use of implants such as those of safety, access, and costs must be attended to. As with any procedure long-term and short-term risks exist. Short-term risks focus on the procedure itself such as bleeding, infections, and adverse drug-related reactions.[807] Long term risks are harder to define and evaluate, but many of them revolve around immune rejection of the implantation. For implantation manufacturers, the challenge will remain to develop a non-toxic device that will not cause an immune system rejection in the body.[808] McGee relates that "these issues are warranty availability, liability responsibilities of manufacturers, industry-wide standards for devices, methods of facilitating upgrades, and procedures for training users in implementing the systems."[809] Moreover, it is crucial to research on the practicality of implants and if certain people benefit from the implants more than others. Unfortunately, some people, such as the mentally disabled – may never be able to learn to use an implant. While still, other people will need a great deal of counseling and advice about proceeding with an implantation.[810]

It seems highly unlikely that a struggling health system that has difficulty in providing basic access and coverage for its participants would be able to include this kind of cutting-edge procedure in its coverage or government subsidy.[811] Subsequently, these concerns will become more complicated as technology has an innate ability to change the normal standard constantly. This ability of technology will only grow and become more difficult to stop or slow progress and add to the already overburdened and understaffed healthcare system in America.[812] Strategies and programs must be developed to limit the inequalities that are sure to arise from technological developments in this field. In the name of fairness and equality, efforts must be made to avoid the failure of the HIV/AIDS epidemic that has caused shortages of the relief drugs that have caused and continues to cause many people to suffer needlessly. Perhaps it is not unreasonable to ask for a commitment to adjust or subsidize pricing for the socio-economically challenged area and countries so that they may have access to the technology for therapeutic purposes at a reduced rate.[813]

Enhancement technology raises numerous ethical, technical, and existential questions regarding its ability even to control humans. Unsurprisingly, brain implants that can provide vision to the visually impaired are highly coveted. What is a very different issue is extending that implant to enable x-ray, night, or long-range vision to the average person. In the same vein, "Enhancement in and of itself is not necessarily objectionable; vaccines, in vitro fertilization, and breast enhancement surgery, are all instances of readily accepted and widely sought enhancement technologies."[814] The boundaries of autonomy, privacy, justice, and what it means to be a person will undoubtedly be pushed by brain-machine interfaces.[815] These interfaces will be able to assist in memory, help in language fluency, recognize unknown individuals, and enable sharing of information without speaking.[816]

It can be assumed that these devices will have three main categories of users. The first is the most obvious, which are therapeutic users with legitimate disabilities. The next category will be the military, which will be used in communication and weaponry systems. The third category will comprise users in data-intensive fields and businesses such as data analytics. The Defense Advanced Research Projects Agency supports funding for these developments: "DARPA is interested in creating new technologies for augmenting human performance through the ability to non-invasively access these codes in the brain in real-time and integrate them into peripheral device or system operations."[817] These devices have the potential and capability to alter the capacities of humans so much that they will be fundamentally changed.[818]

Naturally, many are opposed to this concept of fundamentally altering humanity. "Both essentialists, including those who argue for bodily integrity, and creationists, argue against the development of implantable chips."[819] This tinkering with human nature causes a great amount of fear in many people. Political scientist, economist, and author Francis Fukuyama claims that "human nature, which provides continuity to our species and defines our values and politics, should not be altered."[820] Former President's Council on Bioethics director Leon Kass writes, "If there is a case to be made against these activities – for individuals – we sense that it may have something to do with what is natural."[821] Even though people have been and will continue to be the creators of methods to improve their lives, it is wrong to say that nature is good and technology is bad. Thus, technology is not intrinsically evil – however, its uses by evil people can be. In a more practical sense, numerous ethical, technical, or social questions, comments, and concerns should be addressed before continuing down the path with these implants. "The concerns include apprehensions about safety, risk, and informed consent, issues of manufacturing and scientific responsibility, anxieties about the psychological impacts of enhancing human nature, worries about possible usage in children, concerns about increasing the divide between the rich and the poor, and most troublesome, issues of privacy and autonomy."[822] Any technology serves as a case study for how hard it is to foresee all events and impacts with accuracy. Whatever the case, the next step—however small—must be done to guarantee the ethical use and use of these and other next developing technologies.[823]

4.B.iii.d. Advancing the Ethical Debate

Humanity's ethical discourse progress is substantially different from science and technological progress. Evaluating a new technological advancement ethically and adequately is an intensive and time-consuming activity. Expert mathematicians may adeptly and efficiently use their knowledge to solve a mathematical problem. On the other hand, ethical expertise differs in drawing on an extensive and diverse collection of sources of information.[824] Thoughts, ideas, and questions pertaining to the morality of human enhancement source information concerning how the various technologies will operate, be tested, and what kind of materials will be required to create it and its final cost to the consumer. This kind of information must be taken into advisement despite the desires and interests of the individuals or organizations who, directly or indirectly, are being enhanced. There is no easy path or shortcut to a well-rounded ethical evaluation. As with any investigation, too quick or simple of an evaluation of a piece of evidence can lead to an incorrect and error-filled conclusion. A widely acknowledged tendency for technological progress to outpace ethical understanding reflects differences in the nature of the tasks.[825] The individuals who are focused on improving technology can direct their time and energy on the details of its design, whereas moral and philosophical evaluation is broader. Every new advancement of technology, enhancement included, has the ability to alter forever what it means and how it affects us as humans. All this strongly suggests the need to begin an ethical evaluation of possible future enhancements as soon as possible.[826]

Where does society go from here? Human enhancement's future needs to progress on two fronts – in both downwards and upwards directions. The downwards direction narrows its focus on more minor problems, breaking them up by their contextual features and tackling head-on the choices that decision-makers must make for future enhancements.[827] On the other front, the upwards direction deals with the more significant ethical and practical challenges that arise when society takes a step back and ponders the part that enhancement plays in the longer overall journey and future of humanity as a whole.[828] Nick Bostrom and Julian Savulescu describe the requirements for the future of the enhancement debate:

> This would require discussing how enhancement – including the prospect of future more radical enhancement – might interact with other macro-trends and global problems and prospects such as economic growth and inequality, existential risks and global catastrophic risks, molecular nanotechnology, artificial intelligence, space colonization, virtual reality, surveillance technology, democracy, and global governance, along with the deep epistemological, methodological, and moral questions that arise when one attempts to think about these interlocking issues in a serious and critical manner.[829]

While at first glance, it would seem that these two fronts would be in opposition to each other, that is not the case as they merely describe two coexisting intellectual paths, each with very different but equally important issues requiring attention.[830] A potential problem for the future of enhancement ethics is having it get trapped in the middle of these two frontiers. The potential is high for the future of this century to develop unparalleled advances in science, technology, communication, analytics, and so many more spaces. Undoubtedly, these advances have the power to fundamentally alter the human condition as we know it – displaying both vast benefits and risks. The fate of humanity, now more than ever, is in our own hands.

4.B. Conclusion

It is clear that digital technologies have had and will continue to impact society and the economy immensely. While this impact and technology and society's relationship continue to grow exponentially, the need to take a cautionary "step-back" approach becomes increasingly more relevant to avoid the impending dystopia led by machines and technology with little room for humanity as currently known. Philosophy and ethics must be given a reasonable opportunity to question and analyze digital technologies to prevent a slippery slope of technological developments that could cause a catastrophe. Technological determinism can be avoided by thinking of the possibilities in which the digital world can evoke a robust discussion of norms. Another way is to reimagine the way science and technology relate to action. In these actions, humans, surrounded by the science and technology we create – whether in a digitized form or not – are partaking in the decision-making progress that is slowly shaping the world's future.

These decision-making processes must include the described Precautionary Principle and Technology Assessment concepts. Failure to include these concepts in a decision-making process is irresponsible and unethical as it positions the future ethos towards digital technologies in the wrong way, ignoring a cautionary way of thinking. The application of these concepts extends to human improvement, especially the radical enhancements that give humans the ability to perform actions that would be considered outside the natural boundaries of humanity. Ethical concerns such as safety, fairness, access, and cost are just a few of the questions that need to be addressed moving forward with a cautionary mindset. Without a cautionary approach to digital technologies in healthcare, society could be doomed to a dystopian future because it fell victim to technological determinism.

4. Conclusion

As previously mentioned, the fourth chapter takes a different look at data analytics and focuses on the ethical concerns and challenges this technology can display. The social policy of genomic data, such as genetic discrimination, common heritage, and more concerns with distributive justice, were detailed. The section continued to detail challenges in data analytics with the autonomy paradigm and cloud computing, respectively. These issues pose a challenge to data analytics due to cloud computing’s de-centralization of data storage. A critical factor in respecting the privacy and autonomy of the individual is having secured, centralized data storage that can easily be maintained and traced back in the event of a data breach. The rest of the chapter laid a philosophical/theoretical foundation discussing the impact of technology in healthcare via the digital revolution and its relationship to society while looking at the future of this dynamic relationship and how data analytics could vastly alter this relationship down a slippery slope of a dehumanized world and human enhancement. A cautionary approach is taken in which concepts like technological determinism and the Precautionary Principle are explored. An applied analysis of these concepts was used within the topic of human enhancement citing ethical concerns and providing a foundation to advance the debate.

CHAPTER 5: ETHICS OF GOVERNANCE OF ARTIFICIAL INTELLIGENCE AND INFORMATION MANAGEMENT IN HEALTHCARE

5. Introduction

The fifth chapter begins by looking at a few capabilities of artificial intelligence (AI) and its potential for revolutionizing healthcare. Data is evolving into a new type of money in today's world of interconnected things, fueling process transformation and commercial success. Data analytics is vital to AI, feeds it, and helps it grow. Data from various sources, including clinical records and "digital exhaust" generated by users as they carry out online information, are significant resources utilized to build sophisticated medical services driven by AI.[831] The best part is that a wealth of data is now accessible and expanding exponentially in the healthcare industry that can be utilized for analytics and AI. Since AI acts as the interpreter of all the information it receives using machine learning and algorithms, AI helps scientists, researchers, and healthcare data stewards, among many others, to understand and adapt to the clinical outcomes that the data forecasts. Philosophical concepts such as free will, moral disagreement, and moral agency are explored in light of AI. The section's consideration of the difficulties and possibilities faced by AI in providing healthcare serves as its conclusion. The fundamentals of health information management and its moral and legal considerations are described in the following sections. Applied analysis is detailed within systematic reviews and risk management. The chapter ends with a call for healthcare information governance, outlining its need and essential elements while emphasizing information stewardship and data quality.

5.A. An Applied Analysis of the Ethics & Effect of Artificial Intelligence on the Delivery of Healthcare

5.A. Introduction

It may be difficult for the human mind to comprehend, but artificial intelligence (AI) possibilities are limitless. The technology associated with it is advancing at a pace that is faster than the law, ethics, and society can keep up with. By the time this chapter is published in the dissertation, it will already be outdated. So how does one keep all this knowledge organized and applicable? We, as human beings, cannot, but artificial intelligence can. This section presents the exponential potential of artificial intelligence, strengthened by machine learning and neural networks, and patterned after the human mind. The current state of AI 'awareness' is visited by mentioning the Turing test and other newer versions that show how far AI has come and where it can go.

The narrative then shifts to talking about the philosophy and ethics of artificial intelligence by highlighting its inherent conflict with free will and that moral disagreement will cause problems when designing an AI. The concept of artificial general intelligence is brought up to show that while AI can master a specific task, game, or area – it is far from being a 'jack-of-all-trades' and cannot do more than a few particular tasks at the moment. The philosophical and ethical issues with incorporating ethics into AI and the concept of idealizing moral agency are discussed in this section's conclusion.

The analysis continues by providing an applied study of artificial intelligence in healthcare delivery. Many challenges and opportunities are visited within digital health research in this field, proving that AI's changes in healthcare may not be as dynamic as one would presume. Finally, the section concludes by describing artificial intelligence safety engineering that should be noted as society progresses with building a better and more efficient AI.

5.A.i. Setting the Stage for Artificial Intelligence

Artificial intelligence evokes strong emotions. For starters, our preoccupation with intellect makes humans appear to occupy a unique position among living things. There are inquiries like "what is intelligence?" "how does one measure intelligence?" and "how does the brain function?" All these inquiries have relevance while attempting to comprehend artificial intelligence. However, engineers and computer scientists are primarily interested in the problem of the autonomous robot that behaves intelligently and acts like a person.[832]

5.A.i.a. The Exponential Potential of AI

AI is now the hottest topic in technology. In the business and technology sections of newspapers and publications, AI is often mentioned. According to Hector Levesque, many more companies are following the example set by prominent computer companies, including Microsoft, IBM, Google, and Apple, which have all made significant investments in the development of AI.[833] Toyota made a $1 billion investment in AI in November 2015, and Elon Musk launched a new nonprofit organization named OpenAI that received $1 billion in financing in December 2015.[834]

What exactly is the fuss about? Let us say you think about what those vast amounts of money are anticipated to accomplish. Compared to the AI previously depicted in science fiction literature and films, the technology in that scenario looks noticeably different. There is not much discussion of powerful disembodied intelligence like the HAL 9000 computer in the film *2001: A Space Odyssey* or even sentient humanlike robots like those in the *Blade Runner* movie. Adaptive machine learning, or AML, is the name for the AI that tech firms are now considering. AML's main objective is to use substantial data processing to instruct a computerized system to display human-like intelligence.[835] In reality, a significant factor in the current hype around AI is the potential utilization of what is sometimes referred to as big data.[836]

For the sake of explanation, Levesque gives a hypothetical example where the goal is to create a software program that can identify cats. In other words, its mission will be to separate the photos it receives into those with cats and those without. Then the question becomes how to develop this kind of platform. Previously, AI engineers would have attempted to create software that searched through images with particular cat attributes. It could resemble a cat face, with features like "an inverted pinkish triangle for the nose, whiskers, and fur, as well as greenish or yellowish eyes."[837] The form of a cat, which has four legs, a tail that frequently pitches up, a small head, and triangular cat ears, may also be sought after. Or it could search for the cat fur's particular hue. If a picture has enough of these characteristics, the software will identify it as a cat picture or otherwise discard it.[838]

AML offers an extremely distinct approach, nevertheless. Users begin by presenting the system with a large number of digital photos, some of which contain cats and others that do not. The algorithm is then instructed to hunt for a set of traits that are present in several photographs to compress all of this visual data. A region with a certain uniform hue and brightness might be a characteristic. It could be a region with a noticeable edge-related shift in brightness and hue. The goal is to identify a collection of attributes that may be used to recreate the original photos in a manner that is as close to the original as feasible. Then you instruct your system to detach from those aspects and search for universal traits. There are a couple more rounds after that. Beyond what AI experts may have imagined even a few years back, this unregulated strategy to AML has been discovered to function quite effectively.[839] Levesque notes, “The success of AML is usually attributed to three things: truly massive amounts of data to learn from (online, in specialized repositories, or from sensors), powerful computational techniques for dealing with this data, and very fast computers. None of these were available even thirty years ago.”[840]

Naturally, no one wants to spend a fortune on cat recognition. Imagine instead that the images are mammograms, some of which may include cancers that are difficult for medical professionals to detect. Or consider a scenario where the data is entirely auditory. It could feature audio recordings of the topic of interest speaking on some of the tapes. Consider an alternative scenario where the data relates to financial transactions, some of which include forgery or embezzlement. Alternatively, the information may relate to online buyers with similar purchasing and browsing trends. Alternatively, the information might be the motion of the car's pedals and steering wheel relaying information given by the windshield. Numerous sectors with substantial economic and social repercussions may employ technologies that automatically learn using vast amounts of data.[841]

5.A.i.b. Machine Learning & The Human Brain

It was formerly believed that computer vision couldn't even equal the skills of a one-year-old with visual development. This seems not to be the case anymore since machines can now identify objects in images just as well as the majority of humans can, and computerized cars can drive more securely than a rookie 16-year-old could.[842] However, these machines still have room for development. Additionally, computers have learned to perceive and navigate via experience, following nature's route millions of years ago. Terrence Sejnowski gives an illustrative example, “What is fueling these advances is the gushers of data. Data are the new oil. Learning algorithms are refineries that extract information from raw data; information can be used to create knowledge; knowledge leads to understanding; and understanding leads to wisdom. Welcome to the brave new world of deep learning.”[843]

With origins in computer science, neurology, and mathematics, machine learning has a branch called deep learning.[844] Deep networks learn from inputs similarly to infants' learning from their surroundings, beginning with a blank slate and eventually picking up the abilities required to move about unfamiliar situations. In the past, there existed two hypotheses on how to create an AI in the 1950s, one of which dominated the industry for years and was centered on reasoning and software applications, and the other of which took much longer to develop and was centered on having to learn directly from raw data.[845]

Machine learning is necessary for artificial intelligence, and this goes beyond simple collection or coding issues.[846] If a machine could not learn in a dynamic context, we would not define it as intelligent. On the condition that the system is willing to learn from and adapt to such adjustments, the developer need not anticipate every situation and supply remedies. Evolution worked as the system architect for humans, creating our biological makeup, entrenched impulses, and reflexes over thousands of years. Throughout our lives, we also learn how to modify our behavior. This enables humans to adapt to environmental changes that evolution is unable to foresee. All of an organism's behavior could already be present in short-lived creatures in well-specified habitats. Ethem Alpaydin states, “Still, instead of hardwiring into us all sorts of behavior for any circumstance we might encounter in our life, evolution gave us a large brain and a mechanism to learn so that we could update ourselves with experience and adapt to different environments."[847] Because of this, people have thrived in places worldwide with quite varying climatic circumstances. When we discover the appropriate course of action to take in a certain circumstance, that information is retained in our brains. When the same scenario occurs again, we identify it, remember the best course of action, and take appropriate action.[848]

Artificial intelligence is modeled after the human brain. Neuroscientists and cognitive researchers work to better understand how the brain works. They develop neural network models for this purpose and carry out simulation trials. But much like any technical discipline, computer science also studies artificial intelligence with the aim of creating practical systems. Even though the brain serves as our inspiration, we are not very concerned with the algorithms we develop feasibility in terms of biology. We believe the brain is fascinating because it might improve our design of computer systems. Alpaydin continues, "The brain is an information-processing device with incredible abilities and surpasses current engineering products in many domains – for example, vision, speech recognition, and learning, to name three."[849] If used on machinery, these applications have obvious economic value. If we can comprehend how the mind executes these tasks, we may specify results, rewrite them as algorithms, and then apply them to systems.[850]

Computers are not brains, despite the term "electronic brains" being used in the past. A computer typically contains one or a few processors, whereas the brain comprises several parallel-operating processing units called neurons. The processors are said to be far slower and more basic than a standard desktop CPU; however, the specifics are unknown.[851] The vast connection of the brain is another feature that distinguishes it and is thought to be responsible for its processing ability. Tens of thousands of additional neurons are connected to one another in the brain through connections known as synapses, and they all function simultaneously. In a laptop, the memory is autonomous and idle, whereas the CPU is always working. However, it is believed that computation and memory are distributed across the brain's network; the neurons process information while the synapses between the neurons store it as memory.[852]

5.A.i.c. The Turing Test & Other New Versions

The 1950 issue of the journal *Mind* included an article titled "Computing Machinery and Intelligence" by codebreaker and computer technology trailblazer Alan Turing.[853] It was the first comprehensive academic examination of the idea of artificial intelligence. By the year 2000, individuals will, in Turing's words, "be able to speak of machines thinking without expecting to be contradicted."[854] He believed that machines will be capable of passing the Turing Test, which has since become well-known. There is a gaming component to the Turing Test. Through a keyboard and screen, a third person—the "judge"—conversates with two "players"—one human and the other artificial.[855] In order to determine which player is a human and which is a computer, the judge converses with each participant in turn. The argument makes the case that the computer aims to persuade the judge that it is a human—an achievement that would need human intellect.[856] The machine passes the test if the judge is unable to tell the difference between a human and it. In 1950, Turing foresaw a day when "thinking machines" would be pervasive in the home and office, and computers that could pass his test would be the norm.[857]

Despite Turing's forecast, human-level AI was neither developed nor shown to be on the horizon by the year 2000.[858] The Turing Test could not be passed by any computer. However, one crucial step forward in the area of artificial intelligence has been achieved. Garry Kasparov was dethroned as the global chess champion in 1997 by IBM's Deep Blue computer.[859] Kasparov supposedly said that when he played against Deep Blue, there was an "alien intelligence" on the opposite side of the table, in contrast to earlier chess algorithms he had defeated, which were foreseeable and conventional.[860] Computer chess has now been conquered. Even still, it appeared like we were still a long way from having AI that could compete with humans.

How is this possible? Deep Blue had an issue in that it was a specialist.[861] It was limited to playing chess. In contrast, an average adult completes various tasks employing a variety of sensorimotor abilities. A human being is essentially a generalist or jack of all crafts. A top human chess player can do much more than merely play the game. A human person is also adaptable. Chess is only one of many successful applications of AI research, which stands in striking contrast to the field's inability to create a computer with general-purpose, adaptive intelligence.[862] Today's AI has become much closer to passing the test since the Deep Blue days – however, are ethics and morality being used in these AML data sets? How are these AI being designed from a philosophical perspective?

5.A.ii. Philosophy & Ethics of Artificial Intelligence

Creating sentient robots presents many ethical issues, including how to prevent these machines from harming humans and other morally significant species and the morality of the technologies altogether.[863] This section examines potential ethical issues that might develop when we develop different types and levels of artificial intelligence. As Roberto Simanowski said, "The future no longer rests with politics or even the philosophy of Plato's *Republic*. It rests with science, or more precisely, with computer science... It's people like Sundar Pichai and Mark Zuckerberg who, every day, with every new piece of data, increasingly determine the future we're rushing toward."[864] Do these people have the right to decide how scientific advancements like atom fission and DNA sequencing will be applied in society? Do they adhere to societal pressures to avoid researching technologies whose effects cannot be predicted or managed? Or would they look for a community with different moral principles and governing laws?[865]

5.A.ii.a. Conflict with Free Will & Moral Disagreement

Theresa May said at the 2018 World Economic Forum in Davos: “Imagine a world in which self-driving cars radically reduce the number of deaths on our roads. Imagine a world where remote monitoring and inspection of critical infrastructure make dangerous jobs safer. Imagine a world where we can predict and prevent the spread of diseases around the globe.”[866] But to what degree do science and start-ups control the future? How should we interpret the fact that, concerning artificial intelligence, the risk of unanticipated effects now includes the possibility that the creation may retain its creators as pets rather than serving them as slaves as was originally intended?[867]

There are two ways to think about the relationship between AI and ethics: technology ethics in how it interacts with humans and human ethics in using technology.[868] The first group includes, in addition to the usual subjects of security, equality, accountability, prejudice, and monitoring, the dangers of a “Black Box Society” and the “ethical framework for a Good AI Society.”[869] The second category asks what moral standards we should include in technology to treat humans as partners rather than as pets, even though humans are no longer in authority. At its foundation, the problem is that the technology we develop calls into question our free will in two ways: first, it hinders our ability to do those things entirely differently, even if we truly want to, and secondly because it causes us to lose the ability to want anything else.[870]

One way is that it is difficult to deviate from the rules due to the if-then logic's extreme dominance.[871] When an algorithm drives our cars, we are not authorized to travel faster than the stated speed limit. The situation could be welcomed by police enforcement; however, constitutional attorneys do not welcome such a situation. The existence of autonomous cars at the expense of free, regular human activity was criticized by a German ethical panel on artificial intelligence and self-driving cars established in 2016. The panel, which included a constitutional judge, was critical that AI required drivers to obey traffic laws.[872]

Their reasoning resulted in the following: “There is no ethical rule that always places safety before freedom,” which has a long philosophical history in Germany.[873] It may be found in Kantian ethics, which maintains that doing what is right must be done (as a responsibility) and that evil must exist in order for good to prevail.[874] When AI assumes control of cars and, therefore, civilization, there will not be such a notion as right behavior in the concept of individual choice. However, positive conduct in the sense of tangible effects will be present. What is novel in this situation is that artificial intelligence, which is more aware of what is beneficial to humans, would establish and enforce roles rather than human authority.[875] The subtext of the German ethical commission's concerns is that the self-driving car represents a demonstration of the future cybernetic management of society.[876]

The absence of agreement among moral philosophers over the most appropriate theory of ethics has been pointed out as a challenge to the advancement of machine ethics.[877] The best method to use in creating artificial moral beings may be obvious to someone who adheres to a specific philosophy of ethics. However, it is still uncertain how institutions and society will go ahead. Businesses, authorities, and scholars will have to make a tough decision between conflicting moral frameworks over which approach to use for intelligent machines.[878] Moral conflict may be very problematic for the machine ethics endeavor for two potential reasons. As conflicts among engineers, legislators, and philosophers obstruct cooperative efforts, it might be a practical issue. Kyle Bogosian notes, “In a worst-case scenario, decisions over which research programs to fund will turn into bitter ideological battles, research agencies will become bogged down in disputes, and developers will split up their resources and devolve into a competitive mindset which reduces information sharing and slows research progress, thus making it more difficult to construct more on machines."[879]

Additionally, there could be a moral dilemma. Given how uncertain we are about morality and how split we are among numerous moral notions, it is theoretically improbable that anyone's particular moral theory is entirely true.[880] As a result, if we create AIs based on a certain moral framework, they will undoubtedly make many unethical choices.[881] Whether the computational architecture of a robot is essentially utilitarian or not is unrelated to a utilitarian engineer; as long as utility is being maximized, the engineer is motivated only by self-interest. This is true even when individuals agree on moral decisions while differing on moral theories.[882] In general, if we are certain that computers will behave morally, there is no cause to believe that the precise engineering of machine code is ethically meaningful.[883] Therefore, moral differences across ethical theories would provide comparable practical and ethical issues for the advancement of bottom-up computer morals in the same way they may for the advancement of top-down computing ethics.[884]

5.A.ii.b. Artificial General Intelligence

Even while AI systems have surpassed humans in many specialized fields, such as chess, there is almost unanimous consensus among current AI specialists that artificial intelligence misses the mark of human abilities in some key aspects.[885] Even the IBM researchers who created Deep Blue agree that something crucial is missing from contemporary AIs. Some have argued that once AI researchers discover how to do something, that ability fades away from being considered intelligent. Chess was once thought to be the pinnacle of intellectual prowess until Deep Blue took home the global title.[886]

"Artificial General Intelligence" (AGI) is the growing term of art used to define "real" AI, even though this branch of artificial intelligence is just recently beginning to take shape.[887] As the name suggests, the widespread agreement is that generality is the missing attribute. Current AI algorithms are defined by a purposefully designed competence exclusively in a specific, constrained area, with human-equivalent or better accuracy.[888] Deep Blue won the chess world championship, but it is unable to do anything else, let alone drive a vehicle or find anything useful. Except for *Homo sapiens*, these contemporary AI systems mimic every form of organic life. Bostrom & Yudkowsky give an example, “A bee exhibits competence at building hives; a beaver demonstrates competence at building dams, but a bee doesn’t build dams, and a beaver can’t learn to build a hive. A human watching can learn to do both, but this is a unique ability among biological life forms. It is debatable whether human intelligence is truly *general* – we are certainly better at some cognitive tasks than others – but human intelligence is *significantly more generally applicable* than non-hominid intelligence.”[Emphasis not added][889] It is not difficult to imagine the scope of safety problems that could occur from an AI functioning within a specific context, like Deep Blue in chess. However, the scope of potential safety problems becomes entirely different when referring to AGI functioning across numerous contexts – all of which cannot possibly be predicted by engineers.[890]

In the development of Deep Blue, the human engineers did something revolutionary – they gave up their ability to predict Deep Blue’s local, specific game behavior.[891] “Instead, Deep Blue’s programmers had (justifiable) confidence that Deep Blue’s chess moves would satisfy a non-local criterion of optimality: namely, that the moves would tend to steer the future of the game board into outcomes in the winning region as defined by the chess rules.”[892] Although this prediction about future outcomes turned out to be satisfactory, it prevented the programmers from foreseeing Deep Blue's local behavior or its reaction to a particular assault against its king. This resulted from Deep Blue computing the non-local game map—the relationship between a move and its potential aftereffects—more precisely than its developers could.[893]

Today, human beings can perform a nearly infinite number of actions to feed themselves.[894] While many of these contemporary feeding actions may not be "envisioned by nature," it is no surprise that humanity has evolved and adapted to many of the obstacles to feeding that plagued our ancestors. Bostrom & Yudkowsky continue, "But our adapted brain has grown powerful enough to be *significantly more generally applicable*; to let us foresee the consequences of millions of different actions across domains and exert our preferences over outcomes."[Emphasis not added][895] Despite the fact that none of our predecessors faced a hardship comparable to a vacuum, humans have traveled across space and left footprints on the Moon. Designing a system that would function securely in thousands of situations, including circumstances not expressly imagined by developers or consumers and situations that no person has yet experienced, is a fundamentally different task from domain-specific AI.[896] There may not be a concise local specification of all the methods that people get their daily bread in this situation, nor is there a local definition of good conduct or a clear specification of the actions themselves.[897]

In order to construct an AGI that behaves safely while operating in various contexts, one must define appropriate behavior using phrases like "X such that the consequence of X is not harmful to humans" (where X represents any action).[898] This way of defining AGI acceptable behavior requires predicting the future outcomes of actions, making them non-local. These future outcomes of actions are non-local in the same sense that Deep Blue extrapolated a set of outcomes from chess moves and steered its actions in the winning direction. The actions of the

AGI will be based on how it interprets the consequences of its actions relative to whether or not it causes harm to humans. This specification is only useful if the AGI system clearly extrapolates the consequences of its actions and subsequently implements the output of how the action affects humans into a design characteristic. A toaster, for instance, cannot have this design characteristic since it cannot predict the results of toasting bread.[899]

Suppose AGI's behavior will be based on future outcomes of actions across a variety of contexts. How can developers promise that AGI will act in an ethical manner in all instances?[900] To help illustrate how ridiculous it would be to predict an answer to that question from the developers' perspective, Bostrom and Yudkowsky present the analogy of a statement from an engineer, "Well, I have no idea how this airplane I built will fly safely – indeed, I have no idea how it will fly at all, whether it will flap its wings or inflate itself with helium or something else I haven't even imagined – but I assure you, the design is very, very safe."[901] Clearly, from the standpoint of public relations, this would be a bad situation. So, what can developers do to address the question? It should be noted that purely hopeful expectations have been and will continue to be a major problem in AGI research and development.[902] Building a trustworthy AGI will need new approaches and a fresh style of thought; it will demand that AGI has the mentality of a human engineer who is ethical, not merely a result of ethical engineering.[903]

5.A.ii.c. Building Ethics into AI and the Idealization of Moral Agency

There must be a higher degree of complexity in AI rules of ethics that addresses the conduct of machines. The issue of control may be solved in many ways. In addition to creating codes of ethics, one solution may be to include ethical behavior and decision-making in AI. A mandate for AI work or a suggestion to program ethical conduct into computers may even be included in such codes.[904]

Is designing ethical behavior into AI and computers the logical next step in developing AI? Paula Boddington summarizes the concept of building ethical behavior into AI and computers in her book *Towards a Code of Ethics for Artificial Intelligence,* where she attempts to reconcile the errors of programming ethical AI behavior in the literature that, in her view, idealize or over-simplify the idea of AI as a moral actor.[905] There are compelling reasons to take every precaution in AI development and application to protect security and ensure that machine conduct complies with moral principles.[906] Boddington goes further, "But the question about building ethical decision-making and action into AI goes further than this [precautions in AI development], for it concerns judgment in novel, perhaps unpredictable situations, where decisions and actions would be taken without any immediate human oversight; it goes further than the simple alignment of outcomes with our ethical values if it implies that it's the machine itself which is acting morally."[907]

Numerous antecedents exist of mechanistic actions taken without direct human oversight or intervention, like failsafes (which are safety mechanisms designed to cause a machine to revert to a "safe mode" in the event of a breakdown or malfunction to prevent harm or catastrophe) used in trains to deal with tragedies like driver collapse (in this case would involve an automatic stop of the train).[908] However, the failsafes function in systems with constrained capabilities. Creating mechanisms to make machine judgments "ethical" could appear like an alluring option for networks AI where choices and actions might be made that could have wide-ranging and possibly difficult-to-find impacts.[909] Discussions of difficult moral quandaries are not just a defining feature of ethics literature generally but also of AI ethics literature specifically. Therefore, without a thorough explanation of ethics, efforts to integrate morality into technology may be effectively concentrated at a minimum in seeking to prevent horrible outcomes.[910]

It is challenging to define what exactly are horrible outcomes when it comes to catastrophes. Which is worse: running over a newborn or six people who are 59 years old? Which scenario is worse for an accident victim—death or coma? Many of the potential consequences of AI now lie at the farthest reaches of our capacity for imagination; they swing from "wonderful" to "catastrophe" like an Olympic gymnast swinging from one end of the balancing beams toward the other.[911] Without a clear understanding of our value objectives, designing a computer to answer ethical issues will be challenging. We lack such a clear vision, particularly for difficult-to-conceive, intricate alternatives. So, might we teach a computer to identify our "true" objectives? What criteria would the computer use to determine our genuine objectives? Maybe the machine or we can figure out what our "true" nature is, but do we even have one? Then, is our nature set? Can this be a topic for empirical research? This is a philosophical problem of the utmost complexity.[912]

Furthermore, even if we were to imagine that a computer could be built to ascertain our moral objectives, this would only bootstrap the issue. We would constantly need to be able to confirm that the result met our standards for morality. Boddington gives a stark example, “Are we going to accept that, say, wife-beating was ethical after all, particularly if she’s burnt the dinner and had sloppily applied makeup, just because we’ve got an app that told us it was okay? I hope not.”[913]

One of the main ideas is that ethics must always allow for discussion and collaboration with others who have justifiable interests since they could be impacted or have something to add. This is all opposed to outsourcing ethics to a computer that is not a part of a network of such human interaction.[914] Should technology advance to the point where computers possess the same level of moral agency as people? Even if such a computer had intriguing things to say, outsourcing your ethics to another person would still be unethical.[915]

Like outsourcing our ethical decisions and acts to another human, outsourcing them to a computer has major ethical implications. In consequentialism, just the results of our actions are morally significant; it does not matter how you came to a decision under this agent-neutral morality if it is the right conclusion.[916] Therefore, in theory, you may delegate your ultimate decision to a capable computer. However, note that this computer would develop a decision-making process to apply morality and do empirical calculations to determine the most effective way to accomplish a moral objective.[917]

On the other hand, standing in opposition to consequentialism is deontology and virtue ethics, where intentionality behind the action is key to the morality of the decision. Therefore, if using Kantian and virtue ethics frameworks, you cannot outsource moral decisions to another individual or an AI. In other words, to be a moral agent, you need to take responsibility for your actions, motivations, and decision-making processes. Boddington concludes, “You have to do the right thing, for the right reasons, in the right manner. Even many consequentialists are troubled by this and try to work around it. Remember the Nuremberg trials? The quintessentially lousy excuse of the twentieth century was, I was only following orders.”[918] The realization that individuals cannot delegate moral judgments is the essential moral discovery of the 20th century and the foundation from which all successive standards of ethical conduct and laws have been established. That is a determination of undeniable moral duty.[919] The next section will detail some of the various challenges and opportunities that artificial intelligence can have in the healthcare landscape – from digital health research to ethical, social, and legal implications of AI in healthcare.

5.A.iii. Challenges & Opportunities for Artificial Intelligence

Healthcare is being altered because the digital revolution is disrupting health research. With the development of digital health technology, vast amounts of big data, both qualitative and quantitative, have been generated. These data are significant sources of knowledge about consumer transactions that may be useful to patients and their caretakers.[920] Digital data "exhaust," or the bits of ordinary actions caught in daily digital interactions, is particularly interesting since it captures these behaviors in real time and contains our natural activities. The way these sociotechnical systems affect our daily lives and the way they affect society will undoubtedly depend on the vital social dialogues that take place.[921] Big data, enhanced by artificial intelligence, becomes a socio-technical phenomenon since these technologies can alter our lives in significant ways and change the direction of society for better or worse. It is through intellectual discussion, debate, and reflection that society can choose to let these technologies influence daily life or not. The following sections will discuss the challenges and opportunities artificial intelligence will encounter in society and highlight certain points to keep in mind as the discussion moves forward.

5.A.iii.a. Challenges and Opportunities in Digital Health Research

The usage of artificial intelligence technologies in healthcare is growing as these AIs use data analytics to improve digital health research. Medical records offer training datasets for learning that educate AI systems that can discover abnormalities more efficiently than qualified staff in cancer diagnoses, internal medicine, and ophthalmology, for example.[922] AI assists in health research and development in order to supplement or provide a substitute for standard medical treatments, for instance, digital therapeutics are making an effort to expand and get products into the health sector.[923] Nebeker et al. state, “While the digital health revolution brings transformational promise for improving healthcare, we must acknowledge our collective responsibility to recognize and prevent unintended consequences introduced by biased and opaque algorithms that could exacerbate health disparities and jeopardize public trust.”[924] To prevent these negative consequences, it is essential to raise the minimum safety requirements for digital health technologies to be accessible to the general public. These technologies must endure significant safety examination and have been shown useful in genuine clinical research settings before they are released into the health sector.[925]

Despite the enormous potential of digital health technologies, those making decisions regarding the purchase, evaluation, application, and assessment of technology in healthcare face significant ethical challenges.[926] The leaders in the health sector face ethical challenges due to the absence of policy regulations or standard requirements and a combination of new, quickly developing machinery, new relevant parties (such as tech behemoths, digital therapeutic start-ups, and civilian researchers), humungous stores of data, and continuous new computational techniques.[927] These technologies should not enter clinical settings or research without proper verification. For instance, the adage "if the product is free, then you are the product" is often used concerning digital technologies today.[928] This implies that the information used by businesses to guide product enhancement is generated by our search phrases, keyboard inputs, clicking, and taps. With the help of this "big data," computers are trained to produce, for instance, customized adverts. Customers acknowledge and agree to these terms of service, which are not often intended to be easily readable or comprehendible, by clicking "I Accept" to signify their understanding and agreement.[929] Digital health technologies must demonstrate that they are not using their consumers' personal health information for personalized ad revenues and have undergone rigorous testing to ensure that won't happen to users as this compromises personal health privacy and security.

At times, digital health technologies may be helpful in how they use your health data. For example, a smartwatch can remind you to exercise daily, drink more fluids, or schedule a yearly checkup with your doctor. The AI may be close to being accurate sometimes, yet it can also be completely off. Nebeker et al. give an example "if you were to write something on Facebook that its proprietary AI interprets as putting you at serious risk, it may send the police to your home! Is Facebook getting it right? We do not know; Facebook has claimed that, even though its algorithm is not perfect and makes mistakes, it does not consider its actions to be research."[930] Facebook does not consider its algorithmic actions research because they do not publicize the data nor use any of its efforts to benefit anyone or anything outside the company. Facebook regards that these actions (such as sending the police) are done for the health and wellness of its users and have their best interests at heart, i.e., Facebook claims they are doing the "right" thing. This is most likely far from the case, as each of its users is just another revenue source from personalized ads, and it's in Facebook's best interest to keep as many as possible of those revenue streams open. We should examine the implications of informed consent concerning one's privacy, whether the risk of damage is objectively weighed against the possibility of benefit, and if those involved in the quality testing phase are those who will benefit from it at all.[931]

Applying modern technology and AI systems to digital medicine presents new difficulties and requires various skills. It is possible for technology developers to lack patient-centeredness and produce technologies with minimal practical value.[932] AI may be trained by computational scientists using datasets that are not typical of the general population, which would restrict its capacity to make accurate judgments or predictions.[933] Clinicians can lack confidence in AI-generated choices or knowledge of handling complex data depth.[934] It is crucial for research on digital health and the use of AI in the healthcare industry to understand this separation and develop tactics to close gaps and forge stronger ties across such groups.[935]

Numerous initiatives are being undertaken to address the digital age's moral, regulatory, and cultural ramifications in healthcare. Leading examples of these projects relate to AI. The areas of focus for AI range from autonomous driving to face recognition, the future of work, urban development, and occasionally even healthcare.[936] Nebeker et al. highlight a few carefully chosen contemporary AI initiatives that seemed to be well-funded and cooperative projects whose goals are to explore fundamental issues of AI’s relationship with society.[937] These programs all include evaluating AI's possible ethical, legal, and societal implications (ELSI). Organizations examining AI via an ELSI perspective want to create guidelines that may be applied or changed globally, similar to the impact of the General Data Protection Regulation of the European Union on countries outside of the EU.[938] In reality, however, most current attempts to link ELSI to AI are nebulous, might have overlapping focus, and lack precision. The healthcare technology revolution involves a broad spectrum of technologies, even though AI plays a part in it. Other projects focus more explicitly on ELSI in sensors worn for digital research, social network platforms, and mobile applications.[939] These projects aim to inform governance and policy in a mostly uncontrolled environment. These programs serve as a few examples, however, it is essential to emphasize that several research facilities and institutions are engaged in ELSI for digital health.[940]

5.A.iii.b. Static or Changing Capabilities & Dynamics in Healthcare

In terms of variety and efficacy, it is easy to anticipate that AI systems for healthcare applications will keep expanding. Jim Warren comments, “Supercomputing is now readily available: the graphics processing units in the video cards of home computers turn out to be superb number-crunchers for neural network algorithms, or we can rent scalable computing power through cloud computing services by Amazon, Google or others.”[941] Additionally, as computers are increasingly incorporated into healthcare systems, a growing library of electronic medical records that are ready for examination is a natural by-product. Even though this AI explosion is likely to revolutionize healthcare delivery, there are many grounds to believe that these changes will be gradual, controlled, and perhaps overall beneficial.[942] Here are three reasons why the shift to using AI in healthcare will not be far from the current technologies and practices.

First, deep learning-based AI algorithms are not all that dissimilar from the computer tools humankind has been using daily for years. For example, PREDICT combines decision assistance technology with ongoing, prospectively planned, open cohort research.[943] Wells et al. continue, “The PREDICT software integrates with the practice management system to retrieve patient data, with any remaining required data entered interactively to provide an individualized estimate of the probability of a cardiovascular disease (CVD) event in the next five years, along with treatment recommendations.”[944] A recent study to enhance risk prediction was based on more than 400,000 patient contacts in New Zealand between 2002 and 2015, and participant risk variables were gathered by equipment often linked to government databases, including hospital admissions and mortality from CVD.[945] A regression model, which assigns each risk factor a specific weight, is the foundation of the risk prediction. Despite having a much simpler structural design than a deep learning model, the model offers the benefit of having a simple justification for each suggestion. Deep neural networks are now being researched for explanation capability.[946] When adopting a deep learning AI, patients and healthcare professionals would likely have a somewhat different experience than they would with PREDICT, which has been seamlessly incorporated into the current healthcare system and professional responsibilities.[947]

Second, the relationship between a doctor and patient will be challenged by AI, but information technology (IT) has always posed similar problems. Access to knowledge has been democratized for more than 25 years thanks to the World Wide Web.[948] Patients are free to bring printouts of the most recent study results and maybe dubious information slanted toward revenue-generating into their consultations (although it seems that today's patients are more inclined to wield their smartphones or tablets). Warren notes, “As the web has become more sophisticated and IT reaches ever more intimately into our lives, the diversity of ways patients may bring IT into their healthcare has grown, including mobile apps, fitness trackers, and blog posts. An interesting example is PatientsLikeMe, a web-based network where patients connect to others with the same disease and share experiences.”[949] Together with the planning of research studies, such as those on the efficiency of off-label medication usage, sharing statistical data is encouraged.[950] Eric Topol writes in his book, *The Patient Will See You Now,* that medicine has reached a "Gutenberg moment" in which greater information freedom has allowed patients to take a revolutionary level of control over their treatment.[951] Topol lists various web-based and IT-enabled developments, such as big data sharing and commercial genetic test findings, as shown by 23andme.[952] Interestingly, evidence-based care is beginning to use smartphone message services more often. An example is a program that included behavior-change strategies and motivating messaging that dramatically increased smoking cessation rates after six months.[953] This service is a kind of AI since it combines several operationalized intervention approaches and interaction tactics. It may be downloaded from the internet or prescribed to a patient by a physician.[954]

Thirdly, by regularly investigating the source of information, healthcare practitioners may participate in, support, or restrain the development of AI. AI-based decision assistance could be offered to a patient or linked with the tools one uses at a district health board or primary healthcare organization. Warren concludes, “In any event, you can query where it comes from – who is endorsing and distributing it, and what is their motivation (i.e., is it purely for profit through proliferation – licensing fees or banner-ad revenue – or is it publicly funded; does a medical body endorse it?). Is it part of big data's new wave of AI-based machine learning?”[955] Or maybe, like in the case of quitting smoking above, the capacity is the result of "knowledge engineering," in which methods endorsed by a medical organization are utilized. If data were used to support these endorsed methods, when and where were they gathered? Do you think the data accurately represents the patient group, or are there clear gaps? Is it possible to retrain the system to utilize local data? Does the system have any evidence to support its suggestions, or is it simply a "black box" with no specific data to back up its analysis?[956] Is there any proof of the system's efficiency? If so, how was its performance assessed? In what setting, with what population, for how long, and most importantly, against what? If the answers to these questions are elusive, one should be wary (or at the very least cautious); if the responses are inadequate, one should aggressively discuss the system's shortcomings.[957]

5.A.iii.c. Artificial Intelligence Safety Engineering

In spite of our accomplishments in creating computers that can pass the moral Turing test, performing like a human requires certain unethical activities that should not be tolerated by the robots we build.[958] Or, to put it differently, we need completely safe and law-abiding machinery, not robotic systems that are fully ethical individuals debating what is morally correct. Beautifully said by Robin Hanson: “In the long run, what matters most is that we all share a mutually acceptable law to keep the peace among us and allow mutually advantageous relations, not that we agree on the right values. Tolerate a wide range of values from capable law-abiding robots. It is a good law we should most strive to create and preserve. Law really matters.”[959]

Yampolskiy thus suggests that in the framework of a new discipline he names artificial intelligence safety engineering, scientific activity targeted at constructing safe machines be added to primarily philosophical concerns of machine ethics.[960] In this crucial area, some actual work has already started. An ongoing problem in a study on AI safety is the notion of enclosing a super-intelligent entity in equipment to inhibit it from harming people. These ideas were advocated by futurists in science like Eric Drexler, who proposed containing transhuman robots in order to investigate and use their impacts securely.[961] Similar to this, futurist Nick Bostrom has put forward the concept of an AI oracle that can only respond to questions.[962] Not to mention, in 2010, David Chalmers suggested the concept of a "leakproof" singularity. [963] For safety reasons, he suggested that AI algorithms should first be restricted to virtual simulations until their propensities for conduct can be grasped in controlled settings.[964]

Yampolskiy published a defined idea for an AI containment method that characterizes AI-Boxing as a technology security issue.[965] He adds, “The artificial intelligence confinement problem is defined as the challenge of restricting an artificially intelligent entity to a confined environment from which it cannot exchange information with the outside environment via legitimate or covert channels if the confinement authority does not authorize such information exchange. An AI system that succeeds in violating the confinement problem protocol is said to have escaped.”[966] Asking "safe questions" and allowing just certain replies is the foundation of the suggested approach. A safe question is one that a person might respond to alone, without the aid of a superintelligence.[967] How does this help? Yampolskiy gives a hypothetical example: consider a researcher looking at two treatment options for cancer. Without the AI's aid, each could be tested and verified, but it would take around three years of work. If the scientist thinks both have an equal probability of succeeding, which should be tested first? It will still take three years for humankind to find a cancer cure if the incorrect option is picked to be tried first. What if we could ask the AI to recommend the initial course of action?[968]

For a variety of reasons, this investigation is safe. First, the likelihood that each probable response will be accurate is equal. Second, requesting the AI for aid would just hasten the process without altering the conclusion since a human may respond to it without the AI's assistance. It is the same as getting fortunate while attempting to predict multiple-choice answers. Last but not least, the response to asking AI to recommend an initial course of action from the above example might be programmed in a single bit, making it difficult to conceal subsequent data. A panel of experts might be employed to assess a prospective question to ensure it is secure. All specialists should be qualified AI safety engineers, which means they are knowledgeable about the architecture of the AI, its nature of confinement, and the most recent advances in machine ethics.[969] It may also be necessary for experts to get training in computer psychology, a field that does not exist but might do so in the future. The topic of analysis offered by Yampolskiy et al., which may be very useful in the field of AI development is “artimetrics,” which “identifies, classifies, and authenticates AI agents, robots, and virtual reality avatars for security purposes.”[970]

Yampolskiy suggests that creating safety procedures for self-improving systems is the main difficulty facing AI safety engineering.[971] He concludes, “If an artificially intelligent machine is as capable as a human engineer of designing the next generation of intelligent systems, it is essential to ensure that any safety mechanism incorporated in the initial design is still functional after thousands of generations of continuous self-improvement without human interference.”[972] With each successive generation, the self-improving system would hopefully be able to provide independent verification of its security for outside scrutiny. Allowing a safe, intelligent computer to create a fundamentally risky update, creating a more robust and deadly system, would be devastating. Some claim that either this problem cannot be solved or that, even if it can be solved, the accuracy of the answer cannot be established.[973] The number of design flaws rises proportionally or sometimes even exponentially with system complexity, depending on the system. The most challenging system to debug, a self-improving system, will break all safety assurances with only one defect. Even worse, a problem could be created even after the design has been completed, either as a consequence of a natural event, such as a short circuit that alters a system component or as a result of a random mutation caused by defective hardware.[974]

5.A. Conclusion

This section has demonstrated the impact of artificial intelligence on the world with a specific focus on its application to healthcare delivery. The utilization of AI within healthcare can cause significant changes in the effectiveness, timeliness, and robustness of medical information. Fortunately, the changes to the doctor-patient relationship will not be significantly affected as small changes have been implemented over many years within healthcare, and it has not considerably impacted this dynamic. This analysis aims to bring knowledge and awareness of the exponential potential of artificial intelligence in its impact on society – specifically on healthcare. This goal was achieved by setting the stage for artificial intelligence and providing information about machine learning and how much of how AI operates is modeled after the human brain via neural networks. The Turing test was mentioned, and it is one of many tests now to show the AI’s overall general awareness of how it relates to the world around it.

The philosophy and ethics of artificial intelligence were introduced to provide a context for the many issues involved in designing and building an AI with a proper moral compass. The inherent nature of AI conflicts with humanity’s free will, as detailed in the analysis of autonomous vehicles. In addition, the very nature of moral disagreement will lead to many conflicting views and opinions on which ethical theory or standards should be predominant when developing artificial intelligence. The concept of artificial general intelligence was brought to light in how it describes AI as having the ability to complete only a handful of particular tasks and not being able to handle numerous general tasks. This sets the AI apart from being ‘real’ and is one of the distinguishing abilities between humans and animals. This section described the thought process and necessary philosophical idealization of moral agency when building an AI.

The final section addressed an applied analysis of artificial intelligence in healthcare delivery. It described challenges and opportunities presented within the digital health research field, which AI prominently utilizes. The static or changing capabilities and dynamics in healthcare were addressed in light of AI. The field will not be overtly altered because many changes have slowly been implemented over the years and should not cause significant disparity. Finally, this section analyzed AI's ethics and effect on healthcare delivery in describing artificial intelligence safety engineering and how it must be utilized as society develops.

5.B. The Impact of Information Management on Data Analytics

5.B. Introduction

Information management dramatically impacts the development and organization of big data and data analytics. Health information management is a massive part of this development and has an exponentially growing influence on our society today. Starting from the foundations of health information management (HIM) in its acquisition, storage, and use of this data –one can begin to understand the infrastructure behind this massive management undertaking. Legal and ethical aspects of HIM are crucial as privacy, confidentiality, and data-sharing concepts must be addressed in this growing field. The current complexity of payment encoding systems exacerbates HIM's ethical problems. To remedy this, ethical decision-making must occur when coding HIM systems, and the workplace must foster a strong sense of staff justice. In an applied analysis of HIM, concepts of risk management and risk perception in the information management workplace are crucial to rethinking an ethical approach to HIM. Finally, society must progress towards a health information technology governance in which data quality characteristics are clearly defined. A proper application of normative health information technology governance and information stewardship can reshape the future of the healthcare landscape.

5.B.i. Foundations of Health Information Management

5.B.i.a. Acquisition, Storage, & Use

The concepts of illness and how to cure it have long been intertwined with those of data observation and analysis. Whether we look at the descriptions of diseases and recommendations for treatment in ancient Greek literature or the utilization of sophisticated laboratory and X-ray investigations by contemporary doctors, it is obvious that collecting data and understanding its significance are essential steps in the healthcare process. The sheer volume of data that may be utilized in patient care has increased dramatically with the shift toward genetic information in evaluating individual patients (their risks, prognosis, and anticipated responses to medication).[975] As a consequence, data gathering, storing, and use issues are often brought up in the literature on health information management. This section will provide a starting point for summarizing these information management issues, covering numerous clinical applications.[976]

Evolution of Health Information Management

Data are essential to all aspects of healthcare since they are essential to the decision-making process.[977] Any healthcare-related activity will include acquiring, analyzing, or utilizing data. Information may be used to identify subgroups within a patient population or to categorize any issues a patient may be experiencing. They also help a doctor decide what more studies are required and what actions should be taken to understand the patient's difficulty better or, more significantly, to handle the issue that has been detected.[978]

Health information management has developed into a specialty within the health professions. It combines methods, techniques, ideas, and concepts from several other health professions, making it a distinct specialist field of study. Health information management is a subject of research and a practice that combines elements of the social sciences, the medical sciences, and computing and data sciences.[979] Similar to HIM methodologies, information technologies (IT) are used by health informatics specialists to gather, store, analyze, and disseminate patient data, documentation, understanding, and wisdom. IT and related gear and software are seen as tools that users, clinicians, employers, healthcare providers, and administration may use to attain the objectives of health informatics. Two goals of health informatics are supporting the delivery of care and enhancing everyone's state of health.[980]

Health Informatics History

Generally speaking, the 1950s saw the beginning of the use of computers in healthcare, which is when health informatics began to take shape. The characteristic of this early period in the history of informatics, which continued throughout the 1960s, was using this new technology to innovate in medical and nursing education.[981] The late 1960s work of graduate nursing student Connie Settlemeyer at the University of Pittsburgh School of Nursing offers a local illustration in the discipline of nursing.[982] She created a computer-assisted training application running on a mainframe to teach pupils how to use "the common problem-oriented format known as SOAPE or SOAP."[983] Nelson & Staggers note, “The SOAP note stands for Subjective, Objective, Assessment, and Plan and is used to record the patient’s condition and status by both doctors and nurses.”[984] The University of Pittsburgh utilized this approach to instruct undergraduate nursing students during the remainder of the 1970s.

At that point, filling up the paper documentation required to follow up on doctors' orders that had been scrawled on patients' notes was the responsibility of nurses and unit clerks working under their guidance. In addition to recording the hospital costs related to doctors’ orders, SOAP-templated printed sheets were utilized to correspond the instructions to connected units. One of the earliest components of hospital information systems to affect real patient care was order entry, followed by outcomes reporting.[985] The first group of healthcare professionals immediately impacted by using SOAP sheets in the medical field was nurses and staff members in specialized divisions like laboratories and radiology. The use of computers in specialized sectors began throughout this same decade. One instance of computers used in specialized sectors was hemodynamic monitoring devices in the cardiac lab. Computers were employed in these settings to do computations, providing precise answers in seconds.[986] By the late 1970s, developments in computer science, library resources, and medicine, as well as academic developments in these fields, had created an environment conducive to expanding and developing the recently established field of medical informatics.[987]

Due to its widespread usage across several sectors, the definition of knowledge management varies depending on the application. The context in this section pertains to management and clinical decision-making. Thus, it is appropriate to use Lee's definition of knowledge management: "A discipline that promotes an integrated approach to identifying, managing, and sharing all of an enterprise's information needs. These information assets may include databases, documents, policies, and procedures as well as previously unarticulated expertise and experience resident in individual workers."[988] The use of knowledge resources inside a corporation is a key function of health informatics, which necessitates the adoption of cutting-edge IT. Data generated by biostatistics, diagnostics, medicinal, and public health informatics are all included in health informatics, and they are all integrated with open systems, organization theory, engineering, and behavioral sciences concepts.[989]

5.B.i.b. Health Information Infrastructure

Health information infrastructure (HII) is "community-level informatics systems designed to make comprehensive electronic patient records available when and where needed for the entire population."[990] Privacy, stakeholder participation, securing all electronic information, and economic sustainability are challenging issues that HII systems must solve. Consequently, even though HII has long been sought using a variety of ways in several nations, progress has been gradual, and no established recipe for success has yet been discovered.

Although the creation of the HII in the United States is the focus of this section, many other nations are engaged in comparable operations and have made additional advancements in this direction. Australia, Canada, and European countries have invested a lot of effort and money in their own national HIIs.[991] For instance, the UK has significantly invested several billion pounds in upgrading its health information system over the previous several years.[992] It should be mentioned that the government centrally manages the healthcare systems in these countries. The US's complex, mostly private healthcare system differs organizationally, leading to a unique set of challenges and concerns. The knowledge gained from successful HII development programs worldwide may be successfully shared to decrease the problems everyone pursuing these important goals will confront.[993]

Strategic Dimensions of IT Architecture

Knowing the notions of “reach, range, and richness” is necessary to comprehend how IT architecture and company strategy are related.[994] The many strategic capabilities made possible by IT are described by their reach, range, and richness. Reach is “the degree to which an organization can manage its value chain activities to connect its customers to an accessible product or service.”[995] Simply said, reach is the number of individuals and households in the neighborhood eligible for medical care from a hospital or clinic. One might categorize the community as local, regional, national, or global. In the past, healthcare organizations have always focused locally and developed so that all health treatments should be available to the local community. Traditional definitions of reach in the healthcare industry focused on having physical access to clinical services, which by default constrained healthcare organizations’ vision to the local community.[996] Early on, telemedicine was used to make specific local medical treatments accessible in the area. E-health has developed from telemedicine and now includes various services transmitted across broad geographic areas, and treatments and medications can be given virtually to the patients.[997]

Range is “the degree to which an organization can offer its customers of value proposition containing a breadth of products or services.”[998] It illustrates how effectively a healthcare professional offers the patient various relevant services. The range may be widely defined as a complete health service for a person or family or, more specifically, all the services linked to the care and treatment of a patient with a specific ailment.[999] IT may broaden the scope of services to include preventive and maintenance instead of only immediate and urgent needs. IT can expand the scope of healthcare by offering a wide range of wellness or health maintenance care to become available to a community that may only have health services that focus on acute or chronic conditions – connecting communities and specialists that otherwise would have never met due to geographic distances. However, doing so can only be possible if financial incentives are matched to IT’s enormous potential and regulations hampering any access to the Internet or related IT technologies are relaxed accordingly.[1000] The range of health services that IT can bring can only be extended as far as the infrastructure will allow, recalling the topic of the digital divide addressed in Chapter 4.

Richness is “the degree to which an organization can facilitate the exchange of information to deliver products or services that match customers' exact wants and needs.”[1001] This indicates the ability of a healthcare supplier or clinician to provide patients with individualized or customized treatments, including the integration of services to address specific requirements. By getting over the institutional flaws of big, centralized, and bureaucratic organizations, IT implementation enables the richness of healthcare professionals to give quality recommendations during clinical interaction.[1002] This refers to the ability of a doctor or medical institution to provide patients with specialized or personalized treatment, including the integration of resources to satisfy the unique requirements of each patient. Healthcare providers and organizations who use IT infrastructure to customize their services to specific patient preferences are at a competitive advantage over those that do not.[1003]

Future Prospective in HIM

The boundaries of a healthcare institution are no longer a barrier to the transmission and linking of data, thanks to health information management and information technologies. The migration of patient records to EHRs and EHR systems is made possible by the collaboration of HIM and IT. Successful migration to the EHR system requires well-defined, valid, and accurate data that can be easily transmitted, altered, and aggregated.[1004] Numerous new applications and users will surface as more patient data become accessible in electronic form. In order to secure proper uses of the EHR data and restrict unauthorized users, technological safeguards must be balanced with knowledge and implementation of HIM governance. The early HIM specialists employed the technology available at the time to collect, store, and sort paper patient records and charts. While today's HIM professionals have essentially the same obligations to patient data, their job is much more challenging due to the enormous volume, uses, and users of health information.[1005] To make modern-day HIM professionals' roles even more difficult, their duties and obligations must change to accommodate the demands of the healthcare industry and healthcare reform. The HIM field must continue to set the standard for managing and supervising patient records, information, and EHR systems. The future of healthcare and the intricate, integrated information system required to provide effective, high-quality treatment in a growing and changing healthcare system will continue to depend heavily on HIM specialists.[1006] The next section will discuss some of the legal and ethical aspects these HIM specialists endure in the profession.

5.B.ii. Legal & Ethical Aspects of Health Information Management

Human values should be used as a guide for the health profession's education and practice. Healthcare informatics must address moral dilemmas such as right and wrong, honorable and dishonorable conduct, and suitable and improper behavior, much like other health professions.[1007] It is important for students and professionals in the medical sciences—including informatics—to reflect on their profession's moral underpinnings and ethical conundrums. Although there are ever more ethical problems in research involving human subjects, psychiatry, social service, and allied fields of medicine and nursing, the main concerns are universally understood. Numerous academic, professional, and educational settings have addressed fundamental bioethical problems. Even though some of them have garnered attention for decades, ethical issues and health informatics are typically less well-known.[1008] Among all the health professions, informatics is today the subject of some of the most crucial and fascinating ethical discussions. The following subsections will address health information management's legal and ethical aspects. The first subsection will focus on the internal and external challenges that healthcare information managers might incur and the importance of ethical coding systems and staff justice in the workplace. The second subsection will describe ways to rethink an ethical approach to HIM through Corine Mouton Dorey's matrix and ethical decision-making process.

5.B.ii.a. Privacy, Confidentiality, & Data Sharing

Internal & External Challenges

Health information management specialists have seen increasing difficulty in gaining access to sensitive patient information due to the increased demand for patient data.[1009] A health information management professional has a long-standing ethical obligation to protect patient confidentiality and private communications. Think about a famous patient being admitted to a hospital for acute treatment. It is unethical for hospital personnel or the press to request specific information regarding the celebrity patient's health state since none of these parties has an unalienable right to access such data without the patient's consent.[1010] Dana McWay states, “With the advent of computers, the temptation is to satisfy curiosity by seemingly anonymously gaining access to the celebrity’s health information. Such temptations should be tempered by audit trails, which allow the hospital to determine how frequently the celebrity patient’s health information is accessed and by whom.”[1011] The hospital may implement the necessary disciplinary measures if improper access is discovered.

Another example of unethical behavior in health information management is pressure placed on a healthcare institution to get full accreditation from an accrediting body by "fudging" data showing the department's chart completion rate is higher than the necessary percentage.[1012] Another approach is for a physician to write progress notes after visiting a client and request that the health management system record that the notes were written promptly. Other instances include failing to declare conflicts of interest and giving a false account of one's qualifications.[1013]

Health information managers may encounter external ethical concerns in addition to those that arise inside the healthcare company. Some third parties attempt to get unauthorized access to data about genetics, adoption, or mental health.[1014] Others, including business suppliers, can try to be reimbursed for work that was not done. McWay gives an example of how a false invoice with different line counts than what was billed may be submitted by an external vendor that provides transcribing services.[1015] The management may consider revising the transcribing contract to include penalty provisions for further mistakes and demand more specific information about the invoice if it deems that the disparity is not an error but rather the consequence of an inflated line count.[1016]

Coding Systems & Staff Justice

The complexity of encoding payment systems exacerbates health information technology ethical problems. When health information technology specialists must code and secure payment for delicate patient areas like mental health and genetic information, problems with patient autonomy and confidentiality commonly arise.[1017] Access to celebrity information, as was previously indicated, is of particular significance. Even though there may be firewalls, passwords, and other safeguards in place, they often do not guarantee patient confidentiality.[1018]

The importance of third-party payer payment has increased among experts who handle health information and issue clinical and procedure codes to ensure a healthcare institution's continued financial viability. Eileen Morrison notes, "Most, if not all, reimbursement mechanisms tie the coded diagnosis and procedure to the amount reimbursed to the healthcare facility. Along with the growing complexity of coding and reimbursement guidelines, some coders face the dilemma of focusing on the accuracy of coding versus coding to obtain a better reimbursement for the healthcare facility."[1019] To get the highest compensation for the healthcare facility, the individual coder may feel pressure from healthcare institutions to depend on unreliable, incomplete, misleading information or lack a solid clinical foundation or supporting evidence.[1020] In situations with moral ambiguities, like this one, the American Health Information Management Association (AHIMA) offers principles for ethical coding to direct coding specialists.[1021]

Professionals in health data technology also need to handle staff justice problems in addition to patient confidentiality and integrity concerns. Ethics-based management should be provided to employees who create health information technology systems, keep track of patient data, or code medical data.[1022] Leaders in health information management must thus demonstrate moral awareness. Being morally conscious involves being aware of possible ethical concerns connected to fraud and exploitation of health information technology.[1023] Similar to this, executives in health information technology need to be able to appropriately enforce organizational regulations by comprehending their nature and how they should be used. Fair treatment is also necessary for promotions, overtime distribution, and other staff justice concerns.[1024] To strike a balance between the requirements of the workforce and those of the healthcare organization, administrators in the healthcare field will need to be realistic.

5.B.ii.b. Rethinking the Ethical Approach to HIM

Objectification of Individuals vs. New Scientific Advances with Big Data

Ethics takes precedence over law to use big data to manage health information. Big data eludes the standard structure of clinical research, the practice of medicine, and relationships among patients, donors, doctors, and researchers. Corine Mouton Dorey states, “The three rules of medical secrecy, the patient’s right to the truth, informed consent, and the concept of individual indivisibility are challenged. Moreover, the high speed of big data development requires continuous normative adaptation to legitimize its use.”[1025]

Based on the three components of applied posterior ethics, moral standards, and antecedent ethics, Dorey’s matrix suggested ethical assessment method for big data is structured around the idea of fairness.[1026] A sense of fairness is important because it promotes collaboration, such as making big data's sources, techniques, and results available to the public, along with making reparations when findings have hurt specific people.[1027] A bottom-up "democratic" engagement in big data governance will be favored by the appropriate social justice and equitable information dissemination principles. Citizens' engagement and education would shield patients and medical professionals from uncontrolled anxieties that may result in a cautious attitude and from potential covert population health coercion or the lack of caution in its use or exploitation of big data.[1028] This democratic approach to managing huge health data might improve ethical reflection among healthcare stakeholders, boost their feeling of agency and self-worth, and lessen the possibility of medical or public arbitrariness.[1029]

Big data moral questions may reveal modern normative tendencies in ethical reasoning for handling health information. Dorey elaborates, “Finally, advances in data size and analytic methods in HIM could be seen as a resurgence of scientific positivism, adding new narrative paths in the research for truth, and challenging the moral references for medical and bioethical judgment. Depending on the queries, numerous different plots could be revealed, which not only enhance scientific research, but also carry new patterns in moral thinking for HIM itself.”[1030] The present normative rules of justice may be in jeopardy as a result of the morally challenging tendencies of HIM.[1031] Dorey continues, “The deliberation process starts at the level of posterior ethics with openness and prudence in founding the common good. Then, normative development proceeds by adjustment using anterior ethics, gradually revising public health legitimacy and distributive justice.”[1032] With the anterior ethics section specifying a specific ethical purpose, the matrix also creates limits in light of big data's potentially misleading moral guidance.[1033] The matrix, for example, would restrict excessive demands on one's health and distinguish between one's self-esteem and self-love.[1034]

The matrix deduced from Ricoeur's "little ethics" is a viable approach to ethics for application in the management of health data due to its focus on patient agency, the trust relationship between healthcare institutions, and justice as inclusive and fair engagement in the collective welfare.[1035] Although Kantian and Rawlsian theories have advantages, Ricoeur's ethics asserts that previous ethics supersede moral and legal norms.[1036] There may be ethical problems, but these may be resolved by turning to anterior teleological ethics. In managing health information for clinical practice, research, and public health, the remedy to anterior teleological ethics permits the potential moral conflicts to be overcome and facilitates informed and collaborative decision-making.[1037] This ongoing ethical reflection method may apply to various aspects of technology-assisted healthcare.

Ethical Decision-Making Process

How these ethical dilemmas might be resolved is as varied as how they can be presented. Decisions may be made individually, in a group, via discussion, or by reaching a consensus.[1038] These choices cannot be taken in a vacuum since they may impact other aspects of the same ethical issue. Regulations, ideals, technologies, liberties, society, norms, legislation, religion, and morality, are examples of ethical problems' constituent parts.[1039]

Despite the fact that the literature on ethics mentions several different ways of problem-solving, these approaches may essentially be handled as a part of a multi-step process. Establishing the facts and properly describing the ethical problem are the first stages. The defining stage entails defining the issue, clarifying it, and looking at incongruent values. Data collection may be used to establish the facts. Speaking with people who may know anything about the problem or looking at pertinent documents are two ways to collect data.[1040] Finding out who has a stake in this choice must come after the issue has been precisely identified and facts have been acquired. Sometimes, the party or individual who must make the moral choice is not the same as the one who is the problem's victim. A wider approach to identifying stakeholders is necessary since there may be more parties with interests that need to be considered than are first evident. The connections between the stakeholders should also be investigated, as well as any possible biases or other incentives.[1041]

The knowledge gained at each stage helps the decision-maker identify the possibilities open to them. The pros and cons of each alternative and how they will affect the many individuals and groups involved should be carefully considered. To help in decision-making, each alternative may be weighed against an ethical framework. For instance, which choice supports completing one's duty (deontology), which option supports the rights and dignity of all people (social equality and justice), and which option gives the greatest benefit for the largest number of people (utilitarianism)? The decision-maker explains the rationale behind each choice by relating it to an ethical philosophy. In order to effectively support a HIT ethical decision-making process, a kind of HIT governance must be built to help with the enforcement and compliance with ethics throughout the organization—ensuring that data is kept safe and private and maintains integrity.[1042]

5.B.iii. Health Information Technology Governance

A set of processes known as health information technology governance is in place to ensure that information assets are formally controlled across the entire business and that people liable for adverse consequences brought on by poor data quality may be held accountable. It involves managing the organization's data assets' availability, usefulness, integrity, and security. In the proceeding subsections, HIT governance will be more fully defined, including its need and core components and the essential characteristics of data quality.

5.B.iii.a. Defining HIT Governance

The following subsections will describe the need for HIT governance and the core components of that governance – what it entails and requires to be implemented within a healthcare system.

Need & Core Components

Healthcare organizations must ensure that their health IT initiatives align with their major objectives due to health IT's broad participation in all aspects of a company's purpose and activities.[1043] Additionally, health IT resources are often needed for a healthcare company's strategic and operational efforts to be as successful as possible. Health IT is often required for important healthcare initiatives, such as population health, service pathway adoption, and pharmaceutical safety.[1044] As a result, there will often be a considerable gap between the demand for and supply of health IT personnel (such as analysts and software developers). Nelson & Staggers state, "The critical nature of effective health IT governance then arises from the following fundamental interrelated needs: 1) the need to ensure alignment of health IT resources with institutional priorities and 2) the need to effectively prioritize the use of health IT resources in the face of numerous competing demands for these limited resources."[1045]

In conclusion, there is a growing need for health IT resources and skills, and institutional interests, as well as demands from a wider range of constituents, are becoming less clear.[1046] Without efficient governance, important parties, such as healthcare providers, would experience delayed or insufficient IT assistance and a resource allocation rationale that they do not comprehend, such as how to distribute staff among units in the hospital or how to ration a medication shortage. Furthermore, because of resource allocation, similar organizations (like hospitals) may be sponsoring projects that compete with one another and have opposing goals instead of working together to provide a wider range of health services to their communities.[1047]

Determining goals, allocating resources, and, if required, approving funding to support the growth of immediately accessible health IT assets are all part of the function of health IT governance.[1048] The governance of health IT should be responsible for keeping track of and evaluating the results of these investments. The following elements must be included in effective health IT governance to achieve the funding investments needed to support its growth:

> 1) Organizational structures responsible for clearly defining institutional priorities. Typically, this function is primarily the responsibility of a healthcare organization's board of directors and senior leadership. 2) Organizational structures responsible for ensuring that health IT efforts are aligned with institutional priorities and used optimally. 3) Accompanying processes to operationalize the governance. Establishing such operational processes is much more straightforward than showing a governance structure that appropriately owns and uses these processes.[1049]

As previously mentioned, defining HIT governance includes a description of data quality characteristics since so many of the governance concepts revolve around the quality of the organization's data assets. The next subsection details some of those qualities and why they are important.

Characteristics of Data Quality

The following definitions of "quality" are particularly relevant to the HIM professional, however, there are other connotations as well: "1) a degree of excellence of a thing and 2) a required character or property that belongs to a thing's essential nature."[1050] The accuracy of the data is referred to as data quality. When "qualities of data" is used, it often refers to the qualities or components that go into making up data or factual information. Developing health information systems and tracking data are essential steps in ensuring the reliability and accuracy of the information generated.[1051]

Data quality management (DQM) leads to good data. HIM experts are familiar with the duties and talents of DQM. "Practice Brief: Data Quality Management Model," which the American Health Information Management Association (AHIMA) initially released in 1998 and then revised in 2012, serves as an example of data quality management.[1052] There is also a checklist to evaluate DQM initiatives. Continuous data quality assurance is a part of all DQM operations, including data application, collecting, analysis, and warehousing.

The following ten components characterize data quality:

Accessibility: Data items should be easily obtainable and legal to collect

Accuracy: Data are the correct values and are valid

Comprehensiveness: All required data items are included. Ensure that the entire scope of the data is collected, and document intentional limitations

Consistency: The value of the data should be reliable and the same across applications

Currency: The data should be up to date. A datum value is up to date if it is current for a specific point in time. It is outdated if it was current at some preceding time yet incorrect at a later time

Definition: Clear definitions should be provided so that current and future data users will know what the data mean. Each data element should have clear meaning and acceptable values

Granularity: The attributes and values of data should be defined at the correct level of detail

Precision: Data values should be just large enough to support the application or process

Relevancy: The data are meaningful to the performance of the process or application for which they are collected

Timeliness: Timeliness is determined by how the data are being used and their context.[1053]

The “Practice Brief: Data Quality Management Model” offers examples of each domain's characteristics, along with a graphic depiction of the DQM domains and how they pertain to the many components of data integrity. The model is universal and may be used in any care environment. It serves as a tool or paradigm for HIM professionals transitioning into entity- or organization-wide DQM responsibilities.[1054] Now that HIT governance has been defined, it is appropriate to see how normative ethics play a role in its dissemination in healthcare. The following subsection discusses the ethics of quality and the concept of information stewardship to guide this description of HIT governance.

5.B.iii.b. Normative HIT Governance

The Ethics of Quality

Quality is crucial because it is a Kantian commitment, in addition to ensuring that a good or service satisfies the standards of regulatory agencies and financial institutions and that a business is profitable. The categorical imperative would be satisfied if the patient received safe, efficient, high-quality healthcare that is beneficial.[1055] Additionally, Kant's idea that all people have worth is consistent with delivering top-notch treatment to all patients regardless of their financial situation. Healthcare institutions often use the word "quality" in their mission statements. It makes no sense to have a goal statement encouraging subpar quality when people's lives and health are at stake. The problematic issue, however, does not lie in declaring that one's mission is to provide high-quality care in this period of significant change in the healthcare system and the financial constraints placed on caregivers; rather, it lies in having the moral courage to take actions to ensure that high-quality is present.[1056]

Although for a different reason, utilitarians would concur with the Kantians in this case. The most damage can be prevented, and the most good can be done for the most impacted people by providing effective healthcare services. Utilitarians compare a decision's benefits or drawbacks to its effects. The repercussions of poor treatment might harm patients as well as the sustainability of the healthcare institution. For instance, poor care may worsen patients' suffering and raise the price of their treatment.[1057] Bad patient satisfaction numbers or legal action might affect the company due to poor treatment. In the age of the Affordable Care Act, noncompliance with quality requirements may lead to lower payments, which might hurt the organization's financial line. Reduced income may result in staff cutbacks and a decreased ability to meet patient demands. The conclusion that quality assurance is just good business comes from considering the utilitarian implications of the practice.[1058]

The ethics of quality assurance are subject to the same ethical rules. Think about the idea of nonmaleficence. Patients might suffer if they get subpar treatment, and caregivers' jobs can suffer if they make mistakes with medicine and patient identification.[1059] Although vital, the expenses associated with developing rules, and procedures, holding training sessions and monitoring to ensure excellent practices raise the cost of providing care.[1060] As a result, investing in quality assurance results also improves ethical behavior across the firm. When healthcare practitioners behave with patient-centered care and compassion, the sister principle of beneficence is put into practice. Healthcare managers also show their goodwill toward their staff by enforcing laws that protect their rights, respect their dignity, and promote their growth as individuals and professionals.[1061] A business may show generosity to all workers and convey that they are appreciated by, for instance, investing in a competent employee support program.[1062] A quality assurance program that is properly financed and maintained may encourage the use and implementation of the moral values of beneficence and nonmaleficence, which will improve normative governance.

Information Stewardship

In order to handle information ethically, it is essential to practice efficient information stewardship within an organized and well-defined information governance framework. To summarize, information stewardship is often described as “An approach to information/data governance that formalizes accountability for managing information resources on behalf of others and for the best interests of the organization.”[1063] One should think about broadening this notion from an information ethics standpoint. Since it places a heavy emphasis on the "best interests of the organization" and cannot specifically take stakeholders in larger society into account, as with other definitions, information stewardship is closely tied to organizational ethics.[1064]

The risk is that the current ideas of information stewardship will be applied to the normative stakeholder theory paradigm of ethics. But this does not align with the underlying idea of stewardship, which is widely seen as “the acceptance or assignment of responsibility to shepherd and safeguard the valuables of others.”[1065] Consideration of the notion of stewardship characterizes the idea as the “responsibility for sustainable development shared by all those whose actions affect environmental performance, economic activity and social progress, reflected as both a value and a practice by individuals, organizations, communities and competent authorities.”[1066]

This interpretation of stewardship expands the ethically acceptable range of norms and values. It also paints a complete picture of the participants in the data and operational results the organization aims to provide via its administration and management of data.[1067] Additionally, it underlines how crucial the stewardship method is. In this context, ethical information stewardship may be described as “an approach to information/data governance that formalizes responsibility and accountability for sustainable information management shared by all those whose actions affect the information and process outcomes experienced by stakeholders, both inside and outside the organization, and that is expressed by individuals, organization communities, and competent authorities as both a value and a practice."[1068]

5.B. Conclusion

Information management has dramatically impacted how we view, use, and store data – from the smallest to the most extensive files. Information management affects everyone –those who do and do not work directly with data and with multiple levels of influence. As a result, it is crucial to include a governance framework to ensure that this data is appropriately, ethically, and legally managed since, if not, it might lead to a major tragedy. This section has explained the foundations of health information management and how that can lead to an understanding of the infrastructure of the technology and the system behind it. Then, while striving to reconsider the ethical approach to appropriate health information management, some of the legal and ethical difficulties that may occur in this context were looked at. Next, applied analysis of health information management was described using systematic reviews and risk management principles to highlight the importance of having ethical information management. Finally, a health information technology governance was proposed in which its need and core components were emphasized within a normative health information technology governance and information stewardship.

5. Conclusion

As a reminder, AI and AML require massive amounts of data to learn and improve their computation and processing. Data analytics can assist with this information storage, acquisition, and use – which can be summarized in information management. The way this information is managed and the kinds of ethical and philosophical data input into the system are of the utmost importance. A proper governance system must be integrated at the base level of information management so that the AI will have regulated, ethically robust data to learn from and can be designed with humans in mind. Quality control and information stewardship were just two ways of helping to guarantee that proper information regulation and governance can occur. The next chapter, Technology's Impact in End-of-Life Practices, examines how information management, AI, and data analytics through various technologies can be applied in a specific context in the care of the elderly and aging populations and help to revive the art of dying well in the modern world.

CHAPTER 6: TECHNOLOGY'S IMPACT IN END-OF-LIFE PRACTICES

6. Introduction

The end of Chapter 4 looked at an example of how data analytics could be applied in a negative or dystopian way if humanity is not careful of the slippery slope that human enhancement can lead down. In contrast, the sixth chapter focuses on an overall optimistic or utopian application of various data analytics-driven technologies within the specific context of the elderly population and end-of-life practices such as palliative care and hospice. Why end-of-life practices? Due to the exponentially increasing scope of the aging population, an unmet need has arisen, now more than ever, to care for the elderly worldwide. Thanks to data-analytics-driven technology, machines have changed how the world deals with death and allow people to live much longer than they could a century ago—the historical and cultural background of death and dying outlines systematic changes toward death over time.

Opportunities for technologies in end-of-life practices are explored, such as telemedicine and electronic learning. Challenges such as the digital-divide, professional-patient relationship via technology, and fundamental issues such as the technological imperative vs. humanizing are also described. The chapter continues with ethical considerations of using care robots in aging populations using care ethics. In this narrative about the automation of care labor, the size of the aging population is calculated, the unmet care requirements of the older population are described and how carebots emerge to fill this expanding gap is noted. Care ethics and elements of care are detailed in how they can apply to technology, specifically care robots. This applied healthcare data analytics chapter describes concepts like artificial morality, relational autonomy, and dignity. It ends by noting the ethical challenges of a care-centered framework using a context-sensitive process and human capabilities in an artificial form.

6.A. Technological Opportunity & Ethical Challenge in Hospice & Palliative Care: Help or Hinderance in the Art of Dying Well

6.A. Introduction

Dying is a phenomenon that affects us all one day and therefore causes a universal interest in the experience. However, the general way of thinking in the modern secularized West has focused on how this phenomenon can be controlled, presenting options for assisted dying and mechanical intervention to delay dying as long as possible.[1069] The main idea of this section is to investigate the history and culture surrounding death and to revive the process of *Ars moriendi*, or the lost art of dying well, that can be applied to the modern world by showing how various opportunities and challenges of technology in the fields of hospice and palliative care attempt to achieve *Ars moriendi*.[1070] This will be defined by explaining the systematic changes to death over time through the perceived notion of a ‘good death’ and the advent of hospice and palliative medicine to revive the art of dying well. Subsequently, a new ethical framework is proposed for dying well via critical observations about the field and some contemporary issues that must be addressed for the ethical framework to be valid.

This section then continues by describing the opportunities modern technology affords hospice and palliative care, such as improvements to medical interventions and telemedicine, electronic learning, and the flexibility it provides patients and providers in healthcare. Finally, this section concludes with a description of some of the ethical challenges posed by this technology, including fundamental issues such as technological futility and dehumanizing the caring approach, in addition to more specific topics such as how technology creates a digital divide and stresses the professional-patient relationship within hospice and palliative care. The purpose of this section is to show that while modern technology provides many new and valuable opportunities in hospice and palliative care, it also produces ethical challenges that must be addressed if the future of healthcare and the revival of the art of dying is dependent on it.

6.A.i. Historical & Cultural Background of Death & Dying

6.A.i.a. Systematic Changes Towards Death Over Time

Systems alter as well, as was mentioned in the history of Western views on death. This section will try to summarize and conceptualize those systems changes that went with these significant historical moments that shifted the practices surrounding death. This will be carried out by describing how the localization of the death system changed from the home or community to the hospital, nursing home, or hospice unit. This subsection will explain how and why the hospice and palliative care fields attempt to bring back the art of dying in this contemporary world.

The Modern 'Lie' & The Good Death

Correlated with the localization of death to the hospital or institution, Philippe Ariès describes "the rise of the modern lie or shame of death: the sense that death signifies not spiritual completion but medical failure" in his book *Western Attitudes Towards Death: From the Middle*

Ages to the Present.[1071] He describes that “one dies in the hospital because the hospital has become the place to receive care which can no longer be given at home.”[1072] Further, in the past, the hospital acted like more of a shelter for the homeless or refugees; later, it became more like the medical facility it is today where healing occurred, and people battled death.[1073] Even while it still has that healing capability today, many have started to conceive of hospitals as places where people go to die. Ariès notes, “One dies in the hospital because the doctor failed to heal. One no longer goes to or will go to the hospital to be healed, but for the specific purpose of dying.”[1074]

However, many Americans stated their preference to die away at home, close to their loved ones.[1075] This suggests that death will occur after some notice, giving people time to make arrangements. “Unfortunately, though the numbers have been slightly better in recent years, it is still the case that more than 70% of Americans dying hospitals or nursing homes, in the large percentage die after a disconcerting series of institutional admissions and readmissions.”[1076] This type of ‘medicalization’ of death is stripping away people's chance to die in a way that allows them to experience some of the best and highest values in life, such as family, closure, religious enlightenment, etc.[1077] Even though it would be challenging for everyone involved, it would be beneficial for many patients and their families if medical professionals had the foresight and the guts to inform them that, while this might not be the end, it might be the beginning of the end.[1078]

The notion of the good death or of dying well isn’t a phenomenon that just passively happens to you. It is something you must actively do.[1079] The concept of "tame death" has been around since at least the eighth century, according to several social historians, including Ariès.[1080] Speaking mainly of Europe, he explains that a ‘good death’ meant the dying had the “liberty and presence of mind to set their physical, material, and spiritual affairs in order – unlike in earlier times, particularly in our hunter-gatherer past, where death happened suddenly and often violently."[1081] The pastoral age began when hunter-gatherers built farms and began living more stable lifestyles near to one another. The seasons served as a helpful metaphor for comprehending life and death as a process before the event of death happened, and they gave them the chance and time to make plans.[1082] A repetitive, immobile, and largely unadventurous life gave time to anticipate death and, finally, to prepare for it. Brandy Schillace concludes, "Death as the process became something the dying could participate in *with* the living who remained – not just something that happened after they were gone."[1083]

Hospice & Palliative Medicine

Hospice and palliative medicine, however, provides an alternative to this unartful way of dying, and it contributes to the project of recovering the practices of the *Ars moriendi* by helping to create the prerequisites for patients and their communities to engage in the activities of dying well (and caring well for those who are dying). In theologian/ethicist Paul Ramsey's terms, dying well is both "a gift and a task."[1084] For one to be conscious of the gift and partake in the task simultaneously requires patients to be aware of both their symptoms and their mortality.[1085]

In 1996, the American Medical Association's (AMA) Council on Scientific Affairs published a report titled *Good Care of the Dying Patient*.[1086] The report states that "In the current system of care, many dying persons suffer needlessly, burden their families, and die isolated from family and community."[1087] The default pathway creates enormous obstacles to dying properly and regaining any art of dying by entangling patients in a technologically driven social infrastructure that causes unnecessary pain and isolates them from their communities.[1088] Expanding and improving palliative care and hospice have been the traditional approach to solving this issue and the only solution the Council on Scientific Affairs of the American

Medical Association could confidently identify.[1089] Numerous waves of outreach have urged and helped individuals create advance directives enabling them to refuse unwelcome life-sustaining treatments when they are terminally sick and deliver them to teams of palliative healthcare specialists who will support their death at home.[1090]

Keeping one's "matter in motion" for as long as possible, away from one's community, and under the direction of machines and a system of processes that continue with unrelenting and uncaring logic is not what dying properly means, as both patients and doctors have realized.[1091] As Atul Gawande notes in his book *Being Mortal*, “striving officiously to keep alive within the medicalized privileges of North America comes with severe costs.”[1092] Jeffrey Bishop’s *The Anticipatory Corpse* builds on Gawande’s pathology. Bishop argues that “a more profound medical objectification of the body in the modern West renders it lifeless long before it ceases to function as a living organism.”[1093] In summary, the more we as a society attempt to control death, the more we become removed from moral realism, and the less our theological teachings may be used to address the contemporary death.[1094] Bishop concludes that “the religious traditions of today have a special job in challenging the fundamental assumptions of the medical establishment.”[1095]

6.A.i.b. Toward a New Ethical Framework for Dying Well

A solid and unambiguous understanding of human frailty and a realization that existence has limits are what Ars moriendi strives to achieve. If we do not initially acknowledge our limitations and impending mortality, how can we begin to establish a structure for the practice of dying well? We cannot discuss the art of dying without first acknowledging our own mortality. Careful consideration of the potential for beauty and growth is encouraged by art. We must handle death carefully; we must weigh its excesses against its lack and its beauty against its decay. The art of dying can only be experienced by those who recognize their own death. Can the emergence of a contemporary Ars moriendi be facilitated by a bioethical framework that is sufficiently robust? The following subsection will describe how the overlap of virtue ethics and bioethics can come together to create a framework that includes five significant observations for a modern *Ars moriendi*. While the following five observations are a good start, they are by no means a complete and comprehensive list of all the ways that the field of bioethics can help to usher in a new framework for dying well in contemporary times.

Five Observations for a Modern Ars Moriendi

The first step in developing a framework for dying well is for bioethics to honestly assess the limitations of its own formal, procedural approach.[1096] Everyone who is dedicated to the mission of dying well agrees that it is a virtue-based undertaking. To support this goal, bioethics must fully reimagine its ethical framework to include a virtue methodology. Second, in order to achieve this, bioethics will need to develop the skills necessary to constructively and honestly support meaningful clinical and cultural discussions about goals and means.[1097] Serious considerations regarding the societal aims that such a protocol aspires to achieve would need to be raised if bioethics were to aid medicine in designing a procedure for dying well in the therapeutic environment.[1098]

Third, bioethics will need to seriously consider economic issues rather than just adding up the high expenses of end-of-life medical treatment in a cost-benefit analysis or confounding the problems of who should foot the bill for what.[1099] A profound ethical framework will need to consider the many significant ways that modern economic systems and philosophical viewpoints influence those who enter the clinical setting, determine the framework within which patients and healthcare are provided, and impact the biotechnology and healthcare industries.[1100] These influences are often subtle and unnoticed.

Fourth, we will need to go beyond the clinical context and recreate the geography of dying in addition to going beyond the bioethics' constrained methodology and ethical framework for dying properly.[1101] Restoring death to its rightful, non-medical setting—the home or local community—is the most natural step if we are sincere about lessening the medicalization of dying.[1102] Beyond the intensive care unit, how can healthcare professionals and organizations assist communities in providing for the terminally ill? Lydia Dugdale asks the right questions, “might various religious congregations, for one example, reimagine how they care for the sick? Instead of sending communion ministers to healthcare institutions, might congregations propose vacant rectories as places to care for dying parishioners for whom home care is not possible?”[1103]

Fifth, focusing on the deathbed is missing the purpose, as ancient and modern Ars moriendi literature argues.[1104] The art of dying is more than just a ritual performed once medical intervention has been exhausted and all associated tools and aids have been abandoned.[1105] Those attempting to change the dying experience, from Ariès to Callahan and beyond, make it plain that actions at the deathbed must be connected to a more extensive set of practices acquired throughout life (and after death). “The art of dying – which really is the art of living – is a lifelong process cultivated in the home, in the congregation, and in the community.”[1106] The diverse facets of numerous traditions may thrive there, in which the advancement of the qualities required to die and live well could be accomplished by particular practices and traditions brought about by spiritual development.[1107]

Contemporary Challenges

Another significant obstacle in the art of dying well comes not from shifts in religious and cultural norms but changes brought about by human evolution.[1108] Human evolution, whether biologically or technologically, has caused us to live longer despite the increase in adverse events such as unhealthy lifestyles, poverty, and suicide amongst the general population.[1109] Sarah Coakley points out that "Death comes slowly to a generation serially saved by antibiotics, their lives often further elongated either by economic privilege or 'good genes.'"[1110] However, this increase in longevity isn't without a few adverse outcomes, like for those elderly adults who are plagued by dementia – confusing and isolating the patient from family members who belabor how to deal with the progressive disease.[1111] In previous generations, the elderly patient would have been cared for in a wider social sphere, such as their religious congregation. In the Catholic tradition, elderly individuals are often given *viaticum* numerous times as their fragile lives transition from one life-threatening event to the next.

Coakley then asks where the Christian Ars moriendi comes into play in these instances.[1112] Does even the holiness of the sacrament appear rather dull by its continued repetition (such as within the sacraments of Last Rites, Anointing of the Sick, etc.)? The unfortunate reality for all involved in this caring process is coming to accept the predictable path to death that these end-of-life sacraments often foreshadow.[1113] The challenge for religious leaders and autonomous individuals is to change death preparation from a suppressed subject forgotten about until some last-minute medical emergency intervenes to a lifelong duty that one continually prepares for. In short, "there is no possibility of a straightforward retrieval of a set of traditions and practices that have served the Christian tradition so richly for nearly two millennia, not at least without deep and realistic reflection on how the medical and cultural situation has now changed."[1114]

Throughout time, major historical events have slowly stripped away the art and sense of dying well. From the Bubonic Plague to the AIDS crisis, there has been a shift away from dying with family members in the community to an unattended death in a hospital room with often tricky decisions about whether or not to turn off machinery that is keeping someone alive – machinery that didn't exist centuries ago and has now stretched the definition of death to something brand new. With this new definition of death, we need a new *Ars moriendi*, the art of dying, that is suitable for the current needs of medicine. Palliative and hospice care have been an excellent start to bringing back this tradition, but more must be done to achieve a good death. Hence, a new ethical framework, though still limited in scope, can help to work towards a contemporary art of dying that satisfies the needs of the misguided secularized West.

6.A.ii. Opportunities of Technology in Hospice & Palliative Care

It should be no surprise that the opportunities that technological advancements will provide to the growing needs of the rising elderly population will be profound. This next section will highlight some of the technological advancements that are being utilized in the fields of hospice and palliative care – two areas of healthcare that deal with the increasing ageing population the most outside of geriatrics. The hope is that in this contemporary and digital world, the art of dying well will be revisited and revived through the opportunities that technology now enables and was previously unavailable to past generations.

6.A.ii.a. Improvements

The fields of palliative care and hospice have given much room for technological opportunity to work in attempting to seek out new and innovative ways to revive the art of dying well. Some technological improvements used in palliative and hospice interventions are the digital pens and the videophone. These advances have improved patient access and communication in the fields and helped patients have a higher quality of life when utilizing these interventions. These kinds of technologies can be broadly categorized under the umbrella term of telemedicine, which has brought improvements in the physician-patient relationship and caregivers and will be further detailed in the following subsections.

Medical Interventions

A journal article by Lia Willis et al. reviewed the interaction of palliative and hospice care patients and providers with the Internet and some of its technological interventions involved in care.[1115] The review highlighted several articles. However, two were prominent in using and explaining telemedicine in hospice and palliative care through digital pens and videophones.[1116] Willis et al. noted that "both articles described this equipment as being used to aid communication between patient/caregiver and professional."[1117] Summarizing the use of these telemedicine interventions, the digital pen's main function was to assist in pain assessment by the patient. In contrast, the videophone's main functionality surrounded enhanced communication and better physical evaluation.[1118] Regarding the digital pen, the patient (sometimes with the help of a caregiver) would rate their pain level on a scale on digital paper, which would send the information to a secure server via the Internet and then be seen by healthcare professionals.[1119]

The results in the literature review of the digital pen were mostly positive and supported by the conclusions that patients' care improved along with the communication between them and their healthcare professionals.[1120] The literature review results of the videophone were very similar in that videophones "offer the capability of physical assessment and communication that is more personal in nature due to adding the video component."[1121] Also noteworthy is the conferencing feature that videophones permit enhanced communication and conversation between many different healthcare professionals, further augmenting the hospice and palliative experience for all involved.[1122] The reasons for hospice and palliative providers to use the Internet vary but top reasons include clinical information gathering, live consultation, email, and online journals with “a need for more online training opportunities to obtain continuing education credits.”[1123]

On the other side of care, patients and families generally use the Internet for gathering information and searching for support groups for people who are going through similar illnesses or situations.[1124] The review also indicated that patients enjoy the anonymity factor that is so easily obtained through the Internet support groups.[1125] The literature review is clear that “patients and professionals are using the Internet to find answers to healthcare questions, communicate, and deliver healthcare interventions.”[1126] While the review aimed to focus on palliative and hospice technological interventions, many of the support groups were intended for people with terminal illnesses – mostly cancer related.[1127] In addition, a shift in the mindset of patients and professionals to view these technologies as giving the opportunity to create a social network of sorts that can further connect patients and professionals and enhance the standard of care provided at the end of life.[1128] Willis et al. explain that “the Internet can create peer-to-peer communities, allow more access to information, and address isolation rather than as a substitute for patient care.”[1129] While many people who are currently in hospice may have little to no access or experience with the Internet or telemedicine technologies, in the not so distant future it will be easier to assume that more people who will reach elderly ages will have access and comfortability using the Internet and its telemedicine technologies.[1130]

Telemedicine

Patients with terminal diseases predominantly experience varying levels of both physical and psychosocial issues throughout the course of the illness.[1131] Palliative and hospice care provide a way to manage these issues that prioritizes the quality of life of the patient and family members.[1132] Patients who are home-bound typically receive community-oriented palliative care services from their primary care physician(PCP). Since palliative care is a specialist service, the care it provides at times is not very accessible to patients for several potential reasons including PCPs disregarding the care networks, or the more likely scenario being a physical decline of the patient that would diminish their ability to travel to outpatient palliative campuses.[1133] Yet, this kind of specialist care is much more needed and utilized when difficult problems present during the patient's care.[1134] Hence, many healthcare professionals agree that a multi-team collaborative effort between PCPs, specialist services, and patients should be maintained to provide the best care continuum possible.[1135] It remains unclear, however, how home-bound patients fit into this care continuum since their vulnerability prohibits them from travelling to these various care settings. For these patients, telemedicine may provide a promising opportunity to keep this care connection strong as it permits patient involvement in their care remotely.[1136]

Technologies for telemedicine have been developed to help with patient monitoring and communication who are confined to their homes. [1137] For example, "online monitoring enhances patients' incorporation of illness(es) into their daily routines and yields improvements in cancer-related pain and depression."[1138] In addition, a "tele-hospice" report stated that both professionals and patients were excited about the ability to instantly communicate in a visual manner via videophones.[1139] Another study reported that patient-physician webcam interactions lead to "honest conversations, revealed nonverbal cues, and opened personal spaces."[1140]

On the other hand, it is noteworthy that with telemedicine's potential to help in healthcare, also carries worries and fears that these technologies will dehumanize the relationships through establishing barriers that prevent compassionate care and disrupt the patient's home.[1141] These concerns have prevented telemedicine from being widely used in settings focused on palliative care. In order to better understand how telemedicine affects the patient-professional interaction, which is essential for providing good palliative care, various studies have been conducted.[1142]

6.A.ii.b. Electronic Learning

Reasons for Going Online

There seem to be multitude of reasons patients with life-threating illnesses or diseases as well as family members go online – to engage in telemedicine (via videophone) or the Internet for information (for example, to learn about the processes of palliative/hospice care) are just a few of the reasons.[1143] Patients often use the internet to research their illnesses and discover if there are any available treatments.[1144] This pattern supports the idea that, to varied degrees, patients do in fact want to be included in the therapeutic decision-making process.[1145] With this in mind, the Internet shows its value as an accessible source of information to the general population. Other reasons for this trend include seeking a second opinion and for verification of information regarding their illness told to them by professionals already.[1146]

Rising levels of Internet learning very likely will parallel the rising interest rates in in alternative medicine.[1147] Websites that promote alternative medicine and similar practices appear to be abundant on the Internet.[1148] While there are numerous potential reasons as why a patient may seek alternative treatments, some of the most prevalent are dissatisfaction with the amount of information presented, lack of tangible results from current treatments, and general dissatisfaction with the doctor.[1149] These are just a few of the reasons that explain alternative treatment seeking behavior in addition to a patient's natural desire to control an event that is mostly out of their control. This can lead to experimental treatments, drugs, and therapies that may or may not in the human trials phase of research and development.[1150]

It also happens to be the case that many patients prefer the anonymity factor of the Internet desirable and would be more comfortable and have less anxiety than an in person encounter with a healthcare professional.[1151] Gustafson et al. note that "computer-based interfaces have been noted to increase participants' willingness to engage in frank discussions about health status, behavioral risks, fears, and uncertainties."[1152] Internet-based interactions, such as discussion groups, have facilitated patients' and families' capacity to locate the encouragement and guidance they deserve. Scolamiero suggests "that these virtual support communities may reflect people's tendency toward socialization and is one of the most common health-related uses of the Internet."[1153] Klemm et al. noted some distinct advantages of these online discussion board communities over in-person support groups, such as around the clock availability and the lack of a peer-pressure to participate that a patient will not experience online.[1154] The Internet also provides a way for home-bound individuals to stay connected to their families, providers, and the online support groups that give that can give them answers.[1155] Not many other information resources can compare to the Internet: its speed and sheer volume of content outpaced many other sources decades ago. While lacking formal verification of research, one last reason to note of reasons patients may go online is the removal of an intermediate, such as a librarian, between the seeker and the information, provider faster access to a wealth of knowledge.

Promoting Participation

Recent academic writing has underlined the value of free and open debate. Democracy is seen as "government by discussion," and one should place more emphasis on "social realizations" rather than striving to imagine perfect fairness and ideal institutions.[1156] A democratic society is distinguished more by political engagement, debate, public contact, and deliberation than by its institutions. These systems can express the voice of the weak, the oppressed, and the disadvantaged.[1157] This perspective is refreshing since it is uncommon for marginalized communities' views and ideas to be heard in public conversation.

It is interesting that a number of initiatives concerning participation experiences have been published. One relates to monthly Swiss radio programs that provide voice to vulnerable populations so they are no longer ostracized in public discourse, such as critically sick individuals, people with disabilities, people with chronic conditions, and those who are addicted.[1158] Being vulnerable became a shared experience because to the efforts, which gave those who were vulnerable equal power and responsibility and made others aware of their own vulnerability.[1159] An additional study describes a phenomenological investigation of the hospital experiences of elderly patients. It demonstrates how prolonged observation (shadowing) may give voice to the perspectives of vulnerable individuals who are frequently left out of research studies because they find it difficult to express their feelings.[1160] The case for participation is broadened to include different categories of study. Through participation in research, vulnerability can be decreased. Protecting vulnerable persons or taking extra security measures is insufficient. To prevent exploitation, they should take part in every stage of the study and supervise the trials.[1161]

This claim is connected to the need to identify the autonomy of helpless individuals and communities in the institutional review process of investigation, especially in economically disadvantaged countries.[1162] Vulnerable subjects must be involved so they may speak for themselves, rather than being represented by review boards who speak for them.[1163] Review boards would thus serve as venues for vulnerable groups to gain power rather than just as procedural tools. By promoting and broadening involvement, the institutional review will become a tool for addressing inequality.[1164] As a result, participation and inclusion are strategies to combat disempowerment. As with most technological advances in healthcare, ethical challenges accompany the practice in fundamental and specific areas which hospice and palliative care are no exception. The following subsection highlights a few of these challenges that potentially can limit the modern *Ars moriendi* and prevent the art of dying well from progressing.

6.A.iii. Ethical Challenges of Technology in Hospice & Palliative Care

The development of life-sustaining technology like the ventilator, artificial nourishment, artificial hydration, and dialysis, to mention a few, has profoundly altered how we see and cope with death. These technologies have enabled people to live considerably longer, but not always with quality of life. While the practice of advanced directives and living wills has greatly helped ensure patients' wishes are respected at the end of life, many patients end up without communicating their preferences after a medical crisis. This all-too-common situation puts loved ones in fundamental topical discussions of technological futility and the technological imperative, as described in the following subsections.

6.A.iii.a. Fundamental Issues

The issues of medical futility and the technological imperative are more fundamental in nature because they can affect anyone and everyone – no matter how advanced their country's healthcare is. Every hospital in the world must deal with futility cases caused by the change in mindset of many individuals that now that the technology is available – it should always be used to do everything possible, regardless of the bigger picture or the goals of care for the patient. This subsection dives into more detail on this issue and how technology can pose just as much of a challenge as an opportunity in healthcare today.

Technological/Medical Futility

It is difficult to define what constitutes futile treatment since physicians, academics, and politicians each have a different subjective interpretation of the phrase.[1165] According to one viewpoint, therapeutic procedures that do not result in positive patient outcomes constitute medical futility.[1166] The term medical futility can also characterize "any effort to achieve a result that it is possible but that reasoning, or experience suggests is highly improbable, and that cannot be systematically produced."[1167] In contrast, holistically prolonging medical procedures might not be pointless if they help a patient's family members accept the death of a loved one by reducing their uncertainty, enhancing their wellbeing, or simply by lengthening their life.[1168] Lacking a universally accepted or legally binding definition of futility, debates over the end of life will continue to arise in medicine, politics, and ethics.[1169] Having sincere conversations with patients and their families about their desires for end-of-life care is crucial to dispel mistrust about just continuing care that medical professionals may deem pointless and promote more peaceful death experiences in light of the predicted shifts and cultural demographics in the US population. Patients' and their families' choices to transition to hospice care may be influenced by educating them about the benefits of palliative care.[1170]

Critical illnesses frequently come on suddenly and without warning, leaving no time for thoughtful deliberation or dialogue.[1171] H. Montgomery et al. note "If futile intervention or unwanted suffering is to be avoided, patients must be made fully aware of the limitations of intensive care, such that they can make decisions in advance. It is often too late when the patient is hospitalized, let alone when a sudden decline has begun: the full benefits of collaborative or shared decision-making are only realized when the conversation begins early."[1172] They can start before a crisis ever arises, when the citizen is still at home. However, humanism and compassion should be matched with options and choices.[1173]

The idea of futility has been used in the context of palliative care, even if research and pertinent literature are rare. For instance, it has been observed that relatives of patients who passed away noted futilities in 28% of the instances.[1174] The most common was unnecessary medication (21%), followed by unnecessary diagnostic examinations (19%), treatments (18%), and caring processes (17%).[1175] These unnecessary interventions caused suffering to dying patients, most frequently in hospitals (50%) and less often at home (8%).[1176] These results, of course, show that palliative treatment has not been of high quality. What is troubling about this, though, is that even "caring processes" are seen to be futile; again, it is not made clear what is meant here, and no instances are given.[1177] Insufficient communication and information are also linked to reports of futility. The idea of futility is also used in the policies and statements of organizations that provide palliative care, as when it is stated that there is no ethical requirement to discuss cardiopulmonary resuscitation with palliative care patients for whom such treatment is deemed futile, which is the case for the majority of these patients.[1178]

Technological Imperative vs. Humanizing

Many Americans believed they may be cured or that they could delay dying because of technological advancements and the rise of professional treatment in hospitals.[1179] A new technological imperative emerged, which refers to doctors using more modern technology to "do everything possible to extend the individual's life, prolonging the inevitability of death."[1180] To put it another way, intensive therapies will be used to try to prolong life.

Clinical experts in critical care must balance the use of available technology with patient requirements and expectations, as well as opinions of family, friends, caregivers, and staff, given that these are sometimes difficult to ascertain.[1181] This balance is made much more difficult when considering the patients in the expensive and resource-intensive ICU who use a lot of resources that might be used more equally throughout the hospital.[1182] In many instances, this raises the question of whether or not to act.[1183] It is crucial that the public may participate in the conversation so that society as a whole, not just healthcare experts, can decide what standards of compassion, affordability, and reason it will tolerate.[1184] Intensive treatment centers have gradually become more and more familiar to ICUs.[1185] This has been beneficial for many people since, for example, it can increase survival rates following major surgery. In other instances, though, the need for scientific solutions and the growing capability to give them may limit compassion.[1186] The practice of such excessive therapy may, in certain circumstances, teeter on the unethical when carried out by professionals whose professional ethics instruct them to "first do no harm" to the individual patient.[1187]

Intensive care specialists' first objective should be to humanize the ICU experience.[1188] We must reduce the misery we cause. H. Montgomery et al., in their article "critical care at the end of life: balancing technology with compassion and agreeing when to stop," state, "Circadian rhythm, sleep, and pleasant sight and smell should be maximized. Pain, the administration of disorienting drugs, and noise should be minimized."[1189] In order for them to comprehend the limitations of such treatment and the potential misery it may bring about, healthcare workers must also start a discourse among themselves and later with other medical experts outside the

ICU. H. Montgomery et al., in their article referring to ICU intensivists, say, “No longer should we receive referrals that state that a family or patient ‘want everything,’ when neither clinician, relative nor patient grasps what ‘everything’ really means and where it might lead, and when expectations are often unrealistic.”[1190]

6.A.iii.b. Specific Issues

The following subsection discusses specific issues that plague humanity regarding technology in healthcare. These issues are noted as specific as they do not apply everywhere in the world and are more focused on countries and areas with low socioeconomic groups and poor technological infrastructure. One issue mentioned is the concept of the digital divide, or simply put, the separation of those with access to modern technologies/the Internet/ ICTs and those without. This transitions to the next topic of how this digital divide affects the physician-patient relationship and what barriers this divide imposes on communication, satisfaction, and access to care.

Digital Divide

The digital divide emerges as a problem that requires attention when evaluating the possibilities of information technology.[1191] The term refers to “the gap in computer and Internet access between population groups segmented by income, age, education level, or other parameters.”[1192] In order to reduce this gap, a variety of projects have been started, with a particular emphasis on offering access to technology, online databases, and education. Despite the fact that lower socioeconomic groups are rapidly getting access to the Internet, as new technology become available, it is believed that the digital gap will still remain.[1193] For instance, “as sophisticated multimedia services become an integral part of Internet-based applications, broadband access may become as important for accessing healthcare sites as narrowband access is today for obtaining web-based health information."[1194] In such instance, just because of various access protocols, there may be a digital gap between two groups having PC hardware and Internet connectivity. Additionally, the digital divide has many other dimensions, with infrastructure access being only one of them. Other crucial elements include proper web content and health literacy. These issues are crucial to solving if informatics applications are to be adopted in palliative care and hospice facilities, particularly if they have the ability to be used in the homes of patients and families.[1195]

When all else is equal, impoverished Americans are less likely than wealthy Americans to have access to the information communication technology (ICT) that enables that access.[1196] "Similar gaps exist between the affluent developed and impoverished developing world. Although Internet access is increasing across the world, it is still the case that a comparatively small percentage of the developing world's poor has Internet access."[1197] According to a Statisca analysis from 2022, 63 % of people worldwide have access to the Internet, however "internet penetration in the most economically developed countries is already well above 90 %, there are still approximately 2.5 billion people around the world without access."[1198]

There is a causal link between these disparities in income and access to information and communication technologies (ICTs).[1199] Most often, those with poor socioeconomic level who are struggling to pay their expenses cannot afford Internet connection or any related training. Unfortunately, by preventing access to the opportunities, information, and resources that the Internet may offer, this vicious cycle may prolong poverty.[1200]

The argument being stated here is not whether reducing domestic and global poverty is a complex issue that will be exceedingly difficult to solve, but rather that discrepancies between the affluent and the poor are linked to the moral relevance of the digital divide as an issue that has to be addressed, as well as between extremely wealthy countries and countries that are living in utter poverty.[1201] Although it is possible to make the case that these differences are fundamentally wrong, it appears doubtful given that economic inequalities are seen as harmful more for the suffering they create than for some deontological egalitarian ideal that requires total equality of justice.[1202]

Professional-Patient Relationship

If databases, networks, and computers can improve communication between doctors and patients or between nurses and patients, we will have succeeded.[1203] “If reliance on computers impedes the abilities of health professionals to establish trust and to communicate compassionately, however, or further contributes to the dehumanization of patients, then we may have paid too dearly for our use of these machines.”[1204] Let us imagine that a healthcare professional uses a decision-support tool, which is a procedure that gives physicians, personnel, clients, or other people – in-depth information that is intelligently selected or given at precise times, for the enhancement of health[1205] to create differential diagnoses or test a diagnostic hypothesis, and that the results of that tool determine whether a certain test or therapy should be ordered.[1206] A doctor must be able to explain the extent to which computers aid in their decision-making on whether or not to intervene in a certain situation. This is essential to avoid alienating patients who could otherwise get bored, angry, or confused with the use of technology in decision-making. It is possible that a doctor would prefer to keep this information private in order to maintain patient confidence.[1207]

The procedures that make up human decision-making are not completely unknown to patients. When their physicians and nurses utilize machinery to aid sensitive cognitive activities, though, they may be deceived and lose what little understanding they do have. It is still unclear whether patients should be informed of the automated statistics' accuracy rate before they are given information on prior real-world patients' data.[1208] The question remains if this information would help or hinder the informed consent exchange, or would it just cause confusion and delay decision-making?[1209]

These kinds of questions help to ensure that the future of computers and statistics in the clinical world will be used responsibly. Unfortunately, despite numerous attempts to study whether computer use will alienate patients, the data is inconclusive.[1210] For instance, the statistics cannot predict whether all patient groups would favorably react to all the various sorts of emails that patients may get from their physicians. A healthcare provider should not, as previously noted, communicate a patient a new diagnostic status through email because of common courtesy and moral obligation. Attempting to answer the question now only would help anticipate future problems caused by technology within the patient-physician relationship. The process of obtaining informed consent must always be kept humanized, intimate, sensitive, and sympathetic. Healthcare professionals must maintain their personability during these close patient meetings and avoid becoming overwhelmed by the vast information that health informatics may supply.[1211]

6.A. Conclusion

Technology has broadly impacted the implementation and future of hospice and palliative care. While these fields have been implemented to help bring back the art of dying that has been lost in Western culture, technology can support and challenge this effort. While the location of death and dying has shifted away from home and into the hospital or similar institutions, the movement for hospice and palliative care has contributed to reintroducing the social and intimate element into end-of-life care in the home. This is supplemented by a new ethical framework for dying conditioned by a few observations and contemporary challenges that must be addressed. The chapter discussed the opportunities modern technology can provide to hospice and palliative care fields, such as improved communication with telemedicine and medical interventions. Electronic learning has opened infinite possibilities for both patients and medical experts to investigate, educate themselves about, and get assistance for the illnesses that impact them. The Internet provides a base for an interconnected web of participation in an ongoing learning process about health and healthcare. It will continue to expand such knowledge as time and technology progress.

The chapter continues with a highlight of some of the ethical challenges that are posed by such technology, as there are two sides to every coin. Fundamental issues are described, such as technological or medical futility with life-sustaining technology and the debate about the technological imperative to ‘do everything possible' to keep people alive at all costs vs. the dehumanizing of the patient with all the machinery. The section then concludes with detail of some of the more specific issues that technology has caused in the broader healthcare context, such as the digital divide that explains the socioeconomic gap that is further spread between the poor and rich by the continual upgrading and use of technology in society and the health literacy that goes along with it. Also, technology can strain trust in the professional-patient relationship, in which sometimes clinical decision support systems can lead a professional to withhold information deemed futile, which puts a strain on trust in the relationship when trust is of the utmost importance in end-of-life care conversations. Overall, technology significantly impacts how healthcare is run and maintained, including in hospice and palliative care. Technology provides both opportunity and challenge, and the ethics of all of it should be assessed, so humanity does not blindly put all the faith into it and lose the sense of humanity and personal caregiving that was once so prevalent in the art of dying well. The next section of the chapter tackles this issue in the form of care robots that are increasingly used to care for the growing aging population. Care ethics provides a framework to design these robots so that we don't lose that sense of humanity and preserve the art of dying well for years to come.

6.B. Ethical Considerations of Using Care Robots in Aging Populations

6.B. Introduction

With a growing number of elderly people in need of assistance worldwide, accompanied by a decrease in available caregivers – there is a shortage of epidemic proportions in elderly care. However, recent advances in robotics and assistive technologies provide an opportunity to address the deficit with the use of robots in caring for the elderly and aging populations. This mechanization of care work has already been going on for several years in many countries, but are ethics being considered in the design and implementation of these 'carebots?' This section investigates the question: what are the ethical considerations in designing robots used in caring for elderly and aging populations?

In answering this question, we start with the importance of the design of the robots using the foundational concepts of care ethics – specifically those related to elder care, such as relational autonomy and dignity-enhancing care. The section then moves to a more philosophical discussion about which virtues and values are essential to instill and whether it is possible to have an artificial morality within machines. If so, what would a framework look like for an ethical evolution of these care robots? Finally, ethical challenges are posed when using a care-centered framework, such as implementing human capabilities in care robots, giving the robots context sensitivity, and the whole issue of deception in the care provided by these robots. Care robots and other assistive technologies have enormous potential to enhance the lives of the elderly by helping to open up human caregiver availability, reducing dependence on others, and much more – so long as they are designed carefully and ethically.

6.B.i. The Mechanization of Care Work

6.B.i.a. Scope of the Aging Population

The World Health Organization reports a fast-growing disparity between the number of elderly people who require care and the shrinking pool of caretakers.[1212] For instance, in the UK, it was anticipated that between 2015 and 2020, the general population's population of persons over 65 would rise by 12% (1.1 million), that of those over 85 by 18% (300,000), and that of people over 100 by 40%. (7,000).[1213] By 2020, it was anticipated that there would be more people 65 and older than children under five worldwide.[1214] A long-term trend that started in Europe a few decades ago is population aging. As the number of persons aged 65 and older rises throughout the EU, people are living longer and having fewer children per couple.[1215]

Only 50% of people over 65 said their health was "very good" or "good," compared to 88% of the rest of the population, according to the 2011 UK census.[1216] According to the same census, 56%, or 5.2 million people aged 65 and older, were married, up from 52% (4.3 million) in 2001.[1217] The percentage of married couples climbed from 51 to 54%, while the number of couples who are cohabiting nearly doubled from 1.6 to 2.8%.[1218] The statistics relating to marriage rates are of particular note because these couples are less likely to need elderly care as many couples will take care of and support each other in old age. The percentage of people 65 and older who were living alone fell from 34% in 2001 to almost a third (31%) in 2011.[1219] As a result, welfare states must pay escalating maintenance and social assistance expenses for senior citizens who are unable to live independently.

The senior population in the United States will increase significantly between 2012 and 2050. The number of people 65 and older is expected to increase to 83.7 million by 2050, nearly double the forecast number of 43.1 million in 2012.[1220] Since they started reaching 65 in 2011, the baby boomers are mostly to account for this rise in the senior population. The remaining baby boomers will be older than 85 by 2050.[1221] The population is anticipated to age significantly, as this section's goal describes. According to projections, by 2030, more than 20% of Americans would be 65 or older, up from 13% in 2010 and 9.8% in 1970.[1222]

We shall see a global shortage of care professionals due to the aging population that is rapidly expanding. There is currently a shortage of senior care in several nations, notably Japan. Japan's population is aging quickly as a result of its low birth rate and high life expectancy, with 22% of people over 65 in 2009 and a forecast increase to 34% by 2035.[1223] Numerous institutions including elderly care facilities, the Japanese government, and Japanese families are working together to find a solution to the lack of care specialists that have the knowledge and skill to assist in the continuous care of the elderly.[1224] Jennifer Parks notes, "Japan has responded to this problem by developing technologies to assist with some of the care demands, such as machines to bathe nursing home residents, machines and robots that use surveillance technology to monitor the vital signs and condition of elderly persons, or even robots that can act as companions for the many demented, lonely, and isolated elderly citizens."[1225] According to Motoki Korenaga, a representative of the Japanese Ministry of Trade and Industry, in March 2009: "Japan wants to become an advanced country in the area of addressing the aging society with the use of robots."[1226] His remarks also mentioned intentions for the quick preparation of safety regulations for robot nurses who would likely take care of senior patients over the next five years.[1227] In preparation for the impending age boom, Germany has also created robots for caregiving. According to the German federal statistics office, 85 out of every 100 Germans between the ages of 20 and 60 in the next 40 years will be elderly people.[1228]

6.B.i.b. Elderly Care Needs

The concept of assistive technologies casts a wide net to define these as “user-oriented technologies aiming to provide or assist users with public or private welfare services.”[1229] These “welfare technologies” assist citizen participation in society.[1230] This can include assistance in daily activities, security, self-reliance, and other various forms of participation.[1231] Assistive technologies are grouped into four different ways of providing support: “1) safety and security, e.g., the safety alarm service, 2) compensation and wellness, e.g., memory support, walker, light/heating control, 3) social contact, e.g., video communication, and 4) care and treatment, e.g., blood glucose meter, blood pressure monitor.”[1232] The technologies aim to enhance a person's weakened abilities (like glasses and arm-grasping forceps) or replace lost capabilities (such as a wheelchair or hearing aid).[1233]

When the patient is elderly and cannot fully be independent, healthcare services can enter their home and bring tools and technologies that assist in enabling a more independent lifestyle. These various technologies take over the tasks traditionally completed by humans, such as replacing the manual medication dispenser with a digital one that can remind its user and their provider to take daily medications. Bratteteig and Wagner have noted that society requires more “work to make home care work,” in other words, more effort is needed to progress the tools and technology that enable independent living for elderly adults such that these technologies still require fine-tuning from both the care receiving and providing ends.[1234] Woll and Bratteteig also emphasize that since these technologies change the caretaking process, it affects the relationships of all those involved: the caregivers and receivers, family, friends, and providers.[1235] This take supports their view that desires to put elderly care into a larger context that uses “an elderly-centered way of organizing elderly care.”[1236]

At this point, it is helpful to make a distinction between active and passive uses of technology. The distinguishing factor is that levels of automation can differ in the design of the technologies to support users with a wide spectrum of disabilities.[1237] Woll and Bratteteig argue in another article that “fully automated technology can give users full autonomy, and there is no one-to-one relationship between the level of automation and the user’s autonomy.”[1238] The active use of technology requires conscious interaction with technology for a specific purpose, such as using a lift chair or taking pills from a digital medication dispenser. Such actions would need a necessary understanding of how the technology works and the ability to perform the actions to operate it accurately. This active use of technology is different from passive such that passive, as the name suggests, requires no conscious interaction of the user. The most prominent example of this is a fall alarm automatically triggering activation when the user has an accident and alerts others to give assistance to the user and help them up. These circumstances have the user engaging with the technology without understanding the exact method of operation. Mao et al. give a few more examples of passive-use technologies, such as “shower nozzles/water faucets that provide a constant temperature in the bathing/shower water, infrared water tap flow control, or automatic refrigerator door closer, to mention a few.”[1239]

The passive use of technology creates a unique space for elderly users who may not be able to understand modern-day operations and interactions of technology that may seem abstract or foreign.[1240] Nursing homes may be one of the first places to benefit from such technologies as dementia prevalence will be highest there, and passive technology could significantly support the users in their daily activities there.[1241] People who have been affected by severe cognitive impairments, like dementia, are highly susceptible to struggling in the active use of technology. The example Woll and Bratteteig give describes a situation where a cognitively impaired person falls and does not know or remember that they have the ability to call for help by pushing the alarm button located on a device that they wear around their neck or wrist.[1242] In addition, the fallen user may not want to be a burden to ask for help from other human caregivers, inconveniencing someone else. Hence, these users need an alternative to active-use technologies that can accommodate their increased needs in the healthcare landscape. This is where care robots have become significant in elder care.

6.B.i.c. Rise of Care Robots

There is a quickly rising view that care robots are the key technological invention to answer the growing elderly caregiver/receiver gap. Care robots can be programmed to be partly or fully self-governed. These robots have the ability to support both caregivers and care-receivers with various physical needs. Bedaf, Geldernlom, & de Witte give examples of "My Spoon Robot can aid someone with eating problems, and the Sanyo Bath Robot provides hygienic care to older adults."[1243] While some other robots act as more of a social support to the user, such as the seal-like robot Paro or the dog-like robot AIBO.[1244] Yet, other care robots exist that utilize both assistive and social functionalities. They assist in social interaction, such as Robovie and Pearl robots.[1245] "Pearl is an autonomous robot able to follow patients around, communicate via a touch screen display, and serve as a telepresence device."[1246] Robovie was created to interact with people and is outfitted with a variety of tactile and vision sensors, microphones, and motors that "facilitate interactive meaningful behavior" via robotic arms, eyes, and head.[1247]

According to Vallor, "carebots are robots designed for use in home, hospital, or other settings to assist in, support, or provide care for sick, disabled, young, elderly, or otherwise vulnerable persons."[1248] Amanda and Noel Sharkey provide a helpful description to differentiate between the functionality of carebots: "performing or providing assistance in caregiving tasks; monitoring the health or behavioral status of those receiving care or the provision of care by caregivers; and providing companionship to those under care."[1249]

Aimee van Wynsberghe mentions that no specific capability can be attributed to all care robots. However, they do have a wide variety of abilities, such as motion and types of recognition, including face, voice, and even emotion.[1250] In addition, these care robots have various levels of autonomy, beginning with entirely human-controlled surgical robots (i.e., the da Vinci machine), advancing to TUG (a hospital delivery robot) and RIBA (a robot that lifts patients without human input).[1251] Therefore, a care robot "relies on the idea of *interpretive flexibility*, that a robot is defined by its context, users, and task for use."[1252] In other words, depending on its current functionality, the same robot could go by two different names – each specific to its current task. Wynsberghe gives the example of HAL, or the Hybrid Assistive Limb, to demonstrate how the limb can be used for rehabilitation and care purposes depending on whether it's worn by the patient or used by the nurse to help lift a patient.[1253]

An example of research embedded in the broader robotics research program is the "Acceptable robotiCs COMPanions for AgiNg Years" acronym ACCOMPANY. ACCOMPANY aims to develop:

> a robotic companion as part of an intelligent environment, providing services to elderly users in a motivating and socially acceptable manner to facilitate independent living at home... providing physical, cognitive and social assistance in the everyday home tasks, and ... contributing to the re-enablement of the user, i.e., assist the user in being able to carry out certain tasks on his/her own.[1254]

Amirabdollahian et al. explain that the ACCOMPANY system can operate independently in a smart home while "co-learning" with the user in addition to being mobile and having an operating arm.[1255] They go on to say that the target demographic for the ACCOMPANY system are elderly individuals living by themselves at home whose physical and mental abilities are declining – limiting their independence at home.[1256] ACCOMPANY is just one response of many to addressing the rising number of older persons who need help with daily tasks. This system simultaneously attempts to offer an economically reasonable solution to provide adequate care to this in-need population. [1257]

Before the general public has access to really reasonable, secure, and useful care robots for institutional or general consumer usage, still more work has to be done. The advancement of care robots will certainly continue considering the serious imbalance of caregivers and care recipients in addition to the capitalist mentality to continue creating new technologies that become available for commercial retail.[1258] Carebot designers and developers may easily inflate the future role of these technologies to help promote their products. The direction the designers are heading in is clear – as stated on the RIBA's temporary marketing website(the robot that lifts patients without human input): “There might come a time when robots will replace human caregivers. An impossible vision it may seem, but do not be too surprised about human caregivers being assisted by robots in the near future.”[1259]

6.B.ii. Designing Robots Using Care Ethics

6.B.ii.a. Defining Care Ethics & The Value of Care

Care ethics offers a unique and different approach to bioethical issues from many other well-known methods such as principalism, virtue ethics, deontology, and consequentialism, to name a few. The normative questions these various approaches attempt to answer are all relatively the same: What criteria should we use to judge people's moral behavior? How do we proceed? Which behaviors are morally required? Care ethics tries to answer these questions while considering care – in all its aspects – to be of significant ethical value.

In a Different Voice, written by Carol Gilligan and initially released in 1982, helped the foundations of an ethics of care take off. As a developmental psychologist, Gilligan described psychological and empirical findings that focused on girls' development in their morality as opposed to boys.[1260] Gilligan deduced that there is a significant difference or a "different voice" in how males and females view moral issues. Specifically, females are more focused on interpersonal relationships and are more swayed in their decisions by emotions of love or hate, whereas males value independence and abstract rules of behavior.[1261] Gilligan asserted that "although only some women studied adopted this different voice, almost no men did."[1262] In a subsequent piece, she said, "this meant that if women were eliminated from the research sample, care focus in moral reasoning would virtually disappear."[1263]

In her book *Moral Boundaries*, Joan Tronto outlines the four components of care, which serve as an excellent place to start for describing certain aspects of a care ethic. The four elements of care are: "caring about, noticing the need to care in the first place; taking care of, assuming responsibility for care; caregiving, the actual work of care that needs to be done; and care-receiving, the response of that which is cared for to the care."[1264] Four ethical principles of care "attentiveness, responsibility, competence, and responsiveness" come from these four components of care.[1265]

A comprehensive study of moral action is provided by the ethical perspective known as care ethics. It examines this behavior in the context of particular care partnerships. Care ethics are marked by this "contextual and relational sensitivity."[1266] As a result, care ethics continue to be tightly tied to real caregiving activities and carefully consider how caregiving obligation manifests: “the contextual elements, the typical character of a situation, the way people collaborate, and the emotions involved.”[1267] Care ethics runs the actual risk of emphasizing process-related components at the expense of content that is value-loaded by concentrating on specific contextual and relational features. The duty lacks a normative reference if care ethics really restricts itself to the "pure reconstruction of an actual care situation," such as who assumes total accountability for the care and all its aspects, without consulting any standards or values to judge if this treatment is suitable.[1268]

6.B.ii.b. Relational Autonomy in Elder Care

Over the past few decades, autonomy has become a more important value as healthcare has shifted away from the paternalistic patient-physician relationship.[1269] This is seen as a general improvement in healthcare. However, regarding older adults, especially those with cognitive impairments like dementia, “the privileging of autonomy has caused tremendous difficulties because of competency issues.”[1270] Too often, the mistake is made that we assume elderly individuals lack decision-making capacity. Hence, family members or healthcare professionals use their personal preferences to make decisions for the elderly individual.[1271] We must stop imposing our own beliefs, values, and preferences on others and allow them to have their wishes expressed in the care process. Absent of any bad intentions, decision makers often make their choices with the patient’s best interest at heart. Regardless, several points must be mentioned in this situation.

Despite the best intentions, oftentimes denying a person their autonomy is generally harmful.[1272] Robert Stewart notes that family members or healthcare professionals often override the elder’s autonomy too quickly because they believe the elder is deemed to lack decision-making capacity even before a proper evaluation has been performed, which ultimately dehumanizes the elder.[1273] Also, there are numerous ways to conceptualize autonomy – certain ways are better than others in managing dementia patients. The essential nature of autonomy is the capacity to self-legislate or act independently of others utilizing reason as a compass.[1274] The "independence" and "rationality" elements of autonomy provide challenges for the elderly, particularly those with dementia.[1275] However, these qualities are less important in other conceptions of autonomy. Particularly, relational autonomy has been supported by care ethics.[1276]

Care ethicists have proposed that the popular conception of autonomy is predominately male-centered, based on some empirical research first conducted by Carol Gilligan.[1277] Males and females differ in their values when it comes to relationships and emotional ties, where males place more significance on independence and abstract concepts.[1278] Because our relationships with others play a role in defining who we are as people, Gilligan and others have claimed that these relationships and the emotions that surround them must be taken into account while making decisions.[1279] Therefore, we should consider autonomy in regards of our interactions with others.[1280]

The idea of autonomy that underlies the traditional healthcare ethic, which is based on an individualistic view of man, is rejected by the ethics of care.[1281] This idea of autonomy disregards each person's ties to and reliance on their social environment. It ignores the social contexts in which these characteristics are important and instead defines autonomy as "rationality, individuality, and self-determination."[1282] According to Virginia Held,

> The ethics of care usually works with a conception of persons as relational, rather than as the self-sufficient independent individuals of the dominant moral theories. The dominant theories can be interpreted as importing into moral theory a concept of the person developed primarily for liberal, political and economic theory, seeing the person as a rational, autonomous agent, or a self-interested individual.[1283]

In order to care for persons with chronic diseases, we need a relational definition of autonomy based on a social perspective of man, one that pays attention to the connections in which the individual sees himself or herself. Only in a relationship that enables them to establish their identity and learn to manage their sickness can people with a chronic illness who have been reliant on outside care experience their independence.[1284] A conceptualization of care that excludes all individual values and attitudes is incompatible with this process.[1285]

Responding to the person's vulnerability by family caregivers and professional caregivers is a requirement for integrating dependency and autonomy in elderly dementia care.[1286] Sensitivity and empathy are crucial qualities in care ethics, however, because caring also includes a cognitive component, this does not limit ethics to only an emotional reaction.[1287] Professional understanding of care ethics, which include competence, responsiveness, attention, and accountability in addition to being devoted, involved, and active in the caring process, is necessary to provide effective care for others.[1288] The act of caring requires more than just making the proper choice at a given time; it is a dynamic and continuing process. It necessitates constant participation and decision-making.[1289]

When we think of people as relational, it does not follow that we are unable to oppose the many social ties we were raised in or find ourselves in, or to modify whatever relationships we do have.[1290] However, it frequently calls on us to do so. According to the ethics of care, we should take these decisions into account as they relate to the relationships that shape who we are.[1291] We constantly change our relationships with others – some are maintained, some are ended, and some are created. Yet, as noted in the contractual model, we don’t view these as choices of people acting as though social ties did not exist before making them.[1292] Interestingly, moral agents are inspired by the ethics of care, and while having relationships with other individuals, these moral agents can still be free.[1293] When necessary, the ethics of care seeks to encourage the cared-for person's responsible autonomy. Care ethics needs us to focus on autonomy's physical, mental, and emotional requirements.[1294] Because autonomy is exerted within relationships rather than by abstract, autonomous, free, and equal persons, those lacking certain resources cannot be autonomous in a way that is effective.[1295] In a related sense, human dignity and vulnerability of the elderly can provide a normative foundation for care and care ethics as described in the following subsection.

6.B.ii.c. Human Dignity and Vulnerability of the Elderly

According to Vanlaere and Gastmans, “a person is more than just the sum of rational capacities (like the capacity to think) and powers (such as the power for verbal communication).”[1296] This includes people who lack these capacities and self-awareness. As a result, the body plays a key role in a person being a subject. Janssens notes “that the person’s being a subject manifests itself in the most unique, but in a sense, also the most vulnerable aspect of our being, that is to say our corporality.”[1297] People may get ill physically and mentally, which is a recurrent theme that can be found precisely in our bodily susceptibility. In the journal article “A personalist approach to care ethics,” theologian Paul Valadier mentions the human being's bodily frailty as the foundation of caring by saying, “respect and care for the distorted human nature are aroused by the undignified state in which sick or injured persons find themselves.”[1298] Being unwell is at the core, perhaps more so than susceptibility as the potential for disease. In the article, using the Good Samaritan tale as an example, Valadier demonstrates that the robbed traveler's damaged body seems to be more than simply a body throughout their interaction, and he says that "the body reveals itself as worthy of respect."[1299]

Care begins where a person is lacking in abilities, physical prowess, and mental capacity. Creating dignity is the goal of the compassionate connection between the sufferer and the caretaker.[1300] Therefore, both the one providing the care and the person receiving it develop dignity. Valadier continues, “Dignity manifests itself in the act that makes us focus on the other so that we consider him or her as a person, even if it assumes an appearance of not being human, or even being inhuman.”[1301] Individuals are interested in one another, and at the heart of this interest is being a person. Since everyone is aware of how important one another is, this suggests that people depend on one another in order to be who they are.[1302]

It is clear from the concept of personalism that caring commitments between persons cannot only be viewed as “being rational and symmetrical.”[1303] Care must be defined within this critical duty to the other's vulnerability. Care requires another person to be vulnerable in some form (physically, mentally, or emotionally), it is within the recognition of this duty to act in caring for another that human dignity is respected. The creation of dignity occurs through the care of the body. Care is not based on logical reasoning but rather respecting the dignity of others and the fact that one sees the other as a person despite the other's undignified look.[1304] Margaret Urban Walker in her book, *Moral Understandings: A Feminist Study in Ethics,* defines care as "a practice of responsibility in which the different persons involved take responsibility in the process of reacting to vulnerability."[1305] Her definition parallels the view of vulnerability described by Vanlaere and Gastmans in that her view of care also requires a commitment to the other’s vulnerability and so by extension respects the dignity of others as well. Care appears to be how others relate to people, and this is especially true for those who have limited talents and powers (such as the mentally impaired and those who suffer from severe dementia).[1306] The

Good Samaritan parable was presented earlier as an example of how this treatment might frequently be portrayed while taking care of the body physically.

The essential concepts of care ethics, relational autonomy, personalism, and human dignity must be core to the design of robots for caring for and assisting the vulnerable elderly population. Lacking the foundational concepts or context of care, robot designers do not have the necessary background to program the value of care into a test care robot. While this section only provides a brief of what these concepts entail, it nonetheless provides a starting point from which designers and engineers can work and continue to research and expand their knowledge and implementation of care ethics within the programming of the carebots.

Virtues and Values of Care Robots

Given that the International Organization for Standardization has not yet provided any guidelines for these kinds of robots, there is now a potential to include ethics into the actual construction processes.[1307] Accordingly, "one must first identify the moral precepts of significance followed by an account as to how to operationalize said precepts" if robot design is to take ethics into consideration.[1308] In their arguments regarding how care robots will ultimately replace human caregivers, several care-ethicists also emphasize the benefits inherent to care practices.[1309] These beneficial outcomes are produced for both parties by the morality of the caregiving process involving human carers and care recipients. Consider the reciprocal nature of virtues like kindness, empathy, openness, dignity, and attentiveness.[1310] The question of what will happen to these internal goods emerges because numerous authors deny the idea that care robots have a reciprocal dimension unless they do so fraudulently through deceit (more detail on this later).[1311]

Two moral traits that are fundamental—reciprocity and empathy—may, in some ways, be developed through caring activities.[1312] These are by no means the only significant moral virtues fostered in caring procedures. Shannon Vallor argues that they highlight two crucial points: "(1) that there are important goods for *caregivers* that are internal to caregiving practices, and that (2) the potential on these from the widespread use of carebots merits our careful attention."[1313] Following Mark Coeckelbergh's robo-ethics, which focuses on the ethical behavior robots should develop, informs us that we may want to give more critical thought and delay giving some of these traits to carebots.[1314]

The first of the two moral virtues to be discussed is reciprocity that may be described as a "primitive biological impulse which functions as the seed of human sociality, is the unifying feature of all forms of friendship and, with proper moral and cognitive/perceptual habituation, matures into a social virtue."[1315] According to the idea of personalism, people are inherently or naturally inclined to care for other people. Being a decent person is having the capacity to reciprocate appropriately, in the appropriate ways, at the proper intervals, and as suitable for certain situations and individuals.[1316] However, reciprocity is a virtue that we must cultivate since it is not only a natural disposition.[1317] One of the most fundamental virtues is reciprocity, which is necessary for producing and maintaining the basic necessities for the flourishing of human life.[1318] This might also imply that we have a moral obligation to alter both the societal structures that promote reciprocity as a virtue and those that work against it.[1319] If this is the case, it is even more important to think about how the introduction of carebots can affect the development of reciprocity in humans.

Vallor defines empathy as "an emotive/perceptual capacity that, like reciprocity, develops in most humans from a basic biological impulse, expresses itself fully in the highest forms of friendship, and, when properly cultivated and expressed, constitutes a virtue."[1320] Empathy is the emotional and perceptual ability to share the pleasures and sorrows of another sentient person in a meaningful way.[1321] When developed as a virtue, it takes the form of the capacity to receive these emotions in the right relationships and situations and to respond to the other in a way that is as highly tuned to and suitable to these details.[1322] We will create problems for individuals with whom we sympathize, especially when it comes to caring relationships. When we practice caring, we put ourselves through the pain of observing, experiencing, and reacting to another's suffering in a manner that is appropriate.[1323] Sparrow & Sparrow emphasize the need of empathy in caring as a way to demonstrate how carebots cannot replace human carers, saying that "entities which do not understand the facts about human experience and mortality that make tears appropriate will be unable to fulfill this caring role."[1324]

In order for empathy to persist and flourish rather than wither on the vine, it must be carefully and fully intentionally fostered, much like reciprocity. As a result, while considering the moral consequences of robotic care, these components should always be taken into consideration. If the ease of using robots for care tempts us to give up caring behaviors before we have an opportunity to mature and acquire qualities like empathy and reciprocity (among many others), that might irreparably harm society and its morality.[1325] However, if carebots offer kinds of limited support that encourage us to engage in caring activities, allowing us to feel and give more without having to worry about crushing pressures, the moral impact on carers' character may be quite favorable.[1326] Imbuing carebots with these various moral virtues, such as empathy and reciprocity, brings us to the concept of artificial morality, which describes in more detail some of the ethical and philosophical questions that arise in the processes of picking and choosing which virtues and attributes should be programmed into the carebots.

Artificial Morality

Robotics, AI, and assistive technology are all developing fields that deal with artificial morality. Simulating or modeling human cognitive skills is the goal of artificial intelligence. The study of whether and how artificial systems may be given moral capabilities is known as artificial morality.[1327] Another expanding area for the use of artificial morality is elderly care. The idea is to use morally capable autonomous artificial systems for domestic care, helping to address the previously mentioned demographic care shortfall.[1328] Examples of situations requiring moral judgment in this setting include: What is the ideal frequency and level of intrusiveness for a care system to remind somebody to nourish themselves or receive treatment? If someone has not been moving for a time, should it be reported to the family or a medical service? If yes, how long should they be left alone? Should the system continuously watch the user, and how should it use the information gathered? In this situation, individuality, confidentiality, physical wellbeing, and family interests are ethically significant.[1329]

Artificial morality "takes place between the triad of artificial systems, designers and users where each factor contributes to its own."[1330] In other words, the moral dilemmas that these technologies will face will get more complex as they become more intelligent and autonomous. The benefits and drawbacks of artificial morality must both be taken into account. Determining each agent's contribution and outlining the effects of moral agency and responsibility are two of the most significant difficulties when discussing artificial morality. This is vital to determine whether or not we, as people and as a community, want artificial systems to be capable of morality.[1331]

One of the key issues in artificial morality is the question of whether artificial systems may be regarded as moral agents. However, two more questions are raised by this point. The first is about agency in general. Clarification of the conditions that must be satisfied for anything to be regarded as a moral agent is required, as is proof that at minimum a few artificial systems satisfy these conditions.[1332] The second and third problems, respectively, are what constitutes a moral agent and if artificial systems may be both moral and mere agents. Misselhorn denotes two dimensions required for agency in philosophy "the first dimension, or gradual characteristic of a moral agent, involves the idea that agents are self-originating sources of their doings."[1333] Moral agents are always responsible for their actions. Another way of looking at that is by saying external factors may not determine the agent's actions, nor are they under the agent's control. "The second dimension that being an agent involves is the capacity to act for reasons."[1334] Let us imagine that a robot or other system possesses representational states that perform the same function for it that the equivalent mental states do for humans. In such case, the system may be considered to be functionally equivalent to a human agent. They have the capacity to make and carry out plans. This may be sufficient to state that these systems are operating rationally.[1335]

The second worry is whether or not artificial systems now have the ability to behave morally. If an artificial agent is a "self-originating source of behavior" and its motivations are moral, then it may be said to be moral in the most basic sense.[1336] There are other information processing systems that force systematic change if it is not working ethically, there must be states showing that it is functionally similar to moral beliefs and pro-attitudes.[1337] One must be mindful that an artificial system's presentation of a primitive type of moral agency does not equal the full moral agency exercised by humans.[1338] This is partly because AI systems' moral competence is restricted to certain sectors. Human morality, on the other hand, may be used in any circumstance and has a far larger range of applications. Full moral agency, as granted to humans, also comprises a range of distinct intentional beliefs, phenomenal awareness, free will, and the capacity to submit moral behaviors to analysis and reasoning.[1339]

Framework for Ethical Evaluation of Robots

A framework for the ethical assessment of care robots must take into account the particular context of usage, the individual requirements of users, the jobs the robot will do, as well as the robot's technological capabilities.[1340] Future care robots will need an ethical design framework as a tool, going further than merely a retrospective review of robots.[1341] The rights of the person, the unique requirements of a certain demography of care recipients, or the impact particular to the caregiver are some of the viewpoints from which authors debate ethics and robotics.[1342]

Three dimensions could be described when the ethics of robots are mentioned: “First, the ethical systems built into robots; second, the ethical systems of people who design robots; and third, the ethics of how people treat robots.”[1343] Given that robots are socio-technical systems, might lead one to believe that a framework for treating them ethically should take into consideration all three factors.[1344] The paradigm created in this chapter incorporates care-based ethical analysis into a care robot's construction. The framework intends to foster ethical thought from the standpoint of care ethics tradition and to inspire designers' and engineers' ethical thinking, and to clarify the relationship between a care robot's technical components and the ideals that are finally reflected in a care practice.[1345]

These three dimensions are addressed with the value-sensitive design (VSD), which also concentrates on the framework's objective. Value-sensitive design is “a theoretically grounded approach to the design of technology that accounts for human values in a principled and comprehensive manner throughout the design process.”[1346] The idea that technologies represent values serves as the foundation for value-sensitive design, which also provides a viable way for assessing the present state of technology design during the course of the planning and execution process.[1347] The argument that software and computer systems are ethically neutral and rely on the user to gain moral importance is refuted by this viewpoint. It is currently possible to predict whether a computer system would favor specific moral standards and ideals.[1348]

VSD is used to develop a specific system or object, however its usage in this context aims to establish a generic framework that designers and ethicists may use to assess any care robot's ethical performance or to include ethics into the any care robot's construction.[1349] Coeckelbergh notes, "The VSD blueprint is used to create a framework that examines the connection between technological capabilities and design in order to build care robots with the particular context of their usage, purpose, and clients in mind."[1350] The framework's versatility to be used to current and upcoming care robot designs is one of its main advantages. Designers can understand how their work will affect the care being provided by using previous designs as a guide. The framework may be used to future projects, which by default integrates ethics into the design process.[1351]

6.B.iii. Ethical Challenges of a Care-Centered Framework

A few ethical challenges accompany the implementation of a care-centered framework for care robots. In order to assess the ethical implications of carebots, the capabilities approach's initial problem depends on human capacities. The integration of a context-sensitive method into the care robot design is the second obstacle. Each poses a set of moral difficulties surrounding the design and implementation of the carebots – but these questions must be answered if the process is to move forward so that ethics is designed from the start – not as an afterthought.

6.B.iii.a. Human Capabilities

Capabilities approaches, "rooted in the economic and political philosophies presuppose that conditions of justice require attention to more than just the availability and social distribution of various external goods, resources, or utilities."[1352] Instead, considering justice necessitates paying attention to fundamental human capacities and/or functionings, which are seen as benefits achieved in daily life through particular types of actions and routines.[1353] The needs of justice necessitate that we not forgo these skills' development by people solely to maximize aggregate utility, since their realization is essential to human flourishing. The capacities approach may be used more generally in the framework of ethics to help in conceiving the good life and the ways in which it may be fulfilled, despite the fact that it was established to address shortcomings in other notions of justice (such as utilitarianism and Rawls).[1354]

When analyzing the ethical implications of carebots, philosophers employ capabilities approaches. Borenstein and Pearson give an example of how caregiver moral responsibilities could be met with the help of carebots without compromising their emotional well-being which could undermine their capacity for love, fun, or friendship as human beings.[1355] The capabilities method also aids in identifying inappropriate uses for carebots, such as robbing carers or those being cared for of control over their surroundings.[1356] Consider a carebot that restricted residents of nursing homes' movements in order to lessen the risk of a fall, protecting their physical health at the cost of social isolation and loss of autonomy. The capabilities approach is another example Coeckelbergh uses to illustrate how to think ethically about carebots.[1357] Although he does not think the capabilities approach addresses all of the ethical issues that carebots bring up, he does advise using it as one method to determine if a particular kind of caring meets the criteria for good care.[1358]

Vallor has suggested that we “employ the capabilities approach in one further respect: to help us to conceptualize the goods internal to caring practices for caregivers, goods that might be lost should a person choose to surrender some or all of such practices to carebot.”[1359] The benefits inherent in caring behaviors might be included into each of the ten fundamental human capacities that Nussbaum listed in *Frontiers of Justice*.[1360] However, in this section, we will concentrate on only three of them: affiliation, practical reason, and emotion, each of which indicates improved abilities for carers in the objective of providing care.[1361] Nussbaum defines these as “Affiliation: being able to live with and towards others, to recognize and show concern for other human beings, to engage in various forms of social interaction; to be able to imagine the situation of another.”[1362] “Practical reason: being able to form a conception of the good and to engage in critical reflection about the planning of one’s life.”[1363] “Emotions: being able to have attachments to things and people outside ourselves...”[1364]

These human capabilities are to be used as qualification benchmarks to determine and judge the use of robotic assistive technology in the healthcare sector. Human dignity should be enriched and promoted through good and reasonable care and thus necessitates that the aforementioned human capabilities are standards that should be met with or without technology in healthcare.[1365] In this circumstance, the capabilities include care-ethical dimensions that have been discussed and others that positively affect good care. However, there is a possibility that for certain capabilities and care tasks, care robots and assistive technologies cannot provide them as well as human beings. This should be determined by each circumstance separately, as a society should not reject the use of care robots outright. Therefore, in some care situations and capacities, care robots and assistive technologies may replace care given by humans. Still, in other cases and capacities, they may only be able to assist and not replace human care.[1366]

6.B.iii.b. Context-Sensitive Process

Lacking the foundational concepts or context of care, robot designers do not have the necessary background to program the ability of context-sensitivity into a test care robot. Fieldwork experience in both nursing homes and hospitals is necessary to fully understand the special significance of these concepts in context. For instance, safety in a dementia unit can include keeping patients from wandering outside or keeping them from injuring both themselves and other people. Safety in a nursing home ward often refers to keeping patients from falling or helping them eat so they do not choke. The setting, individual experiences, and particular practice all influence how value is prioritized.[1367] For instance, by lifting, the value of safety is demonstrated by preventing the care recipient from falling or becoming hurt. Safety is of utmost concern in this situation. Contrarily, bathing safety is decided by the water's temperature (ensuring that the patient will not be burned or scalded) and the patient's right placement to minimize risk. While safety is always a top priority when taking a bath, other considerations come first.[1368] For instance, drawing the curtain to offer privacy, speaking to the care recipient to soothe them, and using delicate strokes to show them respect and understanding. These instances highlight the interconnectedness of care values and the value of therapeutic relationships, where the fundamental principles of healthcare are viewed in the context of the relationship.[1369]

The context of the care practice must be determined, as was previously indicated. Consider a particular hospital's ward as opposed to a nursing home or a home environment. Numerous factors contribute to the environment in which the care is provided is important. According to recent research, one's approval of utilizing robots to provide care is correlated with their religious views.[1370] It has been suggested that those who believe in "a god" would not be as open to accepting close human-robot intimacy.[1371] Thereby, negating all the time, effort, and resources used to design, build, and test carebots in various settings. It is necessary to do further study to ascertain if and to what degree religious convictions might be detrimental to the acceptance of care robots. Hopefully, in an effort to not waste any time and energy on their prototypes, designers of the robots would not deceive any elderly person to thinking they are interacting with human when it is really a care robot. The final challenge this subsection will discuss is deception of the elderly when it comes to the use and implementation of care robots.

6.B.iii.c. Deception

There may still be problems with deception in the provision of senior care despite the use of technology, but these issues will likely be at the level of actual care in relationships between caregivers and care recipients rather than being a direct result of using technology.[1372] Philosophically, the issue may be defined as needing to make a decision between a responsibility to respect the autonomy of individuals and a consequentialist obligation to occasionally lie for the benefit of an individual.[1373] However, should these moral intuitions even be characterized as possibilities or as a dilemma? In actuality, both should be balanced and blended while providing care for the elderly.[1374] On the one hand, carers work to uphold the dignity and autonomy of those they care for. Empirically, not all elderly people are entirely autonomous, though. For instance, they could suffer from cognitive difficulties.

Care procedures must take into account this extraordinary factual reality, be sensitive to the challenges that seniors experience, and assist and care for them.[1375] For instance, if interacting with a robot enhances that person's quality of life, elder care may involve assisting a cognitively challenged person with tasks they are unable to perform on their own. The former, of course, should not be taken for granted. Important here is the word "if" - the caregiver needs to evaluate this, though. Deception may thus be used in routine medical procedures. Coeckelbergh stresses “The deontological requirement to respect a person’s transcendental autonomy and not to deceive is, and needs to be balanced with, the consequentialist aim to improve someone’s well-being.”[1376] This issue cannot have a definitive answer, at least not one that can be offered by dispassionate logic. While moral philosophy can help to define norms and principles in this situation, it is not enough. Ultimately, people who provide care for the elderly must choose the course of action that is most practical, taking into account the person's situation and skills as well as moral principles and perceptions, such as protecting autonomy and never exploiting a human as a simple instrument. [1377]

It should be noted that even if a person is not totally factually independent, caretakers may nevertheless choose to treat them as if they are, inspired by notions from Kant or other thinkers about the dignity and autonomy of the person.[1378] Caretakers aim to respect their desires and provide them options. This is a sort of deception since it gives the impression that the individual is completely independent while in reality, they are not. However, when actions are taken for the "benefit" and "happiness" of the people, caregivers may choose to use a paternalistic kind of deception, even if it involves lying or distorting the facts.[1379]

Blackford and Rodogno concentrate on the connection between sentimentality and deception.[1380] Both believe that sentimentality is the over-emotionalization of certain items—in this example, care robots—resulting in a distortion of such objects. Rodogno refers to “the paradox of emotional fiction, which states that one empathizes with fictional characters while at the same time knowing they are fictional, to show: sentimentalizing care robots does not necessarily lead to misrepresenting them.”[1381] Even though robots are not sentient, older folks may be aware of this and yet exhibit feelings toward them. Rodogno also contends that rather than sentimentalization itself, the primary focus should be on the motivations behind sentimentalization.[1382] He contends that the impulse to arouse particular emotions is shown in the desire to sentimentalize things.[1383] He claims sentimentality "involves the attempt to use something to secure the desired feeling or emotional comfort."[1384] This urge for emotional solace is not always driven by cynical factors, such as social isolation. Therefore, it may not necessarily be an issue to sentimentalize care robots. It may be another example of selfish conduct, which sometimes entails misbehavior.[1385] Nevertheless, it creates a challenge "insofar as it disrespects other persons, values, or duties that the individuals have."[1386]

6.B. Conclusion

The central question of this section asked, what are the ethical considerations in designing robots used in caring for aging populations? In the preceding sections, many ethical considerations have been identified; however, many more exist that were not identified in this chapter. The issue of the increasing scope of the aging population was described along with a lack of proportionate caregivers. The many diverse needs of the elderly were described with the subsequent rise to meet those needs with the advent of care robots. The importance of the foundational concepts of care ethics, relational autonomy, and human dignity was described to provide a starting point for engineers and designers to program the care robots. Then philosophical considerations of the virtues and values essential in care robots were told, and the argument of whether or not society can embed moral capacities within artificial systems. A framework for the ethical evolution of robots was highlighted so that the future of care robots can be carefully built and considered with ethics in mind. Finally, some ethical challenges of a care-centered framework were described, such as the implementation of human capabilities in robots and whether or not the carebots can have context-sensitivity in caring for the diverse needs of the elderly population. The notion of deception that the care robots can emit through their care of the vulnerable elderly was also noted. According to this section, the employment of robots in elder care might result in a setting that is quite dystopian in nature if precautions are not made to address these ethical problems. Carefully developed guidelines and even legal restrictions on care robots’ development and use could help prevent this dystopian future.

6. Conclusion

In review, the sixth chapter focused on an overall positive or utopian application of various data analytics-driven technologies within the specific context of the elderly population and end-of-life practices such as palliative care and hospice. The reason for the focus on end-of-life practices was due to the exponentially increasing scope of the aging population, an unmet need has risen, now more than ever, to care for the elderly population around the world. Thanks to data-analytics-driven technology, machines have changed how the world deals with death and allow people to live much longer than they could a century ago. A detailed historical and cultural background of death and dying outlined systematic changes towards death over time. Opportunities for technologies in end-of-life practices were explored, such as telemedicine and electronic learning. Challenges were described as well, such as the digital-divide, professional-patient relationship via technology, and fundamental issues such as the technological imperative vs. humanizing. The chapter continued with ethical considerations of using care robots in aging populations using care ethics. Concepts like artificial morality, relational autonomy, and dignity were described within this applied chapter of data analytics in healthcare.

CHAPTER 7: CONCLUSION

The beginning of the technological revolution has caused profound changes in science, society, culture, and many other facets of daily life. Technology and society are becoming progressively more entwined as time goes on, and this trend influences everyday life and healthcare. Through data analytics, technology such as big data information management, artificial intelligence (AI), machine learning (ML), and care robots are changing the healthcare landscape in ways that even a few years ago were not considered imaginable. These changes are being pushed by organizations and restless people who are not satisfied with the state of healthcare. Clinical and health executives confront a never-ending list of obstacles, such as ever-expanding medical skills, limited resources and personnel shortages, and a more varied mix of patients and customers whose requirements only increase. These technological changes are welcomed by many. This dissertation aimed to explore the ethics of these technological changes in healthcare and how this impacted reform and governance policy relating to data analytics.

Chapter 1 introduced the topic of data analytics and its impact on the healthcare world by outlining the dissertation's argumentative road map and the overall scope of the argument, emphasizing that data must be handled as a strategic asset. Without proper management, data often becomes duplicated, of low quality, and is unable to support the insightful conclusions that come from excellent data. Moreover, improper management and governance of data can cause numerous ethical concerns regarding privacy, confidentiality, and trust. Without proper management and governance, adverse outcomes will ensue, causing patient harm, financial woes, and endless legal paperwork. Therefore, ethical governance of data analytics in healthcare is essential. The thesis of this dissertation aimed to explain the ethics of governance of data analytics in healthcare and the challenges and opportunities that accompany this management. The chapters that followed the dissertation's introduction addressed the thesis by establishing the context through an approach to data ethics that focuses on the key ethical challenges of data analytics from a technological perspective and an applied analysis of data ethics in human enhancement and technological practices in end-of-life care.

After the introductory chapter, Chapters 2 and 3 established the background and context for the dissertation in how data analytics plays a role in the dissemination of healthcare. Blending finance and delivery, data analytics impacts care from an individual level all the way to organizational changes that can fundamentally reform healthcare as it is today. Chapter 2 described how data analytics could be used in a broader system context to initiate healthcare reform within the United States. Invoking its power to collect taxes, regulate, and facilitate commerce, the federal government of the United States has regularly approved the gathering and use of medical data to facilitate its activities since the 1950s.[1387] However, somewhat recently, in 2009, the government created a Federal Coordinating Council for Comparative Effectiveness Research, which established a data steward under health reform.[1388] The enormous volumes of healthcare data submitted to government agencies under Medicare, Medicaid, and countless other federal health services are collected by this data steward. Using the power to gather, combine, manage, and safeguard data while operating under open policy guidelines, this council can make strides in advancing population health while simultaneously exploring and researching a reformed health system.[1389]

The analysis started with a background of healthcare reform in America. The first section of the chapter highlighted one of the critical ethical concepts that data analytics assists in exercising – distributive justice. In this section, the foundational theories of distributive justice were explored through an array of literature indicating the basic concerns of need and contribution within allocation problems. Implementation considerations of a new healthcare system were described by listing criteria for a better system, four conditions that must be met, and a universal access to basic care that technology will help achieve. A universal health insurance program may be the answer to the healthcare reform that America needs, but it has its own set of problems that must be considered. Many of these healthcare problems can be mitigated using data analytics, which can reduce costs, provide more personalized care access, lead to more accurate diagnostics, expedite care, and provide numerous other benefits for all. The second half of the chapter detailed data analytics' current and future impacts on the healthcare landscape. A brief overview of what big data is and why it matters, including ethical challenges of security, privacy, and informed consent, was explored. Social policies of genomic data were described in depth, including genetic discrimination, common heritage, and distributive justice. The autonomy paradigm and cloud computing were used, respectively, to explain the constraints and potential of data analytics. Personalized care using predictive modeling and integrative sequencing were described in their effect on the finance and delivery of healthcare.

More data access to produce information pertaining to how the healthcare system operates will depend on the capacity of politicians to strike a balance between the requirement to protect genuine patient-clinician objectives on the one hand and the significance of health data to the general public on the other. In order to provide proof without jeopardizing these legitimate interests, it is necessary to consider whether data used for research, like that by the Federal Coordinating Council for Comparative Effectiveness Research, can be handled properly and securely. Chapter 3 took the context one step further and described the data battle that data analytics utilizes, creating tension between individual data privacy and public health surveillance for the common good. Concluding the section, the debate between individual data privacy and public health surveillance was at the heart of the argument – with ethical arguments on both sides. The section continued by detailing the imperative to influence policy as technology rapidly changes the norms of everyday life. Changes in policy in the form of ethical governance frameworks that enable regulation and monitoring of technologies that are a double-edged sword are crucial. Since healthcare is such a broad topic in scope, multiple frameworks are crucial to achieving ethical policies, processes, and procedures globally. Ethical governance frameworks are necessary as technological and societal changes continually reshape the global healthcare landscape. These frameworks can withstand the dynamic nature of technology and society's relationship and thus provide a consistent solution to reprioritizing ethics into data analytics governance. Policy at not only a national but global level was conveyed, using examples such as the European Union and UNESCO. While data analytics can assist in creating biometrics governance frameworks, some concerns regarding the use and misuse of data analytics itself were addressed. The next chapter described some of those concerns in two senses: one practical, within genomics, and another theoretical, within the future of digital technologies themselves.

The prior chapters were primarily concerned with the advantages and possibilities that data analytics governance might provide the healthcare environment in terms of financing and delivery, as discussed in Chapter 2. Data analytics governance support was described at the micro level in Chapter 3, with the rights and autonomy of the person being compared to the governance at the macro level with regard to population health and the Common Good. Chapter 4 examined data analytics from a new angle and focused on the ethical issues and difficulties this technology might provide. Chapter 4 addressed the ethical and practical challenges of data analytics in healthcare within genomics and an applied analysis relating to human enhancement.

The social policy of genomic information was explored, including issues with genetic discrimination, common heritage, and further problems with distributive justice. The problems of data analytics within the autonomy paradigm and cloud computing were discussed in this section. Given that cloud computing decentralizes data storage, this problem proves difficult for ethical data analytics governance to overcome. Possessing centralized, secure data storage that is simple to manage and track back to in the case of a data breach is essential for upholding people's autonomy and privacy. The remainder of the chapter described a philosophical/theoretical foundation by discussing how technology has affected healthcare through the digital revolution and its relationship to society. It also looked at the future of this dynamic relationship and how data analytics could significantly alter this relationship, leading to a dehumanized world via human enhancement. Concepts like technological determinism and the Precautionary Principle were addressed with a cautious mindset. Human enhancement was the subject of an applied examination of these notions, which raised ethical questions and served as the context for the discussion. Overall, Chapter 4 presented a more cautionary approach to digital technologies and gave perspective on how to move forward, keeping ethics a priority in the design and implementation of new data analytics technologies.

Chapter 5 began by looking at a few capabilities of artificial intelligence (AI) and its potential for revolutionizing healthcare. Since AI acts as the interpreter of all the data it receives using machine learning and algorithms, AI helps scientists, researchers, and healthcare data stewards, among many others, to understand and adapt to the clinical outcomes that the data forecasts. Philosophical concepts such as free will, moral disagreement, and moral agency were explored considering AI. The section concluded with an analysis of AI's challenges and opportunities in healthcare delivery. The chapter also described the foundations of health information management and its legal and ethical aspects. An applied analysis was detailed within systematic reviews and risk management. Finally, the chapter concluded with a call for health information technology governance – defined its need and core components, and highlighted concepts such as information stewardship and data quality.

If humankind is not mindful of the verge that human augmentation might lead it down, the conclusion of Chapter 4 looked at an example of how data analytics could be employed in a negative or dystopian manner. On the other hand, Chapter 6 concentrated on a generally positive or utopian use of different data analytics-driven technologies within the context of the older population and end-of-life practices like palliative care and hospice. A thorough understanding of death and dying's historical and cultural context revealed how attitudes toward death have evolved. Opportunities for technology, such as telemedicine and electronic learning, were investigated in end-of-life practices. There were also descriptions of difficulties like the digital divide, the professional-patient interaction via technology, and basic problems like the technical imperative vs. humanizing. The last section of the chapter dealt with the moral ramifications of utilizing care robots with elderly people. This chapter on applied healthcare data analytics discussed concepts such as relational autonomy, artificial morality, and dignity.

This dissertation addressed the challenges of data analytics in this fast-developing environment as governance oversight develops effective policies organizationally, nationally, and globally and will help to create a more ethical, secure, and efficient future of healthcare for all humanity. By reprioritizing ethics at the forefront of governance, instead of having it as merely a component of data analytics governance, all those involved with these technologies will be able to produce and maintain ethical data analytics. Thus, each chapter in the dissertation attempted to look at the past, present, and future issues surrounding the governance of data analytics. Understanding the ethical concerns within these issues assisted in providing a forum for those issues that have yet to be addressed by data experts. Further, by locating the commonalities between these ethical implications, it becomes much more feasible to formulate and recommend solutions. Fortunately, this dissertation identified many ethical concerns and provided several recommendations for answers in the form of frameworks for data governance. While these issues are often significant in scope, globally even, usually a concrete solution will not always work practically in all countries. Therefore, this dissertation proposed frameworks for an ethical data governance system that will help organizations and systems worldwide to build and utilize a more ethical data governance for all its stakeholders.

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