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A Comparative Analysis on Global Patients' Rights Charters and their Alignment to Bioethical Principles and Human Rights

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A Dissertation Submitted to the Faculty of Health Sciences, University of the Witwatersrand (Wits), Johannesburg, in fulfilment of the requirements for the degree of Master of Science in Medicine (MScMed) in Bioethics & Health Law.

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05 November 2020

Dedication

It is with sincere gratefulness and a heartfelt thankfulness that I dedicate this disseration to my family.

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Declaration

I, Kelly Kumalo (Student number: 457759) am a student registered for the degree of Master of Science in Medicine (MSc Med) in Bioethics & Health Law at the University of the Witwatersrand (Wits), in the academic year 2019.

I hereby declare the following:

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Abstract

Patients' Rights Charters serve as guidelines for the relationship between health professionals and patients. The charters provide information regarding the standard of care patients should expect and demand as a basic human right. Human rights guard patients' rights at both international and national levels. Internationally human rights are provided for in several declarations and codes, and in South Africa by the Constitution. The bioethical grounding of patients' rights is principlism. These principles, commonly known as the Georgetown Mantra, and proposed by Beauchamp and Childress, are autonomy, non-maleficence, beneficence, and justice. Bioethics is core to health law. Bioethical discourse is critical in the development and ratification of international and national policy and legal frameworks. This research examines how - and if - global patients' rights charters align with human rights and bioethical principles. This study concludes that patients' rights charters are much stronger in addressing patient's needs when robust consideration is given to human rights and bioethical principles. The study concludes that the human rights that are affirmed in all the charters examined are the right to confidentiality; the right to equality and non-discrimination; and the right to informed consent. The least considered right is that of freedom of movement.

Key Words: *Human Rights, Bioethics, Principlism, Patients' Rights Charters.*

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“And whatever you do, whether in word or deed, do it all in the name of the Lord Jesus, giving thanks to God the Father through him” - Colossians 3:17 NIV.

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List of Abbreviations

ACHPR African Charter on Human and Peoples' Rights

AHA American Hospital Association

ARV Antiretroviral

CEDAW Convention on the Elimination of All Forms of Discrimination against Women

CRC The Convention on the Rights of the Child

CRPD The Convention on the Rights of Persons with Disabilities

DHA Dubai Healthcare Authority

ECHR European Convention on the Protection of Human Rights and Fundamental Freedoms

ESC The European Social Charter

HCP Health care provider

HEI Health Equality Index

HIC High income countries

ICCPR International Covenant on Civil and Political Rights

ICERD The International Convention on the Elimination of All Forms of Racial Discrimination

ICESCR International Covenant on Economic, Social, and Cultural Rights

LMICs Low- and middle- income countries

LGBTQ Lesbian, Gay, Bisexual, Transgender and Questioning

NHS National Health System

NHI National Health Insurance

TAC Treatment Action Campaign

UDHR Universal Declaration of Human Rights

UAE United Arab Emirates

USA United States of America

UNESCO United Nations Educational, Scientific and Cultural Organization

WHO World Health Organisation

WMA The World Medical Association

XDR-TB Extensively Drug-Resistant Tuberculosis

Chapter 1: Introduction

1.1 Background Literature Analysis and Critique

"Human Rights are the rights we have by virtue of being human".[1] It is the realisation of an ethical ideal, cutting across country, ethnicity, religion, gender, class, language and conduct.[2] Human rights are norms that support and protect all people from morally oppressive political regimes, injustice, and unfair social practices.[3] Human rights are regarded as universal [4] and, their infringement is "a grave attack to justice".[5]

The premise and application of human rights and bioethical principles in patients' rights charters, draws from legal and moral rights. [6] Others consider moral rights as moral claims and not as legal rights in the strict sense. At international and national levels, these moral claims may or may not be assimilated within law. For example, during apartheid it was argued that the black African majority in South Africa possessed a moral right "to full political participation",[6] even though no such lawful right existed. What many people found morally repulsive during apartheid was the violation of various basic moral rights, including the right not to be discriminated against irrespective of one's skin colour.[6]

Human rights in a legal context requires that the law is comprised of specific types of rules that guide human conduct. The organization of justice is concerned with implementing the rights made by such rules. [7] A "legal wrong" has legal recognition and results in punishment or suppression by the physical power of the country as this is fundamental to the design of the judicial system of the country.

The formal rights of individuals are generally protected in the form of treaties and other sources of law. [7] A treaty is an agreement by states that are bound by specific rules. This serves to protect individuals and groups from actions, such as neglected healthcare and discrimination, as a result of governments interfering with the enjoyment of these rights. Commitments to the treaties must be observed *pacta sunt servanda* i.e., an agreement must be kept "in good faith" once it has come into force and must be binding upon countries involved." [8]

Moreover, a human rights standard may exist as:

(a) a lawful right at the national level (known as a "civil" or "constitutional" right),

(b) at international level as a lawful right,

(c) an imparted standard for genuine human moralities, or

(d) a moral standard that is defensible and underpinned through solid reasoning. [9]

An advocate for human rights would want to promote, uphold and see human rights as based on all four standards being realised.[9] Moreover Griffin,[10] argues "that human rights are grounded in dignity", specifically normative agency; that of autonomy — choosing ones way through freedom from interference, liberty, life, and minimal provision. The latter refers to sufficient information and resources to give one the capacity to enact one's path.[11]

Post-World War I in 1919 President Woodrow Wilson of the United States of America chaired the Peace Conference in Paris.[12] In this conference regulations and rules were formulated for world peace through global consensus and open diplomacy as a covenant amongst nations. In 1919 the final version was adopted known as the 'League of Nations' and became Part I of the Treaty of Versailles, of which the official inauguration occurred in 1920. The covenant has three aims: "to ensure collective security, to assure functional cooperation, and to execute the mandates of peace treaties." [12] However, the convent was abandoned in 1939 when World War II broke out.[12]

The atrocities witnessed from the events of World War II reflect that if human rights are not enshrined through legal documentation, gross violations against people could occur.[13] To rectify this, the United Nations Charter explored the immutable principles to protect humanity against the brutality and injustices witnessed by repressive regimes.[14,15] Between 1947 and 1948, the first part of the International Bill of Rights was drafted. During this time Eleanor Roosevelt who was the chairperson of the United Nations Human Rights Commission famously stated "we stand today at the threshold of a great event both in the life of the United Nations and in the life of mankind". [16]

The International Bill of Rights consist of the Universal Declaration of Human Rights (UDHR),[17] the International Covenant on Civil and Political Rights (ICCPR)[18] and the International Covenant on Economic, Social and Cultural Rights (ICESCR).[19] The UDHR states "that all people are born equal and with dignity", it further states that all people are entitled to: health, right to life and freedom of association.[17] These rights prevail in morality and law at both international and national levels.[9]

The ICCPR[18] and the ICESCR[19] were adopted in 1966 by the United Nations but only came into force in 1976. Since then many countries have ratified these covenants. The ICCPR protects civil and political rights (known as negative rights) and requires government support. The ICCPR is secured by setting judicial guarantees, i.e. by "belonging to the branch of government that is charged with trying all cases that involve the government and with the administration of justice. . ." [20]. A civil right secures people's physical, legal, economic, and spiritual existence. These include the right to privacy, life and dignity through freedom rights such as the freedom of thought, freedom of conscience and religion or belief. Political rights include the right to vote and partake in government. Political rights "include a person claiming a freedom from, for instance, an intervention of the government and its officials." [21] The concept of "Patient rights . . . are themselves not completely economic issues but civil and political in nature." [22]

The ICESCR protects economic, social, and cultural rights (known as positive rights). The ICESCR safeguards specific categories of persons that rely on government to provide certain resources. It relates to the principles of international labour standards and the welfare of States.[21] The social concept of rights is about safeguarding disadvantaged members of society by giving them opportunities in employment and education so that they are equal to other members of society.[21] Economic rights relate to the UN agencies associated with, e.g., agriculture and food. Cultural rights provide for people to partake in a culture without discrimination[23] and are covered by the United Nations Educational, Scientific and Cultural Organization (UNESCO).

It has been stated that, "One of the best-known examples of the judicial vindication of socioeconomic rights in the world"[23] was during the court ruling of *Minister of Health v*

Treatment Action Campaign(TAC).[24] Government denied HIV patients access to antiretrovirals (ARVs) - Nevirapine, and the, TAC relied on the “right to have access to health care services”[24]. Government was ordered by the court to make Nevirapine available in clinics and hospitals. The Judgment from this case serves as a legal framework for universal access.

With regard to provision of health care within a democratic society “the interplay between human rights and medical ethics” is vital.[25] The bioethical theoretical grounding for the International Bill of Rights is Principlism, a theory that consists in a plurality of non-absolute principles of obligation. Principlism has been crucial within in the field of bioethics as can be seen by its influence on the Belmont Report. The report highlighted the ‘mantra’ of bioethics: 'autonomy, beneficence, non-maleficence, and justice'. [26]

Principlism has the following principles enshrined in them:

- Autonomy considers both positive and negative obligations. The positive obligation “implies an obligation to foster the human capacity for self-determination, to enhance it,”[27] The negative obligation holds for professionals that the autonomous decisions made by patients should not be influenced or constrained by others.[27] Examples of autonomy are seen in the Belmont Report where stipulations are made for experimentation on human participants.[28]

- Non-maleficence recognises “do no harm”, compelling physicians throughout their careers to take actions which align with the best interests of the patients.[29]

- Beneficence recognises that actions must benefit others. Actions include advancing the situation of individuals. In health care, health professionals should do no harm but, they also have an obligation to help their patients.[29]
- Justice takes into account fairness. Justice in health care ethics is divided into legal justice (respecting laws that are morally accepted), rights-based justice (respecting individuals' rights) and distributive justice (how to distribute scarce resources). [30] This dissertation will consider distributive justice in patients' rights charters.

If the purpose is to produce net benefit over harm, health care providers (HCPs) should consider principles of beneficence and non-maleficence together.[29] Circumstances in which the two are kept separate is if there is no obligation of beneficence to others. However, the requisite is that no harm is done. The traditional Hippocratic moral obligation in medicine makes provision for medical benefit to patients with nominal harm thereby considering beneficence together with non-maleficence.[29]

Other international and regional instruments that are relevant in healthcare and that also draw on human rights and bioethical principles are**:**

- The International Convention on the Elimination of All Forms of Racial Discrimination (ICERD) of 1965.[31]
- The Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) of 1979.[32]
- The Convention on the Rights of the Child (CRC) of 1989.[33]
- The Convention on the Rights of Persons with Disabilities (CRPD) of 2006.[34]

Similar relevant regional instruments are:

- The African Charter on Human and Peoples' Rights (ACHPR) of 1981.[35]
- The European Social Charter (ESC) of 1961.[36]
- The European Convention on the Protection of Human Rights and Fundamental Freedoms (ECHR) of 1984.[37]

With regard to countries efforts to achieve patient-centred care, many countries have implemented charters on rights for patients referred to as *patients' rights charter or patients' bill of rights.*[38] The National Union of Nurses in 1948 published the first proclamation of patients' rights pertaining to expectations, observance of patients' dignity and respect, legal principles of informed consent, admission without discrimination, and confidentiality of information.[39] The success of a patient charter relies on; "its design, the nature of the rights enumerated, the interaction between the charter and other disciplinary and legal channels, and the scope of the charter's mandate to address systemic problems in health care."[38]

The UDHR has been instrumental in enshrining the concept of human dignity in laws of countries, giving an ethical and legal grounding for enhanced guidelines of basic care and fundamental responsibilities towards each other as part of the "human family".[40] However, "there remains a great deal of work to be done to clarify the connection between human rights and the right to health, together with patient rights"[40].

Patients' rights have been created on the awareness for persons, and the equality and dignity for all individuals. Realisation of patients' rights differ from nation to nation and

in several jurisdictions and is reliant on prevailing social and cultural standards. The patient-physician relationship is underpinned mainly by the fact that patients have actual rights.[40] South Africa has a responsibility to develop and implement national legal systems and processes *vis-à-vis* international and regional conventions and treaties that it is a signatory to. The most important legal instrument in the country is the South African Constitution. South Africa ratified the ICESCR on 12 January 2015. Section 231 of the Constitution of South Africa states that a treaty binds the government to: "Prefer any reasonable interpretation of the legislation that is consistent with international law over any alternative interpretation that is inconsistent with international law".[41] In the South African Constitution under Section 39 (1) on the interpretation of the "Bill of Rights" states that a tribunal, forum, or court,— "(b) must consider international law; and (c) may consider foreign law."[41]

This research looked at patients' rights charters from high income countries (HICs) and low- and middle-income countries (LMICs). The HICs considered were Israel, United Arab Emirates (UAE), New Zealand, Australia, Scotland, Ireland, Finland, United States of America (USA) and China (Hong Kong). The LMICs were Uganda, Kenya and South Africa. The research managed to find these charters by doing wide internet searches and only using those that were available in the English Language.

1.1 Research Question:

How do patients' rights charters globally compare and align with human rights and bioethical principles, and how does South Africa's charter compare to patients' rights charters globally?

1.2 Rationale:

Globally the right to health is enshrined within Patients' Rights Charters. The Charters seeks to ensure that patients entering health facilities are afforded certain rights and dignities as human beings when receiving care. South Africa has its own Patients' Rights Charter. At the time of embarking on this research, no other study had been done to ascertain how the South African Charter compares with Patients' Rights Charters globally and how these charters align with human rights and bioethical principles. This practice area (Patients' Rights Charters) provides an effective arena for examining the clinical significance of human rights ideology within the healthcare context.

1.3 Research Aim:

To critically examine, from a Human Rights and Bioethical perspective, Patients' Rights Charters, and their alignment to human rights and bioethical principles.

1.4 Research objectives:

1.5.1 To normatively define Human Rights Law and its influence in the development of Health Law and Patients' Rights.

1.5.2 To examine with the use of ethical principles, the rights to health and health care.

1.5.3 To do a comparative analysis on Patients' Rights Charters and ascertained whether Patients' Rights Charters adequately align with human rights and bioethical principles.

1.5 Research Design:

The three basic ethical enquiries/divisions of philosophy, that is, normative, ethico- legal and descriptive ethics are used in this study. Normative ethics is a branch of theological enquiry[42] that sets out to answer what' people ought to do[43] thus distinguishing morally good from morally bad actions.[44] For example, the study questions how Patients' Rights Charters aligns with bioethical principles. Critical and logical methodology are used to justify the answers obtained from this research.

Ethico-legal analysis questions the nature of law and legal systems or justification thereof to "normative questions about the relationship between law and morality", [45] for example, illustrating the relationship between the human rights and bioethical principles. Descriptive ethics encompasses describing ethical conduct but not evaluating it in terms of moral codes of conduct, not setting out to answer a normative question, but assumes there is widespread acceptance of a moral norm.[46] Descriptive ethics asks empirical questions such as, what are the factors related to this normative ethical enquiry and adherence to that behavioural norm. The comparative analysis of the charters comprises the descriptive component of the study.

1.6 Research Methods:

For the normative aspects, this study was based on desktop and library-based research in which the literature used was analysed against ethical methodology. This study has not collected or analysed new data. There was no human participation. The study has adhered to the research methods and standards as used in philosophical research. Relevant government legislation and human rights literature related to health was critically

analysed and interpreted. This was done by means of including definitions, clarification and explanations of concepts found in sources.

This study sources of literature included, but was not limited to, research databases such as ProQuest Central, Taylor & Francis, Philosophers Index, EBSCO Host, Bill Tracker, LexisNexis Academic, My Lexis Nexis, Springer Link, Clinical Key PubMed and Google Scholar. Government legislations, books, research articles and research from accredited journals.

For the descriptive (empirical) component this study utilised a document analyses of various countries' charters.

1.6.1 Inclusion and Exclusion criteria:

The Patients' Rights Charters needed to meet three requirements to have been included in the study: Firstly, the charters had to be currently implemented and in use; secondly, they had to be legally binding, and thirdly they had to be in the English language.

The exclusion criteria for the research study were: they were not legally binding or required proclamation and were not in the English language.

1.7 Argumentative strategy:

The study has firstly, defined and described Human Rights. The argumentative strategy of this dissertation used an ethico-legal framework to argue the research aim. The rights explored were the rights to health and its related rights, life, dignity, equality and non-discrimination, privacy and confidentiality, security and liberty of person, freedom of

movement, bodily integrity, participation in public policy, remedy, informed consent; receive information; conscience and religion or beliefs; freedom from torture and cruel, inhumane and degrading treatment; practice religion and use one's own language; a safe environment; adequate housing; and social security. Justice as recognised by legal instruments supporting resource distribution and equity was utilized in the analysis. This dissertation made use of the ethical framework of principlism, that is, autonomy, beneficence, non-maleficence and justice in the context of healthcare and human rights.

1.8 Ethics:

As this research did not involve human subject participation, an ethics wavier was obtained from the University's Human Research Ethics Committee (Medical) (HREC). See attached as Appendix 1.

1.9 Research Outcomes:

- To contribute to discussions and recommendations towards the implementation of the Patients' Rights Charter within the South African health sector.
- A research paper to be disseminated at workshops and published in a peer reviewed journal.

1.10 Limitations:

Due to the limited amount of research conducted on this topic sourcing relevant literature could be seen as a limitation. The research is a normative study and reliant on secondary

sources. All charters were limited to the English language and hence charters from regions like South America that could have been of value to the study had to be excluded.

1.11 Overview of Chapters:

Chapter 1, of the dissertation sets out the background literature analysis and critique; rationale for the study; research question; research aim and objectives; research design, research methodology; argumentative strategy, and research outcomes. Chapter 2 discusses Human Rights and its bearing in Health Law and the Patients' Rights. Chapter 3 discusses with the use of bioethical principles, the context of healthcare and human rights. Chapter 4 provides a comparative analysis on Patients' Rights Charters and ascertained whether Patients' Rights Charter adequately align with human rights and bioethical principles. Chapter 5 produces the findings recommendations and the conclusion.

CHAPTER 2: HUMAN RIGHTS STANDARDS, PATIENTS' RIGHTS AND LEGAL PROTECTIONS.

2.1 Introduction

Human rights standards for patient protections in relation to health law and health care are generally found in patients' rights charters. These specific rights inform patients and HCPs on what to expect when receiving health care; what they are entitled to by law and ethics, and what their associated responsibilities are. Charters also help to guide patients in making decisions concerning their health and health care.

Moreover, human rights in patients' rights charters that are adopted into policy of the countries concerned are formal legal acknowledgement that oblige governments and HCPs to protect, respect and realise the rights of patients. To ascertain whether patients' rights charters align with human rights standards will require an analysis of the "internationally and regionally recognized rights relevant to patients'" rights. [47]

This chapter will first discuss human rights in patient care in the context of health care and health law and its bearing on patients' rights. It will then discuss the rights mentioned in the argumentative strategy, by defining/discussing what the rights mean and entail, and how they relate to patients' rights. It will also state how the human rights are protected in international and national law, and how they may be limited in relation to patients' rights. The chapter aligns to objective 1: To define Human Rights Law and its influence in the development of Health Law and Patients' Rights.

2.2 Human Rights in patient care

Human rights violations in the health care settings gave rise to the “modern movement for patients’ rights”.[47] This became even more concerning in countries where patients expected that as consumers these rights ought to be respected. Patients’ rights are intricately linked with medical / health law. Medical law and health law are regularly used interchangeably as being synonymous with one another.[48] However, health law has a broader notion than the concept medical law. In health law there are different juridical relations that are not related to medical practitioners. The domain of health law incorporates facets of medical service delivery, health awareness and financing. [49]

Health law may be characterised as a form of statutory rules that manages the advancement of securing equitable distribution of offered facilities and health services. Health law manages the status of known parties concerned, for example, institutions, HCP, and patients. Recently, attention has moved to the healthcare industry as an integrated whole.[48]

In 1949 the International Digest of Health Legislation was introduced. The objective of the digest was to handle the legislative concerns relating to health issues. From that point forward the digest has collected, presented, and printed the pertinent legislation, for governments to develop applicable health legislation for their nations. The digest ensured the creation of expertise in the field of health law to influence decision-making.[50]

Before drafting or enacting a law social, cultural and political factors need to be considered. If these are ignored “legislators can typically be frustrated by the results of their efforts.”[51] One should consider different rules and social circumstances and

processes as well when developing policies. For example, Finland sanctioned a statute on patients' rights in law, while Holland has opted to incorporate these rights into their civil code. These decisions emphasise the role government plays in protecting the rights of people, while civil choice illustrates the cooperation between the patient and HCP. [49,51]

Medical Law is concerned with patients' rights, and together with public health law it furthers and protects human rights: by trying to manage engagements of public health and attempting to regulate patient care with professional conduct. Medical law through mainly civil law "governs professional conduct in the patient care".[52] Harm or injury caused by an act on another person, could result in a civil wrong to which liability is imposed by the courts. Injury is the invasion of any legal right and harm is detriment or loss of life of an individual.[53]

Medical law focuses on the duties of the HCP in the patient-physician relationship, where HCPs are respectful of patients' rights and people can access health care without discrimination. Although the rights stem from the patient-physician relationship, it does take on a consumeristic arrangement.[52] The idea of patients being thought of as customers dates to the 1930s, and with it came the rising cost in medical care. In the 1960s as part of the patients' rights movement consumerists welcomed medical law to challenge physician paternalism. [52]

The movement grew even bigger in the 1980s. It was justified because of medical expenditures and the need to protect patients from harm. This consumeristic approach places patients in a contractual obligation with their HCP, (viewed as a service provider).[52] Furthermore, if these duties are not fulfilled it makes for a civil lawsuit, and

compensation for damages are demanded, because rights are violated. What patients can expect when receiving health care is protection found in national and regional instruments. [52] By the early twentieth century, law started interfering with medical activities and patient-physician relationships.[54] To safeguard the implementations of human rights, patients' rights charters were then developed.[47]

2.3 The Right to Health and Relevant Rights

The right to health is found in the provisions of international and national law. Other relevant rights are found through interrelated and essential elements in health care, as well as the core fundamentals that form part of the right to health (discussed below).

2.3.1 The International Law regarding the right to health and the relevant rights

Almost 70 years ago the Constitution of the World Health Organisation (WHO), adopted the words "The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition". [55] Furthermore, the WHO remains committed to the principle - that it is the duty of governments to be responsible for the health of their people. [56]

This is accomplished by social measures and providing adequate healthcare. The right to health is specified in the provisions the UDHR Article 25[17], and Article 12 of the ICESCR[19]:

1. "The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health."[19]

The rights included in Article 12 are:

(a) “Article 12.2 (a): The right to maternal, child and reproductive health

(b) Article 12.2 (b): The right to healthy natural and workplace environments

(c) Article 12.2 (c): The right to prevention, treatment and control of diseases

(d) Article 12.2 (d): The right to health facilities, goods and services”[19]

The UN committee on the ICESCR in General Comment 14 clarifies and explains the package of what Article 12 entails.[57] The committee states that the right to health is an important human right that is indispensable for the practice of other human rights. The outcome of “enjoyment of the highest attainable standard of health is living a life of dignity”[57]. This right to health may be attained through various measures, such as the programmes developed by the WHO, formulations of health policies, or legal instruments. The rights to health depend upon and closely relate to the recognition of other relevant human rights including the rights to access to information, housing, equality, and life. The right to health is understood as a right for individuals to enjoy health services, goods, facilities, and conditions required for the recognition of article 12.1.[57]

The UN committee further states that there are “interrelated and essential elements” in the application of the right to health. This, however, depends on the circumstances in a particular country. These are:

- Availability – of services, goods, and functioning health care facilities that must be available in appropriate quantity within the country.
- Accessibility - without discrimination, be physically accessible i.e., within physical reach in all populated areas.

- Affordability - affordable health services, goods and facilities. Payment for health-care services should be judged upon the principle of equity (discussed in chapter 3, see section 3.6.1.3 Equity).
- Acceptable - affordable health services, goods and facilities should be culturally appropriate and mindful of medical ethics.
- Quality - The health facilities, services and goods must be medically and scientifically appropriate, and culturally acceptable. The facilities should have adequate sanitation, safe and potable water, scientifically approved and unexpired drugs, hospital equipment, and skilled medical personnel.[57]

Moreover, many countries are still in the phase of preventative healthcare. There is a need to move forward and progress in public health and primary healthcare by focussing on treatment and prevention of disease in high risk groups, like the vaccination campaigns and effective medical services in the community in line with universal healthcare.[58] Governments are under pressure to expand access to affordable, safe, and effective services. According to Bloom and Wilkinson, “in a context of economic growth, it should be possible to improve access by the poor to health services substantially”.[59]

According to General Comment 3, the delivery of ‘essential primary health care’ is fundamental for the right to health. The UN committee refers to General Comment No. 3, where governments are obligated to guarantee/ensure, at least, the minimum fundamentals of the rights articulated in the Covenant. The following are the core obligations included in the right to health:[57]

(a) to guarantee a right of access to health services, goods and facilities on the basis of non-discrimination, being mindful to marginalized and vulnerable groups;

(b) to provide nutritional food and safe water, thus to “ensure freedom from hunger to everyone;”

(c) to guarantee basic sanitation, housing and shelter, and safe portable water;

(d) “To provide essential drugs, as from time to time defined under the WHO Action Programme on Essential Drugs;

(e) To ensure equitable distribution of all health facilities, goods and services;

(f) To adopt and implement a national public health strategy and plan of action, on the basis of epidemiological evidence…”[57]

The right to health is also found in the provision of the ICERD Article 5(e)(iv)[31], the CEDAW Article 12(1),[32] the CRC Article 24,[33] the CRPD Articles 25 and 26,[34] the ACHPR Article 16,[35] and the ESC Article 11.[36] Nationally the right to health is protected under Section 27 of the South African Constitution:

“(1) Everyone has the right to have access to—

(a) health care services, including reproductive health care;

(b) sufficient food and water, and

(c) social security, including, if they are unable to support themselves and their dependants, appropriate social assistance.

(2) The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights.

(3) No one may be refused emergency medical treatment."[41]

Section 27(1)(a) can be considered to be in line with General Comment 14, Article 12.2 (d), where it is affirmed that health services will include both mental (with appropriate mental health care and treatment) and physical health, as well as, timely and equal access to basic health education; rehabilitative health services, curative and preventive services, as well as, regular screening programmes; suitable treatment of prevalent injuries, illnesses, disabilities, and diseases, and provision of essential drugs.[23] It is essential to ensure improvement and citizen participation in political decisions relating to the right to health and in the provision of curative and preventive health services both at "community and national levels".[57]

Section 27(2) qualifies the rights of 27(1) (a) (which may be claimed at any time), Section 27(2) is an obligatory duty of government.[41] Moreover, governments ought to adopt legal measures so that the realisation of rights of health care access may be achievable in a reasonable manner. The realisation of the right to health care access and services is subject to limited resources in Section 27(2) of the Constitution.[41]

Special consideration should be given to children as they are vulnerable members of society. Children face health challenges "related to the stage of their physical and mental development."[60] This makes them vulnerable to infectious disease and malnutrition and when they reach adolescence, they become prone to mental, reproductive and sexual problems.[60] In the Constitution children's rights is a priority. Section 28 of the Constitution

protects the rights of children – which include the right to 28(1) (c) “to basic nutrition, shelter, basic health care services and social services”.[41] Of note, these basic rights differ from Section 27(2) rights in that they are not subject to limitations.

Other national instruments that affect the right to health[61] include the: Children’s Act 38 of 2005;[62] Abortion and Sterilization Act 2 of 1975, Choice on Termination of Pregnancy Act 92 of 1996;[63] Correctional Services Act 111 of 1998;[64] Sterilisation Act 44 of 1989;[65] Health Professions Act 56 of 1974;[66] Medical Schemes Act 131 of 1998;[67] Medicines and Related Substances Control Act 101 of 1965;[68] Mental Health Care Act 17 of 2002;[69] National Health Act 61 of 2003;[70] Promotion of Administrative Justice Act 3 of 2000;[71] Promotion of Equality and Prevention of Unfair Discrimination Act 4 of 2000;[72] Births and Registration Act 51 of 1992;[73] and the Road Accidents Fund Act 56 of 1996.[74]

2.4 The Right to Life

Good health is linked to basic human rights such as the right to life.[75]The right to life is an important human right and is subject to the way in which the right to health is perceived through the national medical systems.[76] According to Feinberg[77] the right to life is understood in diverse ways by various writers. The right to life can be interpreted as a right to life-sustaining essentials, and to not to be killed unjustly[78]. Moreover, Bedau states:

> “The “life to which we now think men are entitled as of right is not [merely] a right at the barest level sufficient to stave off an untimely death; rather it is a life sufficient for self-respect, relief from needless drudgery, and opportunity for the release of productive energy”.[79,77]

The right to life is safeguarded in the provisions of the ICCPR Article6(1),[18] the UDHR Article 3,[17] the CRPD Article 10,[34] the ACHPR Article 4[35] and the South African Constitution Section 11.[41] The right to life is normally understood as a claim right, as opposed to the right to privilege or absence of a duty to refrain from. Therefore, if a claim right to life is endowed, it is not justifiable for others to kill one another or let another die when they can be saved with no danger to others.[77]

Feinberg[77] further notes that life ought to be a claim that a person makes against the government for legal enforcement. Claims having a legal and moral binding compel governments to enact these assertions that individuals have toward each other, and to protect them from unlawful punishment and interference.[77]

The UN Human Rights Committee (HRC) general comment 6 of Article 6 (The right to life) of the ICCPR, [80] notes that the right to life is often narrowly interpreted. The statement “inherent right to life” cannot be comprehended in a restrictive way and does not oblige States to assure positive actions towards this right. The right to life relates to healthcare and patients right, in that the committee states that measures should be implemented to increase life expectancy, decrease infant mortality, as well as have measures that eliminate epidemics and malnutrition. It further includes that children with disabilities ought to have the “opportunity to enjoy a fulfilling and decent life and to participate within their community”. [80] Article 12.2 of general comment 14 states “that the right to health embraces a wide range of socio-economic factors that promote conditions in which people can lead a healthy life”[57]. The right to life can be violated by numerous ways in health care, for example:[81]

- Health services that are not inclusive of “preventive screening for many types of cancer”[81] leaving patients finding out when it’s too late for effective treatment.
- Patients that cannot have access or afford low cost medications (because of bureaucratic hurdles and strict patent regimes), leading to life being in danger.
- Ambulances not arriving on time in certain areas.
- Poor prenatal care and reproductive health, with women dying due to complicated childbirth or problems during pregnancy.[81]

Globally unnecessary deaths occur if the right to life is not protected. There are vast discrepancies in LMICs and HICs with regard to healthcare services. Moreover, LMICs capabilities to manage with these healthcare challenges are problematic. Chronic disease is a rising burden and mostly occurs in LMICs.[82] Such countries cannot afford high numbers of chronic disease health burdens as they struggle with strained and limited resources. Concentrating on decreasing known risk factors that are modifiable can play a fundamental part to mortality and incidence reductions.[83] Chronic diseases reflect the population size and represents the epidemiologic transition from infectious to chronic diseases.[83]

There is a suggestion from cross-sectional studies that there is a propensity for mortality to be less in countries with an egalitarian distribution of money. Such countries have an improved public service that is beneficial to health. [84] For example, studies show that individuals living with HIV in high-income countries can anticipate “increasing positive health outcomes” with ARV therapy.[85]

2.5 Limitations of patients' rights

International limitations to human rights are stipulated in the "Siracusa Principles on the Limitation and Derogation of Provisions in the International Covenant on Civil and Political Rights".[86] The Siracusa Principle are divided into the limitation clauses and the derogations in public emergencies. Under "derogations in a public emergency" a state may derogate from its obligations, under article 4 of the ICCPR[18] and ICESCR,[19] when the lives of its citizens are at threat. By official proclamation, states "may take measures derogating from their obligations under the present Covenant to the extent strictly required by the exigencies of the situation, provided that such measures are not inconsistent with their other obligations under international law".[86]

Moreover, should a state avail of "the right of derogation" other state parties' that are part of the present covenant should be informed by "the intermediary of the Secretary General of the United Nations".[86] Threats of public emergencies that affect citizens include threats of physical integrity, internal conflict/unrest, and economic difficulties. The limitation clause stipulates when it is permissible to restrict certain rights in the covenants within a certain context. The interpretative principles relating to specific limitation clauses are: public safety, public morals, public health, rights and reputations of others, public order, prescribed by law, national security, in a democratic society, and freedoms of others.[86] Limitations clauses are only to be interpreted in favour of and strictly for the context at hand. Limitations shall be provided by law, and only applied for the purpose for which it is prescribed. Limitations are not to be applied in an arbitrary manner and should be used to remedy and challenge against abuse. The limitation should not be used to not

discriminate. The limitation is deemed as necessary if it pursues an aim and is proportionate to that aim.[86]

Section 36 of the South African Constitution[41] states that rights in the Bill of Rights may be limited by means of the law of general application to the degree that the limits set forth are justifiable and transparent in a democratic society relying on equality, freedom and human dignity. Determining factors of right limitations include: "(a) the nature of the right; (b) the importance of the purpose of the limitation; (c) the nature and extent of the limitation; (d) the relation between the limitation and its purpose; and (e) less restrictive means to achieve the purpose."[41]

Limitations cannot be applied to the right to dignity (discussed below) and life under Section 10 and 11, respectively, of the South African Constitution.[41] These are non-derogable rights which are protected by the State entirely. In terms of the Siracusa Principles the right to life may not be derogated even in a state of public emergency.

The right to access to healthcare services is subject and limited to Section 27(2) of the Constitution due to limited resources.[41] Article 12.1 of the ICESCR[19] considers the available resources of the State, and the socio economic and biological preconditions. There are limits to what States can do regarding an individual's health, such as, protection from every possible cause of ill health and the good health of the individual.[57] In the case of *Soobramoney v Minster of Health (KwaZulu-Natal)*[87] the appellant was diagnosed with chronic renal failure in need of regular renal dialysis. However, due to a limited resource (20 machines), staff and hospital budget there were no provisions for his needs. As per

the hospital's requirements only patients with acute renal failure were remedied by renal dialysis. Neither was the appellant eligible for kidney transplant.[87]

The appellant made his claim to receive treatment based on the human right to life and Section 27(3) of the Constitution which states that "no one may be refused emergency medical treatment".[41] However, the judge stated that if Section 27(3) was interpreted according to the appellant's claim, it would be difficult for a state to accomplish the primary obligations "under Sections 27(1) and (2)to provide health care services to *everyone* within its available resources."[41] It was concluded that there was no reason to interfere with the decisions of resources allocation, made by the people better equipped to handle such choices.[87]

2.6 The Right to Dignity

The right to dignity is affirmed in the provisions of:

- UDHR Article 1:[17] "All human beings are born free and equal in dignity and rights",
- ICCPR Article 10:[18] "All persons deprived of their liberty shall be treated with humanity and with respect for the inherent dignity of the human person"
- CRPD Article 3:[34] "Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons"
- ACHPR Article 5:[35] "Every individual shall have the right to the respect of the dignity inherent in a human being and to the recognition of his legal status."
- South African Constitution Section 10:[41] "Everyone has inherent dignity and the right to have their dignity respected and protected."

The right to dignity means that all people are equally valuable. In addition, the right to dignity is an authorisation for an individual to utilise social value.[88]

In a democratic society dignity is an aspect that every individual possesses.[89] Dignity does not allude to qualities or abilities belonging to the subject, rather it fundamentally relates to being human.[90,91] The standard for human dignity, moreover, is communicated in Kant's categorical imperative, which relates to treating individuals as an end in themselves and not as a means.[92]

In line with the Kantian imperative, the Royal College of Nursing defines dignity as:[93]

> "Dignity is concerned with how people feel, think and behave in relation to the worth or value of themselves and others. . . When dignity is present people feel in control, valued, confident, comfortable and able to make decisions for themselves. . ."[93]

Health-related studies have identified the importance of recognising the dignity of patients through encouraging a sense of self-identity.[94] Ensuring the dignity of a person respects their mental[95] and spiritual sense.[96] Moreover, dignity in the Merriam and Webster dictionary is defined as: "the quality or state of being worthy, honoured, or esteemed."[97] In the health care setting, patients should maintain pride, hopefulness, autonomy, legacy, acceptance and resilience.[98]

Research has shown that the meaning of dignity in caring sciences (i.e. health care sciences) correlates to the basic assumptions that: "Human dignity means to hold a human position, to serve with love and existing for the sake of others." [99] In healthcare

to have dignity is deserving of claiming respect.[100] Everyone is entitled to healthcare in conditions that enables people to be happy in a healthy environment. Healthcare institutions should respect dignity of people.[75]

2.7 The Right to Equality and Non-Discrimination

The right to equality is guarded in the provisions of Articles 1, 7, and 21.2 of the UDHR,[17] Articles 3 and 25 of the ICCPR,[18] Article 2(2) of the ICESCR,[19] Article 5 of the CRPD,[34] Article 2 of the ICERD,[31] Article 19 of the ACHPR,[35] and Article 14 of the ECHR.[37] The South African Constitution, in Section 9 affirms that: “(1) Everyone is equal before the law and has the right to equal protection and benefit of the law”. (2) Equality includes the full and equal enjoyment of all rights and freedoms”.[41]

According to Pieterse,[23] the provisions for Section 27(1)(a) prohibits group-based divisions in relation to health services. Equality between men and women is stipulated in General Comment No. 28: “The equality of rights between men and women (article 3 of the ICCPR)” [101] and the protection of children should be implemented fairly for boys and girls. Furthermore, States should ensure that girls are treated equal to boys in healthcare. Here, the right to equality represents a right that is against unfair or arbitrary exclusion from programmes, laws and policies, which are associated with health-related benefits and which disagree with inequitable delivery of health care services.[101]

Furthermore, equality in access to health care services may be supported in General Comment 25 of Article 25 (Participation in Public Affairs and the Right to Vote) of the ICCPR, affirming that measures should be put in place which guarantee “equal access to public services”.[102]

This notion of equality has inalienable radical potential. Article 2 of the ICESR states that rights should be guaranteed “without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status”[19]. A formal anti-discrimination policy is fundamentally mandatory and authorised through the courts.[103] The Siracusa Principles state: that limitation measures should not “be inconsistent with their other obligations under international law and do not involve discrimination”.[86]

2.8 The Right to Participation in Public Policy

The right to participation is guarded in Article 12 of the UDHR,[17] Articles 8 and 25 of the ICCPR,[18] Articles 13(1) of the ACHPR,[35] and 14(2) of the CEDAW[32] which is complemented by the interpretive General Comment 25 “The right to participate in public affairs”[102]

The UN states that “political and public participation rights “are essential to promoting a democratic society and crucial to advancing all human rights. The UN recognises this right as a key aspect of a “human rights-based approach” with the objective of removing discrimination and marginalisation and doing no harm.[104] This forms part of Democratic Equality, which means that all citizens are treated equally, which is ideal for the notion of justice.[105]

Moreover, people in society are owed liberty, opportunity, resources and assistance in making everybody sufficiently supported, and to be a fully functioning member of democratic society. It, likewise, incorporates that persons of a democratic society have the right to take an interest and participate in a political procedure that sets laws and

public arrangements and installs state officials to manage these.[105] The right to participation relates to patients' rights in public policy supported in the right to health in general comment 14 under section 12.2 (d) which states that there is a right to "participation in political decisions relating to the right to health taken at both the community and national levels."[57]

2.9 The Right to Privacy and Confidentiality

According to General Comment 25, information regarding public issues between people and elected representatives should be communicated freely.[102] However, during such communications the personal information of patients should be protected so as to avoid stigmatisation. This is protected under the right to privacy and confidentiality.

2.9.1 The Right to Privacy

The right to privacy is safeguarded in Article 12 of the UDHR,[17] Article 17 of the ICCPR,[18] Article 16.1 of the CRC,[33] and Article 8(1) of the ECHR[37]. The Constitution of South Africa Section 14 states that: "Everyone has the right to privacy."[41] The terms 'privacy' and 'confidentiality' are regularly used interchangeably. Although, they are associated, they are not the exact same concept.[106] Warren and Brandeis define the right to privacy as the right to be left alone.[107] Privacy is the right to control access to oneself and also limit physical access to a person. Within the healthcare setting privacy would include closing the curtains during physical examinations.[106] Furthermore, Parent elaborates on his definition of privacy as a: "condition of not having undocumented personal knowledge about one possessed by others. A person's privacy is diminished exactly to the degree that others possess this kind of knowledge about him." [108] Of

interest, is that the right to privacy and confidentiality does not feature in the African Charter, however, recommendations for a resolution on the right to privacy for adoption by the African Charter during an NGO-Forum was proposed.[109]

2.9.2 Confidentiality

Confidentiality is a professional obligation, within a special relationship between a physician and patient. Here, HCPs have a duty to maintain the confidentiality of their patients, i.e., HCP should not disclose patient information without permission, or without a compelling reason to do so. Therefore, “confidentiality protects informational privacy interests” [110] by restricting access to information. Confidentiality ensures deference to human dignity. Stigma, shame and discrimination play a role in considerations of flow of information concerning one's health. Hence, confidentiality is a moral right to be concerned about. Mental health users globally face stigma, and struggle to get the help they deserve. However, confidentiality may be breached to several people, including law enforcement, insurers, hospitals, social workers, family members, teachers and doctors.[111] Patients’ confidentiality can be summarised by the World Medical Association (WMA) as follows:[112]

- Information that is identifiable such as diagnosis, prognosis, and medical condition and all personal information should remain confidential even after death. However, descendants do have a right to access information in case of health risks.

- Explicit consent must be given by the patient, to disclose confidential information.

- The data regarding the patient must be secured in a proper manner. The same applies to identifiable human substances.[112]

Confidentiality is protected in Section 14(d) of the South African Constitution “the right not to have the privacy of their communications infringed”[41]. With regard to minors an HCP may not disclose information without the written consent of a minor’s guardian or parent. Neither can the information of a child who is old enough to have access to contraception or consent to HIV testing, be disclosed to third parties.[113] In addition, the Promotion of Access to Information Act,[114] protects confidentiality and defines “personal information" as information about an identifiable individual, including, but not limited to – “information relating to the . . . physical or mental health, well-being, disability” of a person.[114] Failure to adhere to confidentiality is deemed illegal by the court of law. When patients ask HCP’s to keep their health status confidential, they may not divulge information to anyone including other HCPs. It is considered as wrong and unlawful, as seen in the case of *Jansen van Vuuren NO v Kruger*, [115] where disclosing test results, i.e. personal information to third parties resulted in an invasion of privacy.

2.9.3 Limitations on the Right to Privacy and Confidentiality

HCPs should maintain privacy of patients as common law dictates unless: [113]

- Ordered by the court of law (*Botha v Botha 1972*).

- Information disclosure is used as a defence by practitioners, when patients make a complaint to regulatory bodies against their treatment by the practitioner.

- Patients consent to information to be disclosed.

- An Act of parliament stipulates the limitations.

In terms of the National Health Act: Any information may not be disclosed unless:

(a) consent is made in writing by the person to disclose;

(b) a law or a court order requires information to be disclosed

(c) if failure to disclose could result in a serious harm to public health.[70]

The Promotion of Access to Information Act - Section 31(3) states that if the practitioner is concerned that disclosure of the information could affect the mental and physical health of the relevant person, an information officer may only grant access to that information if counselling is given before and after disclosure of information to alleviate possible harm to the relevant person.[114]

2.10 Health Related Freedoms

If the right to privacy and confidentiality is not upheld, it may affect and limit the freedom of patients. Within the health care sector, the right to security and liberty; freedom of movement, and bodily integrity, should be guaranteed for all patients.

2.10.1 The Right to Security and Liberty of Person and Freedom of Movement

The right to Security and Liberty is recognised in Article 3 of the UDHR,[17] Article 9(1) of the ICCPR,[18] Article 14 of the CRPD,[34] Article 6 of the ACHPR,[35] and Article 5 of the ECHR [37]. As well as, Section 12(1) of the Constitution of South Africa: “Everyone has the right to freedom and security of the person”.[41]

Security is defined as “the state of being free from danger or threat”.[116] It is the safety of patients from criminal activities such as espionage, theft, danger, and terrorism. Security is also defined as “measures taken to ensure such safety, of the state, by feeling safe, stable and free from fear or anxiety”.[116] The right to security is closely associated with the right to liberty.[117]

Liberty is defined as freedom of control. There are two conceptions, negative and positive liberties. Negative liberty is when a person is said to be free to the degree that people do not interfere with their actions. Positive liberty relates to a person’s wish to be self-governed. This means that the decisions patients make depend upon themselves, with no external influences.[118]

Freedom of movement - In some parts of the world, such as Asia and sub-Saharan Africa, patients have been detained in hospital for not paying their medical bills and while being detained were subjected to degrading and abusive treatment by HCP’s.[119] Those detained included vulnerable groups, particularly women and their new-born babies, in need of life-saving emergencies. This violates the right to liberty and security of persons and freedom of movement, and it affects other human rights such as the right to dignity and life. Detaining of patients against their will and denying them the exercise to their freedoms in any clinical setting, goes against moral principles and the law.[119] The right to freedom of movement has provisions in Article 11 of the ICCPR[18], Article 5 of the ECHR,[37] and Article 12 of the ACHPR[35].

In the case of *LB Hillingdon v Steven Neary* (UK),[120] Neary, suffered from autism, and the respite facility decided that Neary should not return home to his father. It was ruled

that “there is an obligation on the State [under Article 5(4) ECHR][37] to ensure that a person deprived of liberty is not only entitled but enabled to have the lawfulness of his detention reviewed speedily by a court”.[120] Mental health care users and their detainment is guided in the Mental Health Care Act in South Africa.[69]

2.10.2 The Right to Bodily Integrity

The right to bodily integrity is not given specific mention in the ICSECR AND ICCPR, however, according to Cohen and Ezer it may be part of the right to security. The right to bodily integrity is provided in Article 5 of the ICERD,[31] Article 4 of the ACHPR,[35] and Article 19.1 of the CRC[33].

Freedoms relating to health are also seen in Section 12(2) of the Constitution of South Africa: “Everyone has the right to bodily and psychological integrity”. [41] The right to bodily integrity is a sacred right grounded in common law for individuals to possess and control his/her own person free from the interference and constraints of others, unless by authority of law. In *Pac. Ry. Co. v. Botsford* it was stated that “the right to one’s person may be said to be a right of complete immunity; to be let alone”.[121]

The physical reality of women’s lives and the challenges they face concerning reproductive health require legal principles “that can reunite women and their wombs”[23] and protect them from government interference. Such principles exist in jurisprudence and security of a person’s physical liberty or bodily integrity.[122] According to Pieterse, section 12(2)(a) clearly ensures reproductive freedom, and might require that legal hindrances relating to freedom of choice regarding procreation, i.e. termination of pregnancy or contraception, be removed.[23] Furthermore, this is guided by The Choice

on Termination of Pregnancy Act[63] that applies to all females at any age. The Act also covers termination of pregnancy regarding severely mentally disabled or unconscious women.

Section 12(2)(a) of the South African Constitution includes decisions concerning the reproduction of men, such as the protection against forced sterilisation, which is enacted in the Sterilisation Act.[65] It is a provision of freedoms and limitations "that a person may not be hindered from sterilisation if they are capable of giving consent, 18 years old and above."[65] Persons incapable or incompetent of consenting for sterilisation are also provided for in section 3 of the Act.

This right as well as security and liberty of a person relates to the principle of autonomy and informed consent and is further explained in chapter 3 (see section 3.3 autonomy).

2.10.3 Limitations to the right to liberty and freedom of movement

The rights in Section 12 of the Constitution may be limited by a court of law as seen in *Minister of Health v Goliath*[123] and relevant Acts of Parliament. Goliath, the respondent was infected with an extensively drug-resistant tuberculosis (XDR-TB), a highly infectious disease. The Minster requested that the respondent be admitted to Brooklyn Chest Hospital and remain there.

It was questioned if it is justifiable to have the respondent in isolation and under compulsory admission and, whether it was a violation of Section 12, of the Constitution. However, the judge relied on the Act of Parliament - Section 7(1)(d) of the National Health Act.[70] The Judge stated the provisions of section 7 read with "health service is wide

enough, in my view, to encompass involuntary isolation of patients with infectious disease at a state funded healthcare facility".[123]

The court also referenced the WHO that states it may legitimately be accepted to involuntarily detain and isolate infected persons, if it assures the prevention and spread of infection to others. The judge stated that isolation of patients is universally recognised - this is also seen in Article 12 of the ICCPR.[18]

Article 25 of the Siracusa Principle[86] on the limitation and derogation provisions in the ICCPR stipulates that public health may be a premise for limiting specific rights, so that governments may deal accordingly to the threat that may affect the health of individuals or the population. Examples of the measures that should be taken by the State is preventing injury, or disease and aiding the injured and sick.[86]

Article 29(2) of the UDHR affirms: "In the exercise of his rights and freedoms, everyone shall be subject only to such limitations as are determined by law solely for the purpose of securing due recognition and respect for the rights and freedoms of others and of meeting the just requirements of morality, public order and the general welfare in a democratic society"[17].

2.10.4 Limitations of the right to bodily integrity are found in:[124]

- Act of parliament: the Criminal Law (Sexual Offences and Related Matters) Amendment Act states that alleged sexual offenders must go for compulsory HIV testing. The Criminal Procedures Act under section 37(3)(b) further notes that

blood samples of the accused are to be taken to “ascertain the state of health of any accused at such proceedings.”[125]

- Common law precedents - as seen in *Botha v Dreyer* -now *Moller*[126] Although a parent or guardian does not consent for blood to be drawn from a child the court may order the child to DNA testing, to determine the other biological parent, which may be seen in the best interest of the child.

2.11 The Right to Remedy

Human rights conventions incorporate different actions towards guaranteeing effective remedies for people whose human rights have been violated. The right to remedy is provided for in Article 8 of the UDHR,[17] Article 6 of the ICERD,[31] Article 2 of the CEDAW,[32] Article 26 of the ACHPR,[35] Article 13 of the ECHR.[37] Moreover, Article 14 of the ICCPR[18] incorporates compensation with respect to a reasonable trial and effective remedies are stipulated under Article 2 (3) of General Comment No. 31 – “Nature of the General Legal Obligation Imposed on States Parties to the Covenant”[127] that patients have access to an effective remedy to support these rights.

Furthermore, remedies should include vulnerable groups, specifically children within health care. Certain vulnerable groups and children should have remedies suitably adapted to consider their needs.[127] The judiciary assures the enjoyments of the right in the covenant through different mechanisms, which include direct application of the covenant, and of comparable, provisional and constitutional law. It is required that the allegations of the violation rights be investigated promptly, effectively and thoroughly by means of impartial and independent bodies.[127]

In the Constitution of South Africa, the right to remedy is seen under Section 34.[41] Patients' rights that are violated are also protected under Chapter 8 section 165 of the Constitution.[41] Courts are subject to the law and the Constitution, which should be applied impartially without favour, prejudice or fear as seen in *Minister of Health v Treatment Action Campaign*.[24] Patients may also seek the help from national human rights commissions and the ombudsman.

2.12 Conclusion

Although medical and health law are used interchangeably, they are distinct and cover different aspects of the medical professions. Within health law the focus is on medical service delivery, whereas the medical law is concerned with patient's rights. The foundation of medical law is to protect the human rights of patients by regulating patient care with professional conduct.

Since the 1980s a shift has occurred within the health care sector from viewing patients as merely consumers and treating them as such, to a more human rights-based approach. The health care sector therefore had to focus on how to incorporate the principles of human rights into the services they provided, hence the development of the Patients' Rights Charters.

Patients' Rights Charters differ across countries. However, the foundations of these charters are based on international and regional laws as well as protocols that seeks to ensure that health is both an entitlement and freedom to be enjoyed. South Africa's Constitution also affirms the rights of patients through the Bill of Rights. The thinking behind the Patients' Rights Charters and human rights intersect on key principles that

recognise the rights to: health, life, dignity, remedy, equality and non-discrimination, participation in public policy development, privacy and confidentiality, bodily integrity, security and liberty of a person, and freedom of movement.

However, as much as law and human rights play an integral part in the relationship between a HCP and patients, bioethical considerations are also important. The health care sector also needs to take into consideration values within the bioethical field to guide ethically and morally sound behaviour of both HCPs and patients. Chapter 3 will discuss how bioethical considerations also have a bearing on Patients' Rights.

CHAPTER 3: BIOETHICAL PRINCIPLES AND THE LINK TO HUMAN RIGHTS

3.1 Introduction

Human rights together with bioethics encompass human sympathy and the application of various principles and rules in decision-making. The normative fundamentals of bioethics and human rights are entrenched in respect for human dignity, equity, and justice.[128] This field is increasingly gaining recognition within developed countries, due to the many new ethical challenges that emerge as a result of biosciences[129] and health policy.[130] Bioethical analysis is important in policy development because many people are affected.[131]

In this chapter a bioethical approach to human rights will be discussed using principlism, also known as the principlist approach "as a way of dealing with ethical decisions".[132] The principles, proposed by Beauchamp and Childress are autonomy, non-maleficence, beneficence and justice. The principles are not absolute, but prima facie and no specific principle has a level of priority over the other. This chapter aligns to objective 2 – to examine with the use of ethical principles, the rights to health and health care.

3.2 Bioethical principles in patients' rights

The most fundamental level of bioethics is clinical bioethics.[133] This falls within in the domain of hospitals and clinics with the implementation of bioethical values, concepts and methods. Within the practice-theory spectrum, this level includes ensuring that hospitals have an ethical orientated focus, in order to improve patient care and delivery of care.[134] Ethicists, lawyers, or clinicians assist within this domain when concerns or confusion, with regard to healthcare and patients' rights, family members, doctors, or nurses arise.[133,135]

Furthermore, these problems are not hypothetical, but they happen in real time. Clinical ethicists are also aware that a decision must be reached in a timely manner regarding the case at hand unlike the academic discussions in bioethics that can take hours. [136]

At another level, bioethics is policy oriented,[137] where bioethical policy analysts help with the development of policies that impacts a large number of people. This concerns the development, discussion and debates over the advantages of contending policies such as medical effectiveness or do-not-resuscitate orders. During the process of planning policy, a bioethical orientated decision includes acknowledgement of individuals' autonomy. This involves the criteria to be free to make informed decisions and to prohibit those that prevent individuals from making such decisions.[138] This occurs at different levels like health systems or hospitals and is discussed by HCPs, administrators, bioethicists, relatives and staff members. It occurs during the ratification of international policy and legal frameworks, with different states as well as national commissions, tasked to formulate policy on crucial issues such as access to health care.[133]

Lastly, at the "end of the practice-theory spectrum, there is bioethics as a theoretical pursuit of truth".[133] This is unrestricted by the practical confines of the national policy and on-site healthcare settings. In this context academic work could be useful to public policy as "a standard motivation for engaging in practical ethics to influence practice".[133]

The "principlist approach to ethical decision making" according to McCarthy, makes three essential claims;

1. "Basic principles and the specific action guiding rules that are derived from them are central to the ethical decision-making process in health care situations.

2. In any given health care situation, any decision or course of action is morally justified if it is consistent with relevant principles, rules, background theoretical commitments, and particular judgments.

3. The success of the task of justification in 2 can be measured by the degree to which it achieves an overall cohesion of all of the elements of the decision-making process."[139]

3.3 Autonomy

The concept of autonomy (or self-rule) is of Greek origins: autos (self) and nomos (law, governance or rule) and is first referenced in ancient Greece (Athens first democracy).[140] Autonomy, is a diverse manner of self-governance that's extends to, privacy, dignity, equality, freedom of persons, liberty and security, making individuals and their behaviour their own.[140]

A few distinctions must be made regarding the different kinds of autonomy. "Moral autonomy" denotes the ability to enforce the moral law with respect to oneself and "a fundamental organizing principle of all morality".[141] On the other hand, what is called "personal autonomy" is intended as a characteristic that people show relative to the facets of their lives, and it is not restricted to questions of moral obligation.[141]

Furthermore, Kant elaborated the notion of autonomy in two components.[140] The first is having control over one's actions, instead of letting the principles by which one decides to be resolved by society, political leaders or authority external to ourselves. [142] Kant called upon the will to direct one's guiding principles for oneself, and by these lines linking the notion of self-government to morality. The second is "one should be obedient to one's

own self-imposed law" as opposed to being submissive to an outside force. [143] This means that self-governed individuals can effectively control and decide for themselves.

Beauchamp and Childress state that autonomy has several conceptions and ideas, thus making it necessary to conceptualize it along certain objectives such as personal autonomy.[144]

3.3.1 Autonomy in Human Rights

Autonomy is recognised in the provisions of:

3.3.1.1 Health Related Freedoms – The right to security and liberty of persons, the right to freedom of movement, the right to bodily integrity.

Essential to personal autonomy, is freeing individuals from limitations and controlling interferences that stop meaningful choices. This notion in the principle is safe guarded in in the rights to security and liberty of persons and freedom of movement (see section 2.10 Health Related Freedoms in chapter 2). There are two essential conditions to be met for the realisation of autonomy: "(1) liberty (independence from controlling influences) and (2) agency (capacity for intentional action)." [144] The autonomous individual – the patient, is free to make an independent choice with understanding, deliberation, reasoning and without any limitation on freedom of movement.[144]

Moreover, from a bioethical perspective diminished autonomy provides another limitation to the right to liberty and security and freedom of movement (see chapter 2, section 2.10.3 Limitations to the right to liberty and freedom of movement). Through diminished autonomy, the patient is incapable of thinking or reaching her/his goals, objectives and,

in some respects, is governed by other relevant persons. Examples of diminished autonomy are persons with mental disabilities and some psychiatric patients because of mental illnesses.[144] Respect for autonomy can be superseded by contending moral considerations. It has only prima facie standing. If bad choices put public health in jeopardy, or others in harm, or require a scarce resource to which no funds are available, then others can justify the restriction of one not to exercise her/his autonomy. [144] This is in line with the Article 25 of the Siracusa Principle.[86]

Autonomy is intrinsic to the right to bodily integrity through health-related freedoms. Freedoms include the "right to control one's health and body, including sexual and reproductive freedom, and the right to be free from interference."[23] The entitlements include health protection through equal opportunities.

In terms of the right to security, Booth notes that a theory of security is essential for the pursuit of "moral politics, empirical curiosity and to raise the challenges of the times".[145] According to Booth in Bourne and Bully,[146] the notion of world security is synonymous with the freedom of individuals and assemblies/groups. This ethical premise for security is constructed on equality and freedom. However, security is not the objective of 'moral politics', it is illustrated as a 'means', while its end is liberation.[147]

Autonomy and liberation may be conceptualized in terms of "how determined one's life is". Having security is having a choice; having insecurity is determined as having no choice, thus living in fear. This may be because of 'structural oppression' i.e., poor patient care and poverty. Therefore, the higher the threats to security the more life-determining they will be. Furthermore, such life-determining threats are removed by access to

liberation and security rights.[146] Bourne and Bulley note that insecurity obstructs the chances for victimised people to attain affirmation towards autonomy. Both liberation and security relinquish the dangers that end or limit autonomy. Security and ethics as a referent subject, is that which is made free, equal and secured and in the end, this is the individual human being.[145,146] To Booth, the individual person remains the 'ultimate referent' for security, governmental issues, and ethics, because they are 'primordial', unlike groups, gatherings, and societies that are not. Individuals are 'irreducible units' of a community and the start of agency.[145]

Autonomy can be achieved for individuals through the community, as an objective security ethics. People are the referent, but the 'community is the site for security'. Booth defines security ethically as a secure foundation from which to act and judge between the correct and incorrect.[145.146] Security may just be portrayed as 'ethics from Autonomy'.[145]

3.3.1.2 Right to Receive Information

Within the health care context there is the tendency to use the authority of physicians to "perpetuate the dependency of patients" instead of enhancing patient autonomy.[144] Respecting patient autonomy means supplying them with the necessary means to overcome dependency - it gives patients the control they desire.[144] This obligation of respect for autonomy encompasses the duty of conversation, disclosure and restoration of sick patients "to a condition in which meaningful action is possible.", thereby facilitating the agency of patients.[144]

Autonomy obligations align with specific moral rules which are:

1. “Tell the truth.

2. Respect the privacy of others.

3. Protect confidential information.

4. Obtain consent for interventions with patients.

5. When asked, help others make important decisions”.[144]

These are not absolute but are prima facia. These principles hold for autonomous persons and are not broad enough to cover non-autonomous persons. Examples include those that are exploited, incapable, immature, ignorant, coerced, drug addicts and suicidal people.[144]

Patients should be provided with proper and sufficient information through means that they can understand.[148] The requirements for informed consent include the right to receive information that is “explained in an understandable language and include the nature of the condition, the proposed diagnostic steps regarding the treatment, the risks and benefits, alternative treatment (even no treatment), and the probability of the treatment’s success”.[149]The right to receive information is safe guarded in: Article 19 of the UDHR,[17] Article 19.2 of the ICCPR,[18] Article 21 of the CRPD,[34] Article 9.1 of the ACHPR[35] and Section 32 of the Constitution of South Africa[41].

3.3.1.3 The right to Informed Consent.

“Autonomy or the right to self–determination is a fundamental ethical principle underlying informed consent”.[150] Informed consent relates to the contractual relationship between

the HCP and patient, by which a HCP will, with the “generally accepted standards”[150] diagnose and treat patients. Moreover, the contract implies that full knowledge of the conditions and willingness to agree to the contract is involved. Legally this is known as a fiduciary relationship i.e. the patient has confidence and trust in the HCP. Consent of treatment can be implied (tacit) by conduct, expressed orally or in writing (signed).[150]

Decisions are supported by “legal doctrines of informed consent and by the ethical process of shared decision-making”.[151] Patient empowerment and patient-centred care is closely related to shared decision-making that allows the patient to make informed decisions with the physician.[151]

Before proceeding with surgical or medical treatment informed consent must be first ethically and legally obtained. In the context of South Africa in the matter of *Isaacs v. Pandile* the doctor sterilized a patient, without proper consent and as a result “breached a contractual agreement.”[152] Performing procedures without consent was constituted as assault, which in turn violated the rights to safety, dignity, privacy and reputation.[152] Failure to acquire proper informed consent is failure to respect patients’ autonomy. Patients may then be placed at a risk, and this may constitute negligence[153] as stated clearly in the matter of *Schoendorff v. Society of New York Hospital* “Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent, commits an assault, for which he is liable in damages.”[154] However, this is limited in cases of emergency where a patient is unconscious and a HCP may have to operate without obtaining consent[153]. Requirements for informed consent include that:

1. The information should be explained in an understandable language and include the nature of the condition, the proposed diagnostic steps regarding the treatment, the risks and benefits, alternative treatment (even no treatment), the probability of the treatment's success.
2. Patients' understanding of the above mentioned should be assessed
3. "Assessment, if only tacit, of the capacity of the patient or surrogate to make the necessary decision(s)." [155]
4. Assurance should be given to patients that they have the freedom of choice for medical treatment without manipulation or coercion.[155, 149]

The right to informed consent is supported by the CRPD Article 15,[34] Article 25 (d) the ICESCR,[19] and the ICCPR Article 7 states that ". . . no one shall be subjected without his free consent to medical or scientific experimentation"[18]. As well as, Section 12(2)(c) of the Constitution of South Africa.[41]

3.3.1.4 The right to privacy and confidentiality

The right to self-determination, pertains to autonomy rights, as in the rights to privacy and confidentiality (see chapter 2, section 2.9 The Right to Privacy and Confidentiality). Confidentiality is pivotal to trust. The HCP should ensure the autonomy of the patient by not disclosing a patient's information without permission, or without a compelling reason to do. Failure to adhere to confidentiality is deemed illegal by the courts. Privacy pertains to the right to control access to oneself, thereby, exercising the principle of autonomy to make an independent choice which includes control or access to one's privacy and confidentiality within the healthcare setting.

Article 12 of the ICCPR affirms that “no one shall be subjected to arbitrary interference with his privacy”.[18] These rights relate to the moral rule of autonomy that one should respect and protect privacy and confidentiality respectively. Moreover, all these rights relate to autonomy by meeting the essential conditions that is negative liberty (free from controlling influences) of persons and positive liberty which relates to a person’s wish to be self-governed, [57] as explained in section 2.10.1 The Right to Security and Liberty of Person and Freedom of Movement.

3.3.1.5 The right to conscience and religion or beliefs

Even the right to conscience and religion or belief draws from liberty and agency. Being respected as an autonomous agent is to recognise and accept patients’ views to make decisions or choices (free from controlling influences) with understanding, deliberation, and reasoning based on values or preferences, beliefs and conscience. [156] HCPs should be aware that patients are at liberty to bring in their personal beliefs to make decisions. Disrespect of autonomy involves actions and attitudes that disregard, demean, insult and ignore the autonomy of others.[144]

Bayle’s theory of tolerance states that rationally every person has a right to conscience and religion or belief without constant persecution of that religious affiliation. The tolerance theory hinges on the notion of freedom of conscience. It is about the HCP respecting patients’ religious affiliations without maltreatment.[157] It is unlawful to utilize violence against people, because of opposite beliefs.[157] The right to conscience and religion or belief is safe guarded in the UDHR Article 18,[17] the ICCPR Article 18.3 and

18.1,[18] Article 8 of the ACHR,[35] and Section 15(1) of the Constitution of South Africa "right to freedom of religion and belief".[41]

3.4 Non-maleficence

Autonomy requires respect for decision-making and communication between the HCP and the patient. Communicating in the wrong way and not respecting a patient's decisions/wishes could result in harm which goes against the principle of non-maleficence.[158] In medical ethics non-maleficence is closely related to the principle "Primum non nocere" "*First (above all) do no harm"*. It is recognised in Gillon as "the cardinal ethical principle sacred to medicine"[29] and is said to have originated from Hippocrates. Gillon contends that the principle does not have the straightforwardness, supremacy, or the importance that the words "*First (above all) do no harm"* suggest.[29] Non-maleficence summarises moral rules like "don't kill . . . don't cause pain. . . don't disable"[159] which are standard. It also includes "don't deprive of pleasure. . . don't deprive of freedom".[159]

Beauchamp and Childress state that the idea of non-maleficence will often be explicated utilising the terms injury and harm. [160,161] Injury refers to harm, on the one hand, and on another hand, it refers to setbacks, violation, injustice or wrong. The expression harm has some vagueness, for example X harmed Y might imply that X wronged Y or dealt with Y unjustly, or that Y's interest was setback, thwarted or defeated by X. Wronging includes disregarding and violating somebody's rights.[161]

Moreover, a harmful intrusion by a party on another's interest might not be unjustified or wrong, even though it may be a prima facia wrong. Some harmful actions are reasonable against another's interests, such as, justified criminal punishment and war.[161]

Likewise, with actions that punish different peoples, wrongness or rightness relies upon the quality of one's support for the action. Beauchamp and Childress note what one essentially considers as harm to one individual may not be a harm at all to someone else. Moreover, because of contending notions, it can result in difficulty or a setback to interests including liberty, privacy, property and reputation. In this expansive definition, harms can be recognised from minor to severe harms by the level and scale of individuals' interests.[161]

Different definitions of harm consider only setbacks to physical and mental interests like those in healthcare. Regardless, Beauchamp and Childress focus on "pain disability and death, without denying the importance of mental harms and setbacks to other interests."[161] Because of the many types of harm, the principles of non-maleficence supports more specific moral rules such as:

1. " Do not kill.

2. Do not cause pain or suffering to others

3. Do not incapacitate others

4. Do not cause offense to others

5. Do not deprive others of the goods of life" [161]

The specification and principles are not absolute but prima facie. Beauchamp and Childress state that their principles have no level of priority over the other.

Hence, the duties to do no harm and not to impose risk on others are the values entailed in non-maleficence. Even without bad or malicious intent, a person may be placed at risk by another, and thus, the person that caused harm may or may not be legally or morally responsible for the risk caused. There are instances where the person is responsible for a harm they did not intend to do or was unaware of doing at the time. Regarding risks imposition, the standard of due care is recognised by morality and the law. [161]

3.4.1 Non-maleficence in Human Rights

Non-maleficence is recognised in the provisions of:

3.4.1.1 Right to freedom from torture and cruel, inhuman and degrading treatment

In the ICCPR, Article 7 states: “no one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment”.[18] This is related to non-maleficence in that the principle’s moral rule is not to cause pain, disable or kill and to do no harm. According to Sanders[162] in the clinical context, non-maleficence obliges HCPs to prevent patients from being harmed. This includes emotional, physical, and psychological harm. In the matter of *Topham v Member of Executive Committee for the Department of Health (Mpumalanga)*[163] it was found that personal injury or harm suffered by a patient from a HCP was as a result of negligence to which “delict gives rise to a civil action at the suit of the injured party.”[61]

In the matter of *Oppelt v Head: Health, Department of Health Provincial Administration (Western Cape)* the doctor (defendant) failed to prevent the spinal cord injury of a patient. The doctor failed to "guard against the eventuation of the harm in the form of permanent paralysis."[164] The case relied on negligence formulated in *Kruger v Coetzee* "For the purposes of liability culpa arises if— (a) a diligens paterfamilias in the position of the defendant— (i) would foresee the reasonable possibility of his conduct injuring another . . . (ii) would take reasonable steps to guard against such occurrence; and (b) the defendant failed to take such steps".[165]

Avoiding negligence implies that a reasonable man would have anticipated the probability of harm and taken steps to prevent or guard against it. For example, if hospital managers can foresee harm to patients and not provide preventative measures, they are liable for resultant harm incurred. This makes health care mangers liable "for negligently failing to repair or replace medical equipment or obtaining the required medical items (including drugs) when resources were available".[166] This right is further protected in the UDHR Article 5,[17] the CRPD Article 15,[34] the ACHPR Article 5,[35] and the Constitution of South Africa section 12(d)(e).[41]

3.4.1.2 Health Related Freedoms – The right to security and liberty of persons, the right to bodily integrity

Non-maleficence is safeguarded in the right to security and liberty of persons as per Beauchamp and Childress's definition of harm being broad enough to include setbacks to liberty and bodily integrity.[161] Moreover, non-maleficence rights are closely linked to autonomy rights as can be seen by the right to liberty and security. Article 7 of the

ICCPR[18] may extend to General comment 14 on the right to the highest attainable standard of health (Article 12)[57] which states that the right to health contains freedoms, which include the right to freedom from torture and unwanted interferences. The Human Rights Committee on general comment 20 of Article 7 (Prohibition of torture, or other cruel, inhuman or degrading treatment or punishment) of the ICCPR states that the "the prohibition in Article 7 relates not only to acts that cause physical pain but also to acts that cause mental suffering to the victim."[167] The Committee further states that protection of Article 7 should be emphasized to patients.[167]

3.4.1.3 The right to practice religion and use one's own language

Article 27 of the ICCPR states that ". . .minorities shall not be denied the right . . . to profess and practise their own religion, or to use their own language"[18]. Because medical negligence relates to harm to patients, a reasonable HCP would reduce the probability of harm and take steps to prevent or guard against it, for example, by providing medical information in the patients' language.[168]

Communication difficulties in the health sector impacts the care patients receive. Studies have shown how poor communication "coupled with a lack of common ground and understanding of cultural issues"[168] impact the care women receive, leading to midwives failing to offer psychological support to women who do not speak English.[168] It has been stated that HCPs tend to focus on the physical aspects when caring for their patients. As a result, they cause psychological harm by not caring for or noting emotional problems. Moreover, failure for HCPs to communicate leads to frustrations in their non-verbal cues, thereby possibly worsening the psychological harm and hence, not respecting the

principle of non-maleficence.[168] Nationally this right is found in Section 31 of the South African Constitution.[41]

3.4.1.4 The right to dignity

Article 1 of the UDHR states that “all human beings are born free and equal in dignity and rights”[17] (see chapter 2, section 2.6 The Right to Dignity). This right relates to non-maleficence as integral to harm such as failure to disclose medical errors and misleading patients causing unnecessarily worry thereby violating their dignity. When inflicting harm on a patient, failure to disclose the error to a patient, makes the conditions and circumstances worse.[169] This is misleading to a patient as he/she may unnecessarily worry about their extended stay or deteriorating condition thinking it may be due to some underlying disease. As discussed in chapter 2 the right to dignity claims respect, and part of the moral rules of non-maleficence is to “not cause offense to others”.[161] Respect for dignity prohibits degrading treatment. instrumentalization, commercialization, stigmatization, and discrimination human beings. [170]

HCPs have a moral obligation to uphold a patient’s right to dignity through the principle of non-maleficence by refraining from:

(1) “preventing patients from undergoing beneficial treatment without good reason,

(2) exposing patients to unreasonable risks, and

(3) reducing the therapeutic effect of an effective medical intervention.”[171]

The idea of dignity incorporates not only the worthiness of specific treatments from HCPs, but also the fact that there are ways of acting that befit dignity.[100,172]

3.4.1.5 The right to Life

The right to life is normally understood as a claim right (see chapter 2 section 2.4 the right to life). Therefore, if a claim right to life is endowed by person A, it is not justifiable for others to harm or kill when they can be saved with no harm to others which aligns to the principle of non-maleficence. If person A's life was a mere liberty it would equate to no more than the absenteeism of a duty to kill or to fail to save themselves.[40]

The right to life as understood by Feinberg is a double-barrelled claim with two distinct sets of claims. Firstly, it is an obligation to not cause the death of another person by an individual or group of people. Secondly, HCPs have an obligation not to neglect saving a patient's life.[40]

3.5 Beneficence

According to Cook,[173] beneficence and non-maleficence are distinctive with different commitments. Guidelines of beneficence requires positive necessities for an act that is voluntary and is normally a more demanding rule than non-maleficence. As opposed to non-maleficence however, legal punishment is rare when there is a failure to abide by the rules of beneficence.[173] Rules and guidelines of non-maleficence are negative prohibitions for an act that must be followed fairly. Persons that do not adhere to these rules can end up in trouble with the law. From the perspective of a physician non-

maleficence and beneficence are commonly seen together in their roles and responsibilities.[173]

According to Beauchamp and Childress[174] the principle of beneficence requires that we promote the welfare of a person. Positive necessities for an act that is voluntary are requisite. They state that although non-maleficence is to prevent and remove harm, such prevention and removal requires positive actions that benefit others.[174] In English beneficence is equated with actions like charity, mercy and kindness. Beneficent actions are broad and entail actions that intend to benefit others. [174]

There are two norms that comprise beneficence: positive and utility beneficence. Positive beneficence necessitates “the provision of benefits”.[174] Utility beneficence necessitates “that benefits be balanced”.[174] The principle of beneficence, in biomedical ethics, emphasises the duty to help others (patients/ communities) and further their interest.[174]

Beauchamp and Childress contend that part of the central dynamics of biomedical ethics are obligations that weigh risks and benefits of certain actions and so prevent and remove such harm.[174] Utility beneficence is regarded as an extension of positive beneficence, because in life one does not generally get the chance to produce and eliminate benefits and harms, respectively, without producing risks or incurring costs. The utility principle, also known as proportionality, is often criticised because societal interest overrides individuals’ interests and rights.[174]

It is ideal for beneficence to require an act of generosity and altruism. However, it is not common to require of people to benefit others in all circumstances.[174] The ideals are much greater than the obligations of beneficent actions and to distinguish between the

ideal and obligation is difficult. Positive beneficence produces more specific moral rules such as:

1. “Protect and defend the rights of others
2. Prevent harm from occurring to others
3. Remove conditions that will cause harm to others
4. Help persons with disabilities
5. Rescue persons in danger”[174]

Confusion has arisen regarding non-obligatory moral ideals and obligatory beneficence. This could be addressed by understanding general and specific beneficence. Specific beneficence is to specific parties e.g. patients, the elderly, and adolescents, whereas general beneficence encompasses special relations to all persons in general. [174] People agree that general beneficence is a more demanding social obligation which entails being obliged to enhance the interest of other people outside the domains of relationships and spheres and to act impartially. Specific beneficence, includes the duty to help identifiable persons that are in need. This is formed in special moral relationships like friendship, parenthood and patients-doctor relations.[174]

3.5.1 Beneficence in human rights

Beneficence is recognised in the provisions of:

3.5.1.1 The right to health

Beneficence is considered in the right to health (see chapter 2, section 2.3 The Right to Health and Relevant Rights) by beneficent actions that prevent loss or damage and rescue persons in danger. The person is to expect more gain than harm.

With specific obligations of beneficence, person X only has a determinate obligation of beneficence towards Y if the following conditions are met:

1. “Y is at risk of significant loss of or damage to life or health or some major interest
2. X’s actions needed (single or in concert with other) to prevent this loss of damage
3. X’s action (single or in concert with other) has a high probability of preventing it
4. X’s actions would not present significant risks, cost, or burdens to Y
5. The benefits that Y can expect to gain outweighs any harms, cost or burden that X is likely to incur”[174]

Beauchamp and Childress[174] state the fourth action is important because it guides people on how to act or solve problems. Furthermore, it may be difficult to specify the burdens, costs and risks. However, it remains clear that implicit assumptions of beneficence in health and medical professions should enhance the welfare of patients and not only just avoid harm through the right to health.[174]

3.5.1.2 The right to social security and adequate housing

Beneficence in health care enhances the welfare of patients and relies upon charters to include the right to adequate housing and social security. The UDHR states in Article 22 “Everyone, as a member of society, has the right to social security.”[17] The UN reported

that about four billion people – more than half of the global population – lack social security protection. Lack of social security leads to ill health.[175] This right to social security relates to beneficence by acknowledging the roles of social determinants play in health such as, food, a healthy environment, housing, and safe water and hence promoting the welfare of patients.

Socially centred actions are in line with the Hippocratic Oath that pledges HCPs as follows: "they will . . .come for the benefit of the sick" will give treatment "for the benefit of the sick according to [their] ability and judgement. . . will keep from harm and injustice".[176] Socially centred actions of beneficence include preventative and active public health interventions. This is further supported by Article 25(1) "everyone has the right to a standard of living adequate for the health and well-being of himself/herself and of his/her family."[17] As well as, Section 27 of the Constitution.[41] Health care cannot be considered in isolation without taking into account the social determinants of health. This section is analysed below in chapter 4 (section 4.3.1.1 The right to health and related right) alongside the core obligations of General Comment 14 discussed in Chapter 2 (section 2.3.1 International Law regarding the right to health and the relevant rights).

3.5.1.3 The right to receive information

In the ICESCR, Article 19,[19] the right to receive information relates to informed consent and beneficence, in that, it is in the patient's best interest to receive all pertinent information. Patients have the right to receive information that is explained in an understandable language and includes risks and benefits. The best interests of a patient require information that weighs the risks and benefits of certain actions and in so doing

prevents and removes certain harms. Beneficence in health care enhances the welfare of patients which relies upon received information. Receiving information meets the conditions of beneficence where a patient may see the benefits expected, and cost or burden that is likely to incur as discussed in section 3.3.1.2 the right to receive information.

3.6 Justice

Rawls conceptualised a social contract methodology through demonstrating that justice is essential for a social contract, where people are equal and free. Furthermore, justice was limited to the conceptions of the basic structures of society[177,178] "for example how ought society to distribute the primary goods?"[179]

Primary goods are categorised into social primary goods and natural primary goods. Goods distributed by natural lottery rather than by societal influences and institutions are known as natural primary goods.[180] These are intuition, intellect, strength and imagination. Social primary goods also known as "chief primary goods"[181] are at the disposition of society. These goods, Rawls states, are "rights and liberties, powers and opportunities, income and wealth."[181] Rawls recognises the importance of social goods in his theory for a basic and just structure of a society.[181]

Rawls states that for an individual to have or even figure out their rational life plans there ought to be a fair distribution of social primary goods. This implies that without social primary goods being distributed and made available to individuals, their rational life plans may not become a reality. Moreover, another critical aspect of fairness is the principle that enables a well-ordered society.[178] A just society will enable that ""everyone accepts

and knows that the others accept the same principles of justice, and the basic social institutions generally satisfy these principles."[182]

3.6.1 Modes of resource allocation

The WMA medical ethics manual states that there are three levels of distributing resources or 'resource allocation.[183,184]

- The first is the Macro level. Here it is decided out of the overall budget how much governments should allocate to health; which healthcare services will be free of charge and which will require payment from the medical insurance or out of pocket payment from the patients. Furthermore, HCP's remuneration is calculated from this budget as well as research, education of health professionals, and treatment of "specific conditions such as tuberculosis or AIDS".[184]
- The second is the Meso level which takes place within institutions. This includes healthcare agencies, clinics and hospitals. At this level healthcare authorities make decisions on what services to offer, including the amount of money to spend on staff, security, expansion's and renovations.[184]
- The third is the Micro level which is concerned with the individual patient. HCP's are concerned with what tests should be done, whether referrals are needed, if patients should be hospitalised or not, whether generic drugs or a brand-name drug is required. "It has been estimated that physicians are responsible for initiating 80% of healthcare expenditures".[184] Here HCPs have large discretion to what patients have access to.[184]

3.6.1.1 Difference Principle and Least Fortunate

Rawls contends that inequalities are allowed if they maximise the welfare and expectations of the least fortunate.[185] In such a social order moral discretionary factors do not affect and deny the least well off. Problems of injustices echo problems of poverty. Poor individuals are short of an average level of welfare and this is unreasonable.[185,179]

Accessing health care is a social contract exclusive to moral factors. Such contracts should safeguard the advancements of freedoms and human rights and ensure human dignity. This social contract is a Rawlsian standpoint, in that the common agreement among members of a society and governments as well as justice is safeguarded where rights and responsibilities are fairly adjusted.[186]

When disadvantaged members of society are at an even standard with advantaged members, then one will move towards the objective of achieving equality. The difference principle then in this manner recognises that in an unequal social order benefits/opportunity ought to be given for disadvantaged members so that they may accomplish and attain a better life plan.[179] To understand and comprehend justice in its full capacity the notion of equity should be understood as a formulation or guideline to help the least advantaged groups and it is paramount that equity should be obtained in health care.

3.6.1.2 Equality

Normatively, equality is the idea that people ought to be treated in the same manner. Equality is attained through differential and special treatment. Distributive justice

underscores the importance of equality but recognises that equity plays a major and important role in justice. In contrast equality deters from the notion of equity (demonstrated below) in that people accept equal treatment, irrespective of their inputs – all members in society receive an equal distribution of rewards.[187]

In terms of special needed treatment, equality does help or make provisions for this. Globally there are many challenges that ensure the least well-off people get access to decent healthcare. Such measures can be achieved by means of the notion of equity. Equality of health is a fundamental criterion for measuring equity in the distribution of health. Equality of a person's well-being is qualified with an individual's autonomy and the prohibition of any discrimination on health and well-being. Equality of health can be regarded as a better equity objective.[188]

3.6.1.3 Equity

Lack of political will makes the issues of equity in health difficult. Political readiness to prioritise the idea of justice in healthcare through which equity plays a role, "is at best uncertain".[189] Moreover, individuals who are higher up in the social classes and those with more authoritative power, appear to be less prone to diseases. National policymakers ought not to just decrease wellbeing inequalities between contrasting status groups, but ought to in general raise the mean outcome. This means "closing equity gaps is about raising the position of those at the lower end while continuing to make progress on the upper end of the continuum." [189]

Culyer and Wagstuff identifies two meanings of equity according to need and access.[188]

3.6.1.3.1 Equity according to need

According to Cuyler and Wagstaff, the notion that health care ought to be dispersed based on need is often found in policy documents and academic literature. The principle stems from two versions. A vertical version: “persons with greater needs should be treated more favourably than those with lesser needs”[188] and a horizontal version: “persons in equal need should be treated the same.”[188] This, then necessitates that individuals that are unequal, need to be treated to the extent of their inequality in need.[188]

3.6.1.3.2 Equity according to access

Because of its popularity in certain areas of social policy, the notion of equity with regard to access is popular in healthcare. This notion asserts that health care ought to be the same for everyone.[188] This notion is tied in with equity, bearing in mind that for those with equal needs, access should be the same. Individuals that require different needs should have different access. Therefore, the horizontal-vertical discrepancy comes into play.[188,190]

3.6.1.3.3 Equity according to (i) process, (ii) outcomes, and (iii) a mix of process and outcome

Equity can also further be explained according to (i) process, (ii) outcomes, and (iii) a mix of process and outcome. According to Saltman, a meaning of equity that relies upon process is seen as “fair equality of opportunity”.[189] Equity in health is to be characterised as the state guaranteeing that each person has equal providence to different content or substantive conclusions of a health framework. Thus, the duty of the state is to eliminate

situations that impede people from having a “fair chance”.[189] Such an equity can be seen by low-income countries attempting to ensure health insurance coverage, for people who can’t afford access to health care. The weight of equity relies on “opportunity”, that is, on the conditions that people “require to take action for themselves. It is a process-oriented form of equity.”[189] Saltman further emphasises that opportunity relates to an individual level rather than being outcome-based for a collective group of people.

According to Saltman, the second definition concentrates around equity of outcome, that is, with respect to accomplishing “equality of health status”.[189] Advocates of this notion stress the moral commitment of a socially responsible community to not just provide mechanisms to seek help in health services (for the least well off and ill people) but to also implement an appropriate standard of care.[189] Furthermore, with regard to those that are least advantaged, chronically ill or in a status of poor health, compensation of such members of society should ensure that a *greater* healthcare service is provided to enhance their health outcomes, or try to bring their health as close to their fellow members of society as possible.[189]

The third approach combines the process and outcome, which focuses on equity and social justice rather than just health on its own. Walzer in Saltman states that in different societies different criteria of distributive justice should apply that consider “the intrinsic characteristics of each sector and its role in a good society”.[189] Justice therefore is applying the right standard of equity to the proper segment of society. Thus, regarding healthcare, a distributive justice criterion should apply that meets the social and moral objectives of this specific segment of society.[189]

Equity in health is not solely related to only health and health care. Its interpretation should be extended to include other features of the health sector such as social arrangements and resource allocation. Furthermore, it should be inclusive in the considerations made by states to pay proper attention to the role of human life and freedom.[191]

3.6.2 Justice and the Relevant Rights to Health and Health Care

Justice is recognised in the provisions of:

- **The International Bill of Rights**

The General Assembly, in September 2015, "adopted the 2030 Agenda for Sustainable Development".[192] This includes 17 Sustainable Development Goals (SDGs). Goal 3 relates to healthy lives and promotion of well-being for all at all ages. Part of its targets is universal health coverage, which includes access to good basic health care services and access to vaccines, and affordable, effective, safe and essential medicines for all.[192]

General comment 14 on the right to the highest attainable standard of health (Article 12) states that "More determinants of health are being taken into consideration, such as resource distribution and gender differences"[57] and that "Inappropriate health resource allocation can lead to discrimination that may not be overt".[57]

The WHO states that there should be commitments that progressively realise the right to health – through supports of "maximum available resources".[193] One of the core elements of the right to health recognised by the WHO, is the "progressive realisation using maximum available resources". It does not matter the amount of resources countries have at their disposal, "progressive realisation",[193] necessitates that

governments take measures to fulfil these rights. Despite the capacity of resource, non-discrimination and developments in the juridical and legal arrangements must be realised immediately.[193]

General comment 20 of Article 7 states that governments that fail to eliminate "differential treatment"[167] on the grounds of limited available resources is not a reasonable justification. This relates to justice in that closing equity gaps and raising the position of those that are disadvantaged are essential.

- **Regionally in the African Charter**

Regionally rights related to justice are safeguarded in the ACHR under Article 21(1) "All peoples shall freely dispose of their wealth and natural resources. This right shall be exercised in the exclusive interest of the people. In no case shall a people be deprived of it."[35] This relates to equity according to need in that States' resources should aid those with a greater need more favourably than those with lesser needs. It relates to justice in health as government resources ought to be available to everyone equitably and that people should not be exploited by economic circumstances (equity according to access and equality).[187,188]

- **The Constitution of South Africa**

Nationally resource allocation for social goods is affirmed in the Constitution. Section 27(2) of the Constitution states that "the state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights".[41] These rights are limited and not absolute; the realisation depends on

available resources. However, children's rights differ in the sense that "children have the right to healthcare – not simply the right of access to healthcare".[60] The general population can suffer if decision makers fail to make the right decisions related to resource distribution.

The National Health Act affirms that vulnerable groups are to be provided with healthcare. Equitable resource distribution of healthcare is provided for with attention given to the elderly, woman, children and persons with disabilities.[70]

South Africa is making strides, through the passing of the National Health Insurance (NHI) Bill towards universal health coverage for all South Africans "irrespective of their socio-economic status"[194]. Here public and private providers at hospitals and specialists and will be accredited "based on need". It aligns to distributive justice by providing access to services that include: hospital, pharmaceutical, laboratory and radiology services. It also aligns to the difference principle and equality by stating that priority will be given to those with the greatest needs and vulnerable groups. Moreover, it is in line with equity in that priority will be given to people that experience the most difficulty in obtaining care. Part of the NHIs principles is efficiency where "health care resources will be allocated and utilised in a manner that optimizes value for money that combines allocative and productive efficiency".[194]

3.7 Limitations of the rights associated with Principlism

According to Beauchamp and Childress, if bad choices put public health in jeopardy, or others at harm, or require a scarce resource to which no funds are available, then others

can justify the restriction of one's autonomy. However, this justification may only be on the premise of another overriding or contending moral principle.[144]

According to article 2 of the ICCPR – article 7 is a non-derogable right.[18] Section 58 of the Siracusa Principles states that "No state party shall, even in time of emergency threatening the life of the nation, derogate from the Covenant's guarantees of the right to life; freedom from torture, cruel, inhuman or degrading treatment or punishment, and from medical or scientific experimentation without free consent; freedom from slavery or involuntary servitude."[86] Nationally the Constitution of South Africa states that the rights in 12 (1)(d)(e) and 12.2(c) are non-derogable and shall not be limited.[41] The other rights limitations relating to the four principles were discussed in chapter 2. (See sections 2.5 Limitations of patients' rights, 2.9.3 Limitations on the Right to Privacy and Confidentiality, 2.10.3 Limitations to the right to liberty, and 2.10.4 Limitations of the right to bodily integrity).

3.7 Conclusion

The principles of Biomedical Ethics are respect for autonomy, non-maleficence, beneficence, and justice. Most bioethical decisions are analysed using the four principles. The foundation of autonomy is that of making decisions without limitations and controlling interferences that stop meaningful choices on the basis that it is intentional and with understanding. Respecting one's autonomy is to recognise and accept individuals' views to make decisions or choices. The diminished autonomy of persons incapable of thinking or reaching their goals and objectives, in some regards, are governed by another person.

Furthermore, the principle of autonomy mandates that confidentiality in the professional relationship is respected.

Non-maleficence is a principle that has strong affinity to the notion of morality in that doing no harm, killing, causing pain or disabling are prohibited. Not adhering to this principle will lead to a strong case for negligence. The importance of non-maleficence is that the focus is on preventing an incident of harm and ensuring that the moral rules are adhered to and a patient is protected. Communication plays an important role in patient care, through principle of non-maleficence, allowing patients the right to practice religion and use one's own language. Communication difficulties in the health sector impacts the care patients receive

The extent to which this is protected and respected is dependent on the level of beneficence. Beneficence implies action to prevent harm; eliminate conditions that are harmful; help persons with disabilities and rescue those in danger. Beneficence is the ethical duty for healthcare professionals to take actions in the best interest of their patients, promote the positive welfare of patients and utilise their expertise for the benefit of their patients.

Healthcare is a basic need because it impacts on the opportunities of individuals and thus aligns with the principles of justice. Justice also dictates that when governments distribute resources, they should consider the least well-off members of society. Equity in the healthcare services should be pursued to not only ensure the fulfilment of human rights, but that those who require medical needs the most, actually receive it. Thus, the alignment of bioethical considerations and human rights come together with the use of the four

principles discussed in this chapter. In the chapter that follows an analysis of patients' rights charters from relevant countries globally, is presented.

Chapter 4: COMPARATIVE ANALYSIS ON PATIENTS' RIGHTS CHARTERS

4.1 Introduction

Normative frameworks regarding patients' rights have grown significantly since the introduction of the UDHR. Reasons for increasing patients' rights in legislation are to: (i) ensure quality improvement of health services; (ii) guarantee ethical treatment of all patients; and (iii) meet the necessary physical, mental, and social health needs of patients. In certain countries, health care organisations have established charters for patients' rights.[195] With the use of human rights and bioethical principles, relevant patients' rights charters around the world are compared. Patients' rights vary between different countries; therefore, it is important to identify how these diverse charters align to internationally recognised human rights. Furthermore, it also helps identify the human rights and bioethical gaps that exist among and between them.

This chapter responds to Objective 3 which is a comparative analysis of patients' rights charters and explores whether they adequately align with human rights and bioethical principles.

4.2 Analytical Approach

Twelve patients' rights charters are examined in this chapter. These charters were obtained by undertaking extensive desktop research. They were included in the analysis if they were available in English. Patients' rights charters have been obtained from both HICs and LMICs. Charters from HICs are from Israel,[196] United Arab Emirates (UAE),[197] New Zealand,[198] Australia (relating to the State of Victoria's Government which has

produced a health care rights brochure that describes the Australian Charter of Healthcare Rights under the Victorian healthcare system),[199] Scotland,[200] Ireland,[201] Finland,[202] USA represented by the American Hospital Association (AHA) (which produced a brochure known as the AHA Patients' Bill of Rights)[203] and Hong Kong.[204] Charters obtained from LMICs are from Uganda,[205] Kenya,[206] and South Africa.[207] Owing to language barriers and lack of information through desktop research, no country from South America was included.

The comparative analysis was carried out using human rights and bioethical principles and drawing from the previous 2 chapters. The rights used in the analysis are:

(i) practice religion and use one's own language

(ii) freedom from torture and cruel, inhumane and degrading treatment

(iii) Justice

(iv) a safe environment

(v) adequate housing

(vi) social security

(vii) health and its related rights

(viii) life

(ix) privacy and confidentiality

(x) security and liberty of person

(xi) freedom of movement

(xii) bodily integrity

(xiii) participation in public policy and remedy

(xiv) conscience and religion or beliefs

(xv) informed consent

(xvi) dignity

(xvii) equality and non-discrimination

(xviii) receive information

4.3 Results of the Analysis

In Table 4.1 (below) each right that is affirmed in the charters is recorded with a tick sign, and those that are not are marked with an X sign. The ticks are then counted to determine the total number of rights to which each charter aligns. The higher the score, the more the charter adequately aligns to human rights and bioethical principles. This score can represent a positive expectation and health outcome for patients when accessing their national health services. Based on Figure 4.1, in terms of human rights and bioethical principles alignment, the results show that South Africa's, Ireland's, Australia's and Scotland's charters have the most 'number of ticks' 87% for the total elements of human rights possible, followed by Uganda (78%), New Zealand and UAE (70%), AHA and Kenya (61%), Israel and Hong Kong (57%), and Finland (52%). This suggests that South

Africa, Ireland, Australia and Scotland's charters includes the most human rights and bioethical principles compared to other countries.

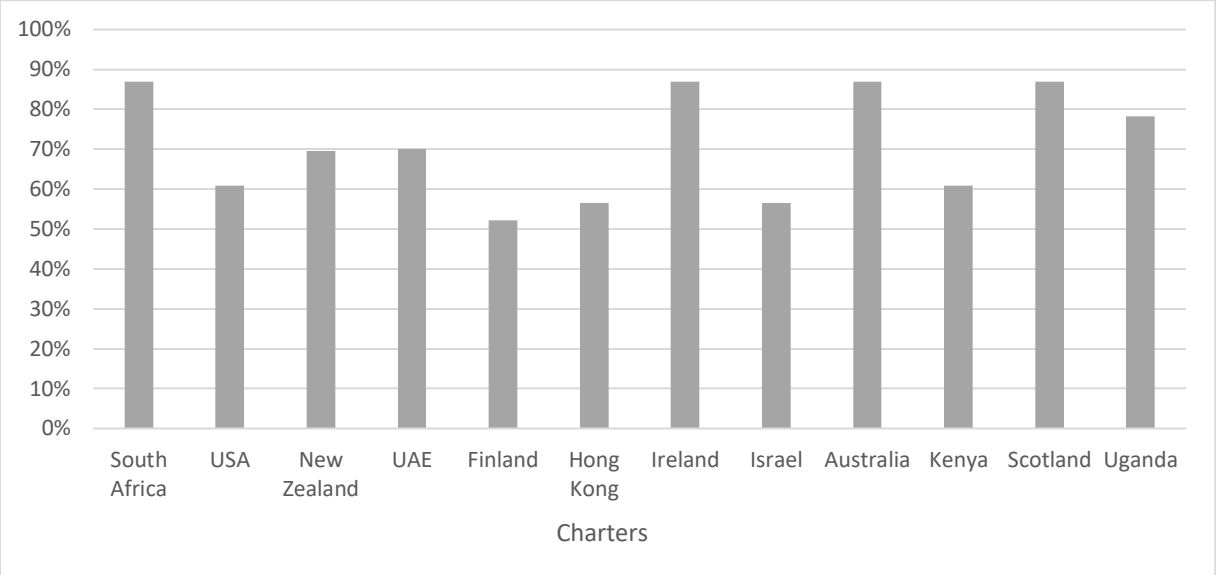

Figure 4.1 Total score for the alignments to human rights and bioethical principles.

4.3.1 Human rights and bioethical principles analysis

The following subsections provide an overview of the content of each charter pertaining to human rights. It should be noted that some of the charters have been sourced on brochures, posters and pamphlets which ensure it is understandable to the general public. Based on picture illustrations and written content of the charters an analysis was made using the rights listed in the following order:

- the right to health and related rights.
- the right to dignity.
- the right to life.

- the right to privacy and confidentiality.
- the right to freedom of movement.
- the right to security and liberty of person.
- the right to equality and non-discrimination.
- the right to participation in public policy.
- the right to remedy.
- the right to informed consent.
- the right to receive information.
- the right to conscience and religion or beliefs.
- the right to freedom from torture and cruel, inhumane and degrading treatment.
- the right to practice religion and use one's own language.
- the right to a safe environment.
- the right to adequate housing.
- the right to social security.
- Justice

4.3.1.1 The right to health and related rights

In this subsection the right to health and the related rights under Article 12.2 of the ICESCR include:

- "Article 12.2 (a): The right to maternal, child and reproductive health,
- Article 12.2 (b): The right to healthy natural and workplace environments
- Article 12.2 (c): The right to prevention, treatment and control of diseases, and
- Article 12.2 (d): The right to health facilities, goods and services".[19]

Included in these rights are the interrelated and essential elements of General Comment No. 14 that is:[57] Quality and Acceptability which is part of Article 12.2.(b). As well as, Availability, Affordability and Accessibility which is part of Article 12.2(d). In addition, the minimum core obligations are included in the right to health.

"*Article 12.2 (a): The right to maternal, child and reproductive health"*

Only South Africa[207] and Kenya's[206] charters affirm this right. South Africa's charter takes into consideration maternal, child and reproductive healthcare. The charter notes that "provision for special needs" will be made for new-born infants, children and pregnant women. Moreover, the charter states that patients can access health care without discrimination on reproductive health.[207] Kenya's charter affirms that patients have a right to access reproductive care.[206]

"Globally, in 2018 there were about 7000 neonatal deaths every day resulting in 2.5 million infants dying in the first month of life".[208] Although infant and child mortality rates have declined internationally, there is great disparity in the level of neonatal mortality across

regions and countries, with “children born in sub-Saharan Africa or in South Asia being ten times and nine times more likely to die in the first month respectively, as compared to children born in a high-income country”.[208] Therefore, there is a need for LMICs to recognise the importance of including maternal, child and reproductive health care services in their charters. Although, HICs neonatal death rates are low they are affected by these statistics (less than 12 deaths per 1 000 live births), therefore, they should consider adding this right to their charters.[208] The right to maternal, child and reproductive health cannot be realistically achieved if charters do not take into consideration a healthy and safe environment or comply with high quality and acceptable services and facilities.

“Article 12.2 (b): The right to healthy natural and workplace environments”

- Both South Africa’s and Uganda’s charters affirm this right by stating that patients have the right to a “healthy and safe environment that will ensure their physical and mental health or well-being”.[206,207]
- Scotland’s charter takes into consideration that a patient will receive treatment in an appropriate, safe and clean environment.[200]
- Australia’s charter is similar; patients are entitled to a safe, secure and supportive healthcare environment.[199]
- Ireland’s charter affirms Article 12.2 (b) by noting that patients can expect to receive healthcare in an environment that ensures the patient’s safety.[201]

Part of the right to Article 12.2 (b) is interrelated and essential elements of General Comment No. 14 on the Quality and Acceptability of the health facilities, goods and

services states that they must be medically, ethically and scientifically appropriate, as well as culturally appropriate (see Chapter 2, section 2.3). Ten charters under consideration in this study align to Article 12.2(b) directly or through the interrelated and essential elements - that of quality and acceptability (Uganda,[205] Ireland,[201] Scotland,[200] Israel,[196] AHA,[203] South Africa,[207] Australia,[199] New Zealand,[198] Kenya[206] and Hong Kong[204]). Two charters did not align to this right (Finland[202], and the UAE[197]) as they do not mention this right or the interrelated and essential elements on quality and acceptability of health services and facilities.

- ***Quality and Acceptability***

The following countries affirm the essential elements of quality and acceptability of health facilities:

  - Scotland's charter affirms that patients are entitled to care that is safe, and hygienic according to the National Health System (NHS).[200]
  - Australia takes into consideration that patients can receive high quality care that meets the safety of patients.[199]
  - The AHA takes into consideration quality and states that patients have a right to "high-quality hospital care in a clean and safe environment".[203]
  - New Zealand's charter affirms that patients have the right to services that optimise the quality of life and HCPs should provide quality and continuity of services.[198]

- Uganda's charter states that appropriate health care will be given professionally and through quality assurance based on clinical needs.[205]

- Ireland's charter aligns to quality and acceptable care by stating: "Services will be provided with professional care, skill and competence".[201]

- Israel's and Kenya's charters state that patients will have the right to quality care products and services.[201,206]

- Hong Kong's charter affirms the interrelated essential element of quality in that patients have the right to medical treatment in accordance with the standards of contemporary medical practices.[204]

New Zealand's charter is the only charter that mentions services that must comply with ethical standards.[198] Both contemporary and ethical standards must be explicitly mentioned in all charters. The right to high quality care in a clean environment goes hand in hand with the right to prevention, treatment and control of diseases.

"***Article 12.2 (c): The right to prevention, treatment and control of diseases"***

The right to health cannot be achieved without the services that produce a favourable health outcome for patients. However, some charters will differ in the services they deliver due to limited resources or health facilities.

The following countries affirm this right:

- Ireland adequately affirms this right by providing services that will promote health, prevent disease and support as well as empower those with chronic conditions.[201]

- Uganda's charter takes this right into consideration under its definition 'medical treatment' which includes preventive care and nursing.[205]

"Article 12.2 (d): The right to health facilities, goods and services"

The remaining interrelated and essential elements of the right to health are: availability, affordability and accessibility. This chapter incorporates these essential elements with Article 12.2(d),[19] because there cannot be a right to a health facility without proper access and availability within a specific region of that country. Furthermore, a patient cannot have the right to goods and services if the services are limited and do not meet the needs of the patient. All charters that align to article 12.2 (d) are listed below.

- South Africa's charter also provides access to palliative and rehabilitative services. The charter makes certain provisions like ensuring counselling for persons living with HIV or AIDS.[207]

- Kenya's charter also makes provision for palliative and rehabilitative care. Kenya also provides for curative care services for patients.[206]

- Ireland's charter differs by mentioning access to services that are non-discriminatory such as screening and immunisation.[201]

- Scotland's charter services include "GP practices, local pharmacies, hospitals or clinics, and emergency services".[200] It is also the only charter that provides for free eye examinations by an optometrist who provides NHS services in Scotland.[200]

- Finland's charter aligns to Article 12.2(d) whereby patients can receive emergency examinations, treatment or medical rehabilitation services without discrimination to service the patient's healthcare needs. It takes a unique approach by providing waiting times or timeframes for specific health care services. It also makes provision for mental health services to children and young people.[202]

- Australia's services include "clinics, medical specialists, aged care and disability services, mental health services, community health centres"[199] and care by allied HCPs (This is the only charter to include these elements as part of its services). Moreover, it provides for services to psychologists, dentists, naturopaths and occupational therapists.[199]

- The UAE charter aligns services without discrimination but does not provide details on the type of medical services that patients are entitled to.[197]

- The AHA bill of rights does not stipulate what kinds of service it entails; however, it does take into consideration that patients will have access to health care according to their needs.[203]

- Israel and Uganda's charters state that a patient will have access to treatment with no discrimination and "impartial access".[196,205]

- New Zealand and Hong Kong's charters does not stipulate the kind of services patients can expect but does affirm the right Article 12.2(d) by stating that patients have the right to medical treatment.[198,204]

- ***Affordability***

  - Ireland and Scotland are the only charters to mention that patients will receive healthcare free of charge.[200,201]

  - Uganda states that patients do not have to pay a deposit fee prior to care or to ensure continuity of care without abandonment.[205]

  - Australia's charter affirms the essential element of affordability by stating that public patients will not be charged for medical and healthcare services; however, patients must pay for dental and physiotherapy services.[199]

According to the UN committee on the ICESCR in General Comment 14, services should be inclusive of the core obligations which guarantee the minimum essential delivery of 'primary health care'.[57]

Core Obligations

In terms of the core obligations as stipulated in General Comment No. 3 (see chapter 2 section 2.3.1 International Law regarding the right to health and the relevant rights) only South Africa, Uganda and Australia align with access to adequate water supply for

patient. .[199,205,207] Scotland provides ‘access to basic shelter.[200] Australia also provides the “right to health care and to other services essential to health … housing and health-related education”.[199] It is the only charter to include health-related education.

None of the other charters align to or mention the core obligations of General Comment 14:

- “access to essential food which is nutritionally adequate and safe, to ensure freedom from hunger to everyone
- access to basic shelter, housing and sanitation, and an adequate supply of safe and potable water;
- essential drugs, as from time to time defined under the WHO Action Programme on Essential Drugs”[57]

Patients’ rights are centred on the right to health and its related rights. Health facilities may offer quality services, and meet the essential requirements, and ensure that respect for a patient’s dignity is critical as described in the next section.

4.3.1.2 The right to dignity

Dignity is strongly affirmed in the charters, and some have dignity as a principle on its own under which other rights fall. Other charters have dignity included under another principle such as access to healthcare or under the right to privacy. However, all charters except Uganda take into consideration dignity whether explicitly or by notions of patients’ dignity.

- ***Charters that explicitly mention dignity***

  - New Zealand's charter notes that services will respect the dignity of individuals.[198]

  - Kenya's charter states: "patients to be treated with respect and dignity"[206]

  - South Africa's charter states that a HCP will demonstrate human dignity and courtesy.[207]

  - Ireland has dignity as part of its eight principles under: 'Dignity and respect'. This charter elaborates on dignity by mentioning what a patient is entitled to and how a person should be treated by healthcare staff. From this principle patients can expect "care that is provided in a sensitive, kind and compassionate way". It is the only charter that stipulates that 'End-of-life' care is to be dignified.[201]

  - Scotland like Ireland also has dignity as part of its six principles "Respect: the right to be treated with dignity and respect".[200] The charter provides comprehensive details on how people shall be treated. The charter also states that people should be treated with dignity and respect in a manner that takes the patient's needs, understanding and culture into consideration.

  - Israel's charter affirms dignity by stating that HCPs will respect the patient's dignity during all stages of treatment.[201]

  - Hong Kong's charter affirms that patients have the right to dignity.[204]

  - Australia's charter states that patients have a right to be treated with dignity.[199]

Most of the charters tend to use ‘dignity’ and ‘respect’ as notions that are closely related. For example, dignity may be affirmed through the word ‘respect’, to which instead of explicitly mentioning ‘dignity’ (see charters to follow) it is inferred that respect is owed allowing for dignity to be upheld. Therefore, the following subsection examines respect for patients in the charters that do not explicitly mention dignity.

- ***Charters that do not explicitly mention dignity but where dignity can be inferred***

    - Finland’s charter does not mention dignity per se, but the charter mentions that the patient’s human rights must be respected. Although Finland ratified the ICCPR in 1975 which includes the right to dignity, their patients’ rights charter is lacking in that it does not explicitly mention the right to dignity.[202]
    - The UAE charter notes that patients will: “receive impartial care respecting your personal values and beliefs from all staff”[197] and this can in part qualify as dignity
    - The AHA bill of rights states that a patient will have the care they need, when they need it, with respect.[203]

4.3.1.3 The right to life

The right to life is related to how the right to health is observed. None of the charters explicitly mention the right to life. However, they do provide services according to subsection “Article 12.2 (d):[18] The right to health facilities, goods and services*”* (mentioned above) that contribute to realising the right to life. This includes emergency and rehabilitative service care.

4.3.1.4 *The right to privacy and confidentiality*

Health facilities should be set-up in such a way that it guarantees a patient's right to privacy. According to General Comment 14 the right to health is associated and dependent upon the right to privacy.[57] The right to privacy includes the right to control access to oneself.

Seven charters under consideration in this study have affirmed the right to privacy (Uganda,[205] Ireland,[201] Scotland,[200] Israel,[196] UAE,[197] South Africa,[207] Australia[199] and Hong Kong[204]). Four charters did not adequately align to this right or did not mention the right to privacy at all (namely, Finland,[202] Kenya,[206] New Zealand,[198] and AHA[203]).

- ***The right to privacy***
    - Uganda's charter notes that patients are entitled to "the right to privacy in the course of consultation and treatment".[205]
    - In Ireland, privacy forms part of the charter' eight principles. The charter states that HCPs will do their best to guarantee that patients have adequate personal space and privacy during the use of health services. Patients are to be afforded personal space during examinations, whilst receiving treatment and when discussing their "condition and treatment".[201]
    - Scotland's charter affirms the right to privacy and provides the most information regarding this right. The charter stipulates that privacy will be respected when receiving healthcare, during examination "in a private place that is appropriate to the circumstances".[200] The charter is the only charter to mention the right

may be limited in the case of emergency. Patients also have the right to say whether they want students present or not. It is also the only charter to mention that overnight patients “can usually expect to be in a single sex room or ward, but this may not be possible” in emergency situations.[200]

- Australia’s charter takes into consideration personal privacy.[199]
- Israel’s charter affirms that privacy will be retained “at all stages of treatment”.[196]
- The UAE charter states that patients may “enjoy privacy while carrying out all examinations, and procedures”.[197]
- South Africa’s and Hong Kong’s charters mention the right to privacy and are the only charters that elaborate further on this right using pictures.[204,207]

The remaining charters mention the right to privacy, but it is related to confidentiality.

- ***The right to confidentiality***

Both New-Zealand and Australia mention the right to privacy rights subject to their National Acts.

- New Zealand states that privacy must be in line with Part VII and VIII of the Privacy Act 1993. This relates to confidential information regarding “public register personal information”[198] and complaints regarding the commissioner and referrals.

- Australia references the Victorian Health Records Act 2001 to which health services must comply with the right to privacy is also linked to confidentiality of information.[199]

Uganda and Scotland's charters give the most detailed explanation regarding patients' confidentiality.

- Uganda's charter affirms the right to confidentiality stating that information may not be disclosed without informed consent. The charter further informs a patient that the management staff will ensure that HCPs shall not disclose information during duty or work. Even for the purposes of publication in medical journals or research, all identifying details of the patient will be protected.[205]

- Scotland's charter takes into consideration the WMA guidelines that patient's information will be kept 'secure' and patients may know where it is stored. Confidentiality is safeguarded by the Data Protection Act of 1998 and professional standards.[200]

Both Uganda's[205] and Scotland's[200] charters mention that confidentiality may be limited by court order or for the protection of public health taking into consideration the limitations of the Siracusa Principles. Scotland's charter does inform patients with reasons as to why this might happen, for example: "to prevent the spread of a communicable disease or to investigate a serious crime".[200]

- Ireland's charter is like Scotland's in that information must be stored securely and accessed by those who need it for the patient's care. Ireland is the only

charter to state that health records may be accessed for audit reasons as part of assurance to the Health Service Executive for the quality of service.[201]

- Both Israel's[196] and South Africa's[207] charters mention confidentiality in similar ways that health information will not be disclosed without consent. Both charters also state that this may be limited to the law. Furthermore, South Africa's charter takes into consideration the limitation of this right according to the National Health Act.[207]

- Kenya stipulates that confidentiality will be upheld even after death.[206]

- Finland's Charter states that information will always remain confidential and the next of kin cannot have access to information without consent. Moreover, the charter states that certain exceptions to this rule are set out in their legislation.[202]

- UAEs charter states a patient will enjoy confidentiality.[197]

- Hong Kong's charter states that information will not be passed to third parties without permission.[204]

- The AHA bill of rights states that confidentiality will be respected. However, it is the only charter in this study to mention that patients will receive a "Notice of Privacy Practices"[203] which will stipulate the disclosure and protection of information. Ensuring that patients' rights to privacy and confidentiality are adhered to will also ensure that patients have a right to health-related freedoms.[203]

4.3.1.5 Health-related freedoms

In this subsection the health-related freedoms include the right to freedom of movement; right to security; right to liberty, and the right to bodily integrity.

4.3.1.5.1 The right to freedom of movement.

Australia's charter is the only one to adequately align to this right as it states patients have the right to decide when and how they leave the hospital and may discharge themselves against the doctor's advice.[199]

4.3.1.5.2 The right to security

The right to security is considered in relation to section 4.3.1.1 "Article 12.2 (b): the right to healthy natural and workplace environments".[18] Charters that take into consideration the right to security alongside article 12.2(b) are Ireland, Scotland, South Africa, Uganda and Australia. These charters mention that patients will have access to a safe environment; however, there are other notions that align to the right to security.

- **Other notions related to security**
    - Ireland's charter states physical, racial, sexual and other kinds of harassment or abuse are unacceptable.[201]
    - Scotland's charter ensures security by mentioning that patients who are physically and verbally abusive will be removed. Moreover, it is part of the patients' responsibility to "not be abusive, violent or aggressive towards staff or other patients, their carer and family members".[200]

- UAEs charter states that patients will have protection during treatment from any psychological, verbal or physical assault.[197]
- The AHA bill of rights affirms that patients will be free from abuse.[203]
- New-Zealand's charter affirms that patients have a right to be free from harassment and harm.[198]
- South Africa's charter states that patients have the right to access counselling without violence on health matters.[207]
- In Uganda the "patient has the right to safety and security to the extent that the practices and installations of the health facility"[205] does not cause any harm.[205]
- Finland, Israel, Hong Kong and Kenya's charters do not adequately affirm this right.[196,202,204,206]

4.3.1.5.3 The right to liberty

The right to liberty is the most affirmed health-related freedom, as all 12 charters align to this right. They affirm the right by either mentioning the right to refuse treatment; choosing a HCP; and having the right to a second opinion. All charters state that patients have the right to refuse treatment.

- Finland's charter makes provisions for persons under 18 and children on matters of treatment.[202]

All charters also align with the right to choose a HCP.

- South Africa's charter states that patients have "the right to choose a particular HCP for services or a particular health facility".[207]
- In Finland, patients may also choose health centres within their municipality.[202]

The only charters to mention any limitations on refusing treatment are Israel, South Africa,[207] Uganda[205] and Kenya[206] which align with the Siracusa Principle[86]. All charters affirm the right to a second opinion.

4.3.1.5.4 The right to bodily integrity

All charters align to the right to bodily integrity either through: The Right to Bodily Integrity concerning reproductive health, which is analysed alongside section 4.3.1.1 "Article 12.2 (a): The right to maternal, child and reproductive health";[19] as well as the right to informed consent (discussed below). Other notions that relate to bodily integrity are found in:

- Kenya's charter allows for the "right to donate his or her organs and/or any other arrangements/ wishes upon one demise".[206]
- Scotland's charter affirms that patients have the right to have their organ donation wishes to be respected.[200]
- New-Zealand's charter states that patients possess control over their body. It is also the only charter within this study to make provisions for patients having the right to decide on the disposal or return of any bodily substance or parts.[198]

4.3.1.6 The right to equality and non-discrimination

With the exception of Hong Kong[204] all charters take into consideration the right to equality and non-discrimination. South Africa only mentions prohibition of discrimination during counselling.[207] It does not mention the examples of discrimination based on Article 26 of the ICCPR[18] or Section 9(3) of the South African Constitution[41].

The rest of the charters mention the grounds that discrimination is prohibited, for example, religion and belief, sex, race or nationality among others.

- New Zealand's charter refers patients to the National Acts and regulations when taking into consideration non-discrimination. Furthermore, New Zealand refers to Part II of their Human Rights Act 1993 which provides a detailed account of what the grounds are for prohibition of discrimination.[198]

- The UAE refers to its Dubai Health Authority (DHA) regulations when mentioning the right to non-discrimination.[197]

- Ireland does not explicitly mention 'non-discrimination' but states that "patients will receive respect regardless of age, sex, sexual orientation, faith or political beliefs".[201]

- Kenya's charter affirms the prohibition of discrimination on the grounds of mental disorder, illness, pregnancy and disability.[206] These examples are not found in Article 26 of the ICCPR[18].

Some charters go further in terms of non-discrimination protections, for example:

- Australia's charter prohibits discrimination based on socioeconomic status and social circumstances.[199]
- Scotland takes into consideration prohibition of discrimination based on the grounds of gender reassignment.[200]

It may be of interest to note that Australia, Israel, Ireland and Scotland are the only charters to include sexual orientation. Mentioning sexual orientation is considered important, as "some physicians lack knowledge and awareness about health issues"[209] specific to the lesbian, gay, bisexual, transgender and questioning (LGBTQ).[209] Since 2011 the Healthcare Equality Index (HEI),[210] recorded 626 hospitals and healthcare facilities which put in place measures, practice and policies with provisions for LGBTQ inclusion. In 2019, 99% of the measured health facilities established full LGBTQ-inclusive patient and employment non-discrimination policies.[210]

4.3.1.7 The right to participate in public policy

Only charters from Uganda, Ireland, Scotland, South Africa and Australia affirm the right to participation in public policy.

- Uganda notes that "every citizen has the right to participate or to be represented in the development of health policies and systems through recognized institutions".[205]

- Ireland's charter recognises that people can comment and make suggestions on the national charter and which can be part of the organisational process through telephone, e-mail, fax, and letter. This is significant in that patients are provided with the means to participate in policy.[201]

- In Scotland there is recognition that patients' feedback could help improve service as patients won't feel as though their complaint is a waste of time and irrelevant. It is the only charter that mentions that patients are entitled to a representative to participate on a patient's behalf.[200]

- According to Australia's charter, participation extends to planning, and design of services. It is the only charter to note that "Health Boards must involve the people who live in their board area in the planning and development of services, and in decisions that significantly affect the operation of those services".[199]

- South Africa's charter affirms that every citizen has the "right to participate in the development of health policies".[207]

4.3.1.10 *The right to remedy*

The majority of charters with the exception of the AHA[203] provide for the right to remedy.

- South Africa and Uganda's charters state that patients have a right to complain, with Uganda's charter providing a telephone number and email.[205,207]

- In Kenya the charter states that complaints will be received and a response from health authorities will be given within a period not exceeding 12 months. Moreover, Chapter 3 of the charter includes dispute resolutions - patients may contact a HCP where he/she will take relevant measures to resolve the dispute.[206]

- Ireland's charter notes that even if patients are unhappy about how their complaint was dealt with, the facility will appoint a review officer to examine the complaint further. The charter provides an email address, web page, telephone and fax number.[201]

- Scotland's charter provides the most information under the principle 'Feedback and complaints'. This charter is the only charter to state that relatives or carers may also complain. Furthermore, patients "have the right to information and advice on how to provide comments".[200]

- In Finland patients may complain to the relevant "Regional State Administrative Agency or the National Supervisory Authority for Welfare and Health"[200] or through a written objection directly to the HCP. [202]

Both Scotland[200] and Finland[202] refer to a Health Ombudsman to be appointed at all health care units to provide advice and guidance to patients. Patients can apply to the 'Patient Insurance Centre' for compensation. Scotland's charter is also the only charter to mention compensation - which is an important aspect of the right to remedy.[200]

- Israel's charter states under the 'Right to Public Inquiries' that the patient has the right: "to receive findings and conclusion of the investigation".[196]

- UAEs right to remedy is taken into consideration with the right to complain, make suggestions and comment on services through the 'Communication and Customer Relations Office'.[197]

- Hong Kong's charter states that patients have the right to complain as well as how complaints will be investigated.[204]

- In New Zealand the right to remedy is affirmed by stating that "providers must facilitate the fair, simple, speedy, and efficient resolution of complaint".[198] It is the only charter to acknowledge that the process must be fair and provides timeframes for these complaints.[198]

- Australia's charter has assigned hospital's patient representatives to have complaints addressed to and patients may also complain to the Victorian Health Services Commissioner.[199]

4.3.1.11 *The right to informed consent*

All the patients' rights charters covered align to informed consent. South Africa, Uganda and Kenya's charters state under their principle of "informed consent", that everyone has the right to be given information about their "illnesses, diagnostic procedures, the proposed treatment".[205,206,207]

- Uganda's charter goes further to state that such information will be given to the patient as soon as possible in a manner that the patient is expected to understand "to make a free informed, and independent choice".[205] Furthermore, the charter explains that informed consent may be given either in writing or verbally. It is the only charter to state that written or verbal informed consent must be witnessed.[205]
- Kenya is the only charter that acknowledges that informed consent must be based on the *willingness* of patients and *free from duress*.[206]
- Ireland's charter mentions informed consent under the principle of participation, and it affirms that informed consent must be obtained before any procedure with information on the options available; their possible side effect(s); success rates and expected results.[201]
- Scotland's charter does not take into consideration informed consent under any of the eight principles of the charter. However, it refers patients to the leaflets and factsheets available in the facility which informs patients on how to be involved in decisions about their health care and treatment.[200]
- Israel's charter is the only charter to state that patients "have the right to appoint a proxy, who will have the authority to consent to medical treatment"[196] in case the patient cannot do so.[196]
- The UAE charter states that informed consent must be in writing (according to DHA rules and regulations) before any minor surgery, anaesthesia and only after receiving all information.[197]

- The AHA bill of rights states that patient should sign a general consent to treatment. Furthermore, in cases pertaining to experimental treatment or surgery the patient must have confirmed in writing that he/she understands what is planned and agree to it.[203]
- New Zealand's charter is the only charter to state that this right may be subjected to law. It is also the only charter to make provision for a patient's diminished competency.[198]
- Australia's charter recognises that an accredited interpreter should be provided at important points during patient care to discuss what is required to give informed consent.[199]
- Finland's charter affirms that "all decisions relating to patient care must be taken in mutual understanding with the patient".[202]
- Hong Kong's charter refers to informed consent in the context of medical research only.[204]

4.3.1.12 *The right to receive information*

All the charters align to the right to receive information.

- The South African charter includes information such as the "illnesses, diagnostic procedures, the proposed treatment and the costs involved, for one to make a decision that affects anyone of these elements".[207]
- Uganda's charter states the patient shall be entitled to medical information concerning themselves, including a copy of their medical records.[205]

- Kenya’s charter states that all patients have the right to receive full accurate information and patients have the right to access and obtain their health information.[206]
- Ireland’s charter states that patients have the right to appropriate communication about the care, what is wrong, and what the treatment aims to do, the recommended treatment and medication, including the potential risks and alternatives. The charter also states that there are relevant leaflets available to help a patient understand their illness.[201]
- Scotland’s charter states that the patient must be given information about care and treatment options available, including the risks and benefits. The charter mentions that patients should ask for more information if they want to know more.[200]
- Finland’s charter states that all decisions relating to patient care must be taken with the mutual understanding of the patient. This means that doctors must provide the patient with information of their medical condition; the treatment options available; the effects of the treatment; and any risks associated with it; the medical institution and medical information. It is the only charter to inform patients after release that they will receive a summary course of treatment or hospitalisation, in writing.[202]
- UAEs charter states that patients will receive comprehensive information in an understandable manner and be informed of any “changes in their health status and causes of such changes, alternative treatment, probabilities of treatment success or failure, therapy advantages and disadvantages,

possible problems related to treatment and expected results of ignoring the treatment".[197] The charter also notes that the patient will receive information about organ donation.

- Australia's charter states that patients have the right to information concerning likely costs, possible side effects and alternative treatments. The HCP should also present the opportunity for a patient to ask questions.[199]
- Hong Kong's charter affirms that patients have the right to information about their medical condition, with diagnosis, prognosis and of the treatment proposed.[204]
- The AHA bill of rights states that information should include the benefits and risks of each treatment, whether the treatment is experimental or part of a research study, as well as, the quality of life that may change due to possible long-term effects. Moreover, it is the only charter to inform patients and family members what to do after they leave the hospital.[203]
- Israel's charter states that people have the right to medical information.[196]
- The New Zealand charter states that patients have a right to information with an explanation of their condition. Information should include the results of the tests and procedures.[198]

4.3.1.13 *The right to conscience and religion or beliefs*

Only Ireland, Finland, New Zealand, AHA, UAE and Hong Kong's charters affirm this right.

- Ireland's charter affirms that patients will receive care that respects their culture and beliefs in line with clinical decision-making.[201]
- The UAE and Hong Kong's charters notes that patients will receive care that respects the patient's personal values and beliefs.[197,204]
- Finland's charter states that the patient's human rights and beliefs must always be respected.[202]
- New Zealand's charter states that every patient has the right to be provided with services that consider the beliefs of different cultural, religious, and spiritual beliefs.[198]
- The AHA affirms that spiritual beliefs will be considered during hospital stay.[203]

4.3.1.14 *The right to use one's own language*

The South African,[207] Kenyan,[206] Irish, Scottish[200] and New Zealand[198] charters state that health information will be made available in the language understood by the patient.

- Scotland's charter is the only charter to acknowledge sign-language interpreters, or other communication support, and that patients must ask a member of staff to arrange this in advance.[200]
- UAE,[197] Scotland,[200] Australia[199] and New Zealand[198] charters mention interpreters to provide a patient with medical information.
- Australia's charter further states that the interpreter must even inform the patient when they may give informed consent.[199]

4.3.1.15 The right to freedom from torture and cruel, inhumane and degrading treatment.

- South Africa's charter makes provisions for special needs including for those in pain.[207]
- Uganda's charter states that under the right to safety and security, the health practices and installations of the health facility should not cause any harm.[205]
- Ireland's charter states patient will receive care where "Healthcare professionals [...] do everything that they can to control your pain".[201]
- Scotland's charter states that patients will get support to manage their condition, "how to control pain and how to access other services that could help".[200]
- The UAE charter states that the DHA respects the right to appropriate assessment and management of pain through evidence-based practices.[197]
- The New Zealand charter states that services will be provided in a manner that will minimise any potential harm and patients will be protected during treatment from any physical, verbal or psychological assault.[198]
- Ireland's,[201] Scotland's,[200] UAE's,[197] AHA's,[203] New-Zealand's,[198] South Africa's,[207] and Uganda's[205] affirms the right to the right to freedom from torture and cruel, inhumane and degrading treatment by relying on the

responsibility of patients to refrain from being aggressive, violent or abusive towards staff, patients and family members.

- Finland,[202] Israel,[196] Australia,[199] Hong Kong[204] and Kenya's[206] charters do not adequately affirm this right, because they do not mention the protection of patients from verbal, psychological or physical assault and neither do they make provisions for patients in pain (as in the other charters mentioned above).

4.3.1.16 The right to a safe environment

The right to a safe environment is analysed in 4.3.1.1 above. "Article 12.2 (b): 'the right to healthy natural and workplace environments".[18] Charters that take into consideration the right to security alongside Article 12.2(b) are Ireland,[201] Scotland,[200] South Africa,[207] Uganda[205] and Australia[199]. These charters mention that patients will have access to a safe environment.

4.3.1.17 ***Right to social security***

- South Africa,[207] Uganda[205] and Australia[199] include access to adequate water supply for patients. Scotland provides 'access to basic shelter'.[200]

- Australia also provides the "right to health care and to other services essential to health … housing and health-related education".[199]

4.3.1.18 *Right to adequate housing*

Only Scotland and Australia affirm this right. Scotland provides “access to basic shelter”.[200] Australia also provides the “right to health care and to other services essential to health … housing and health-related education”.[199]

4.3.1.19 *Justice*

The SDGs Goal 3 calls for healthy lives and promotion of well-being for all at all ages. Part of the target is universal health coverage, which includes access to good basic health care services and access to vaccines, affordable, effective, safe and essential medicines for all.[193]

Justice in health care relates to how governments ought to distribute resources to be available to everyone equitably. Justice in health further notes that people should not be exploited by economic circumstances (equity according to access and need), and aid is made available to those with the greater need and they should be treated more favourably than those with lesser needs.[185-189]

4.3.1.19.1 Distribution of resources

None of the charters explicitly mention fair distribution of resources.

- Uganda’s charter does take into consideration that communicable and non-communicable diseases consume most of their resources, and states that hence the charter was developed for patients and to raise the health care standards.[205]

- Scotland's charter states that the health board must make decisions on the most efficient way to use the NHS resources. These decisions must meet the local area's needs.[200]

4.3.1.19.2Equity

All charters align with the principle of equity either by providing services according to the patients' needs or stating that patients have a right to access services and health facilities and that free or affordable health care should be provided. This is analysed in relation to sections 4.3.1.1 above and in line with "Article 12.2 (d): 'the right to health facilities, goods and services", and the interrelated and essential elements of the right to health which is availability, accessibility and affordability.

- The charters of South Africa,[207] Kenya,[206] UAE,[197] Israel[196] and Scotland[200] are similar in that both take into consideration of equity according to access, affirming that everyone has a right to access services without discrimination.
- Uganda's charter states that patients will have impartial access to health care services.[205]
- Ireland's charter affirms equity according to access in that patients have access to different services regardless of physical, sensory or intellectual ability.[201]
- Scotland affirms that patients may never be refused access to the NHS and denied access based on discrimination.[200]
- South Africa takes into consideration equity according to need where services include provisions for special needs.[207]

- The AHA aligns to equity by providing services according to the patients' needs.[203]
- The New Zealand charter affirms that patients' 'health needs' must be considered.[198]
- Finland's charter states that treatment must commence according to the patient's healthcare needs.[202]

Table 4.1 Patients' rights charters and the alignment to human rights and bioethical principles.

Human Rights	South Africa	Uganda	Kenya	Ireland	Scotland	Finland	UAE	Israel	Hong Kong	USA	New Zealand	Australia
Right to Health and Relevant Rights of the ICESCR												
Article12.2 (a)maternal, child and reproductive health	✓	x	✓	x	x	x	x	x	x	x	x	x
Article 12.2 (b) healthy environments	✓	✓	✓	✓	✓	x	x	✓	✓	✓	✓	✓
Article 12.2 (c) prevention, treatment and control of diseases	x	✓	x	✓	x	x	x	x	x	x	x	x
Article 12.2 (d) health facilities, goods and services	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Right to Informed Consent	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Right to Receive Information	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Right to Privacy and Confidentiality												

Right to Privacy	✓	✓	x	✓	✓	x	✓	✓	✓	x	x	✓
Right to Confidentiality	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Non-Derogable rights												
Right to Life	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Right to Dignity	✓	x	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Right to Equality and Non-Discrimination	✓	✓	✓	✓	✓	✓	✓	✓	x	✓	✓	✓
Health Related Freedoms												
Right to Security	✓	✓	x	✓	✓	x	✓	x	x	✓	✓	✓
Right to Liberty	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Right to Freedom of Movement	x	x	x	x	x	x	x	x	x	x	x	✓
Right to Bodily Integrity	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Right to freedom from torture and cruel, inhumane and degrading treatment.	✓	✓	x	✓	✓	x	✓	x	x	✓	✓	x

Right to use their Language	✓	x	✓	✓	✓	x	✓	x	x	x	✓	✓
Right to Conscience and Religion or Beliefs	x	x	x	✓	x	✓	✓	x	✓	✓	✓	x
Social Rights												
Right to Remedy	✓	✓	✓	✓	✓	✓	✓	✓	✓	x	✓	✓
Right to Participation in Policy	✓	✓	x	✓	✓	x	x	x	x	x	x	✓
Right to Social Security	✓	✓	x	x	✓	x	x	x	x	x	x	✓
Right to a Safe Environment	✓	✓	x	✓	✓	x	x	x	x	x	x	✓
Right to Adequate Housing	x	x	x	x	✓	x	x	x	x	x	x	✓
Justice												
Distributive Justice and Equity	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

4.2 Conclusion

The analysis of the 12 charters on patients' rights show that countries have focused and incorporated the international standards, conventions and treaties well into their charters. There are, however, human rights that the majority of the charters did not incorporate; these include Articles 12.2 (a) and Article 12.2 (c), of the ICESCR. The inclusion of the right to security, privacy, social security and the right to freedom of movement are not included in some instances.

The human rights that are unanimously adhered to in line with Article 12.2(d) of the ICESCR are: the right to confidentiality; the right to life; the right to liberty; and the right to bodily integrity. It appears that these rights are what international standards consider to be the most important within the health sector.

In terms of bioethical rights and the alignment of patient charters, the right to informed consent, right to receive information and distributive justice feature in all the charters. However, from a bioethical perspective (in terms of beneficence) and human rights perspective – the right to adequate housing and social security - do not feature as strongly in the charters that were analysed.

What is clear, however, is that the charters do not differ based on income classifications, as in some cases are similar despite these differences, e.g. the charters from Uganda, Ireland, Scotland, Australia and South Africa have the highest scores in terms of affirming human rights and bioethical principles in their patients' rights charters.

The next chapter will provide recommendations on how the South African government can enhance its own patients' right charter.

Chapter 5: Recommendations and Conclusions

5.1 Introduction

Patients' Rights Charters inform people of what they are entitled to by law and by virtue of being human. Human rights and bioethical principles are essential in the development or improvement of patients' rights charters. This research focused on pertinent human rights and bioethical principles that are included in Patients' Rights Charters globally. What is clear is that the 12 Patients' Rights Charters examined in Chapter 4 adhere to international conventions and treaties. However, the real challenge today is to merge bioethical considerations with that of the Patients' Rights Charters. Bioethics is an emerging area of study within the medical profession and its appeal and basis for its inclusion is to ensure that no undue or unnecessary harm befalls patients and that HCPs always act in the best interests of their patients. Moreover, in an under-resourced country such as South Africa, justice requires that resources be distributed fairly and equitably. Therefore, this is at the centre of certain policy recommendations that can be made to the government of South Africa as emanating from Chapter 4 above.

The following chapter will provide recommendations on areas where the South African charter can be strengthened to better align with international standards, the Constitution and the NHI goals.

5.2 Recommendations

The NHI states that "The implementation of the Patients' Rights Charter will be strengthened to ensure physical and mental well-being".[194] The Patients' Rights Charter

for South Africa is similar to Uganda and Ireland in that it, provides a glossary of terms that align with the NHI to assist with patients' understanding. In terms of Article 12 of the ICESCR and Section 27 of the South African Constitution, as well as, the principle of beneficence, the charter can be further strengthened to include the following glossary of terms taken from the White Paper on the NHI,[194] the National Health Act[70] and the WHO[56]:

- **Services**: Include (i) emergency, (ii) primary health care, and (iii) hospital-based emergency services.
    - *(i) Emergency,* includes, but is not limited to, the, unexpected response to illness or injury that could result in disability or death without quick intervention.
    - *(ii) Primary Health Care Services,* include, but are not limited to:
        - maternal care;
        - “women and child health;
        - family planning and reproductive health services” (which aligns more adequately to Article 12.2(a) and the right to bodily integrity);
        - chronic non-communicable disease;
        - HIV and tuberculosis; and
        - violence and injuries.
    - *(iii) Hospital-based emergency services* include, but are not limited to:
        - emergency medicine;
        - surgery;

    - "organ transplant (including but not restricted to lung, liver, kidney, and heart)";
    - oncology and cancer treatments, including but not restricted to dialysis.[194]
- **Allocative efficiency:** refers to resource allocation to maximise the welfare of patients based on efficiency. Decisions are based on a combination of healthcare programmes to produce the best health outcomes.[194]
- **Health outcomes:** these refer to "changes in health status, which are usually due to an intervention".[194]
- **Office of Health Standards Compliance (OHSC):** "an independent body to ensure that both public and private health establishments in South Africa comply with the required health standards".[194] This is an important term for patients to familiarise themselves with, as according to the NHI, that HCP, health establishments inspection and certification of health facilities and services should be compliant with the standards of the OHSC.[194]
- **Health Care Provider (HCP):** according to the National Health Act, an HCP is a person providing health services in terms of any law.[70]
- **Health facility:** according to the National Health Act a health facility is the whole part of a building, place, institution "whether for profit or not, that is operated or designed to provide inpatient or outpatient treatment, diagnostic or therapeutic interventions, nursing, rehabilitative, palliative, convalescent, preventative or other health services".[70]

- **Health worker:** “any person who is involved in the provision of health services to a user but does not include” a HCP.[70]
- **Health:** “A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”.[56]
- **Charter:** This charter entails what rights a patient is entitled to by the law and their responsibilities.

5.2.1 Rights that should be strengthened

The following recommendations are made as part of a holistic approach to ensure that universal access to healthcare becomes a reality and that the healthcare needs of all in society are met. The following rights, freedoms and principles are discussed below. Firstly, the right to health and relevant rights; secondly, the non-derogable rights; thirdly, privacy and confidentiality; fourthly, health-related freedoms; fifthly, social rights, and lastly the bioethical principle - justice.

The right to health and relevant rights

When compared to the other global Patients’ Rights Charters, South Africa’s charter falls short when it comes to mentioning the quality of services. Part of the NHI’s initiative is the implementation of quality improvement.[194] It is therefore recommended here that the charter should note that patients will receive quality health services in compliance with the OHSC. This means the charter could go further to mention that quality of care is based on:

(i) patient’s rights;

(ii) infection control;

(iii) safety and security of patients and staff;

(iv) cleanliness; and

(v) availability of medicines at facilities.

- ***The right to receive information***

Another recommendation is that South Africa's charter should be extended to include interpreters to ensure patients understand all the medical information they require. It needs to further state that patients have the right to communication support that they feel comfortable with. Patients must especially have the right to an interpreter to assist with understanding information necessary for informed consent (which may be subject to a limitation of confidentiality especially when the interpreter is giving patient information on their health). Moreover, South Africa should include the social determinants of health in its charter, i.e., the right to adequate housing, access to both food and water, and health-related education.

- ***The right informed consent***

It is recommended that South Africa's charter should note that informed consent must be given verbally or in writing and must be given prior to any medical procedure.

A further recommendation is that South Africa's charter should also state that patients have the liberty to bring in their personal beliefs in their decision-making and that HCPs will respect a patient's conscience, religion or beliefs throughout their treatment. In this regard the charter should state that patients will have access

to healthcare where HCPs and health workers respect, recognise and accept that patients make decisions, choices or actions based on their beliefs, consciences, and values.

Non-derogable rights

- ***The right to dignity***

South Africa's charter, like all other charters in this study, mentions dignity. However, it is recommended that South Africa's charter should rather consider dignity as a part of its principles, like Ireland. Under such a principle, the charter should specifically state that patients can expect health care that takes into consideration different cultural backgrounds, which would also be similar to the UAE's charter, In this regard, therefore, South Africa could include the aspect of respect for 'personal value', whereby dignity would be preserved 'especially' to dying patients.

It is worth noting that some charters have the prohibition of non-discrimination included under the principle of dignity. Therefore, similar to Scotland's charter, South Africa's charter could mention the right to privacy under this principle as well.

- ***The right to equality and non-discrimination***

By comparison with the other charters under review, South Africa is weak in terms of the right to equality and non-discrimination as it only mentions the prohibition of discrimination during counselling. It is recommended, therefore, as in Kenya's charter, that South Africa's charter should include prohibition of discrimination on

the grounds of mental disorder, illness, and disability. In addition, in terms of a modern update Australia's charter also includes equality for socioeconomic status and social circumstances, which, if included in South Africa's charter would strengthen it substantially. South Africa is also behind some of the latest trends in that it does not include non-discrimination based on sexual orientation as upheld by the charters of Australia, Israel, Ireland, and Scotland.

- ***The right to life***

  It is also recommended that South Africa's charter should mention that everyone has the right to life. The right of life as seen in the analysis can also be respected under the quality of services provided.

Right to privacy and Confidentiality

- ***The right to privacy and confidentiality***

  The right to privacy is depicted through a picture. Therefore, it is recommended that the charter should specifically state that patients are entitled to privacy during their stay or course of treatment at any health facility. Also, when discussing the patient's condition or treatment, it should also state that this privacy may be constrained in the case of an emergency.

  In terms of confidentiality, the South Africa Charter should state that the patient's data will be secured properly and only accessed for auditing and research purposes. Furthermore, it is also recommended that, similar to Kenya's charter, the South African charter should state that confidentiality will be maintained even after death.

Health-related freedoms

- ***The right to freedom of movement***

  The charter should include that patients are free to discharge themselves when they want to – even against doctor's advice. This may only be denied by court order, law, or act of parliament and for the safety of other patients or the health of the public. In line with the limitation of this right are (i) Section 36 of the South African Constitution;[41] (ii) Article 25 of the Siracusa Principle,[86] and (iii) Article 29(2) of the UDHR.[17]

  Moreover, the charter should note that patients will have the freedom to move within the health facility provided it does not affect their health, other patients' rights and privacy as well as the workspace of HCPs and health workers.

- ***The right to security and liberty of persons***

  It is also recommended that South Africa's charter, like UAE charter, should also state that patients will have protection during treatment from any psychological, verbal or physical assault and also have a right to be free from harassment, as in the case of the New Zealand's Charter.

  Although South Africa's charter aligns with the right to liberty, it is recommended that it goes further to state that patients have the right to freedom of control with limited interference on their actions and decisions from an HCP or other relevant persons. The charter should also state that this may be limited as in the right to freedom of movement above.

- ***The right to bodily integrity***

  The right to bodily integrity is stronger in South Africa compared to the other charters in that the South Africa charter notes provision for special needs in the case of children and pregnant women. However, South Africa's charter should include – like New Zealand's charter – the right to decide on the disposal or return of any bodily substance or parts. The charter should state that patients have the right to bodily integrity with sole possession and control over their own bodies. However, it should also include that a person who is free from the interference and constraint of others may be subject to a court order or Act of parliament.

- ***The right to freedom from torture, cruel inhumane and degrading treatment***

  South Africa's charter can more adequately align to the right to freedom from torture, cruel inhuman and degrading treatment. This can be done by stating that patients can expect health care that is free from degrading, cruel and inhumane treatment from an HCP or health worker.

  Health practices and services of the health facility should not cause any harm. South Africa's charter should state that patients will be protected during treatment from any physical, verbal or psychological assault as is the case in New Zealand's charter.

Social rights

- ***The right to participation in public policy***

It is recommended that South Africa's charter should provide email addresses, contact numbers and fax numbers for public engagement. Here the South African government could provide a website specifically for public participation in health policies. The website may not be limited to participation but also to provide relevant information regarding patients' rights and to update the public on all relevant health matters.

- ***The right to remedy***

Moreover, South Africa's charter does not elaborate as to how complaints are to be received nor does it give a time period for resolution. It is recommended that South Africa's charter follow Uganda's charter and put forward the name of a designated person to advise, assist, educate and instruct patients on their human rights. This could be someone from the Office of the Health Ombud. Moreover, as in Finland's charter, the South Africa Charter should include information on compensation which patients are entitled to. This could be part of the OHSC that became operational in 2016 to ensure that "complaints lodged by users of health care services are appropriately and speedily investigated".[194]

Bioethical principle - justice

- ***Justice***

The NHI[194] refers to the WHO guidelines for countries progressing towards universal health coverage (UHC) based on three dimensions: (i) population coverage; (ii) service coverage; (iii) cost coverage as follows:

- In terms of population coverage, the NHI states that there will be an increased "coverage to all South Africans irrespective of their socio-economic status".[194] Out of the population precedence will be given to vulnerable groups or those with the greatest needs including those experiencing the greatest difficulty in obtaining care. People who are identified as having the "greatest need will be based on criteria consistent with the principles of NHI".[194] "Progressively, the population will be defined according to need and coverage will be extended to ensure access to defined and comprehensive health care services".[194] Therefore, South Africa could enhance the "provision for special needs in the case of new-born infants, children, pregnant women, the aged, disabled persons, patients in pain, a person living with HIV or AIDS patients"[194] in its charter with provisions of health coverage to vulnerable groups with the greater needs and easy access to healthcare for those who have the greatest difficulty in obtaining care. Access is made according to the need for everyone – irrespective of socio-economic status.
- In terms of service coverage, the NHI states that it extends to a range of quality health services which will address the health needs of the population. The Patients' Rights Charter should include:
    (i) that patients have a right to access a range of quality health services;
    (ii) "eliminate the burden of premature mortality and disability in children under-15 years of age; and"[194]
    (iii) Eliminate the burden of disease in adults.

- In terms of cost coverage, the NHI states protection against financial ruin can be achieved by:

  (a) “Increasing government expenditure on health; (b) reducing out-of-pocket payments (OOP) in the broader funding context; (c) implementing national measures of financial protection; (d) Ensuring the poor are not left behind”.[194]

Therefore, it is recommended that the South African charter could state that patients have the right to:

- free unsubsidised healthcare;
- financial protection in health;
- healthcare regardless of the ability to pay, thus ensuring no one gets left behind.

5.3 Conclusion

Since the 1980s a shift has occurred within the healthcare sector from viewing patients as merely consumers and treating them as such, to a more human rights-based approach. The healthcare sector, therefore, has had to focus on how to incorporate the principles of human rights into the services they provided, hence the development of the Patients’ Rights Charters.

While Patients’ Rights Charters differ across countries the foundations of these are based on international and regional laws as well as protocols that seek to ensure that health is both an entitlement and freedom to be enjoyed. South Africa’s Constitution also ensures

the rights of patients through the Bill of Rights. The thinking behind the Patients' Rights Charters and human rights intersect on four key principles (autonomy, non-maleficence, beneficence and justice) that ensure:

- the right to health and related rights.
- the right to dignity.
- the right to life.
- the right to privacy and confidentiality.
- the right to freedom of movement.
- the right to security and liberty of person.
- the right to equality and non-discrimination.
- the right to participation in public policy.
- the right to remedy.
- the right to informed consent.
- the right to receive information.
- the right to conscience and religion or beliefs.
- the right to freedom from torture and cruel, inhumane and degrading treatment.
- the right to practice religion and use one's own language.

- the right to a safe environment.
- right to adequate housing.
- the right to social security
- justice

However, as much as law and human rights play an integral part in the relationship between a HCP and patients, ethical considerations are also important. The biomedical ethical principles are in respect of autonomy, non-maleficence, beneficence, and justice. Most bioethical decisions are analysed using these four principles, which are necessary within healthcare because it impacts on the opportunities of individuals. The shift of focus to human and social security has occurred only over the last few decades, therefore, Patients' Rights Charters need to merge existing human rights with the relevant bioethical considerations.

This study's analysis of 12 countries Patients' Rights Charters shows that the focus has been to incorporate the international standards, conventions, and treaties well into their charters. There are, however, human rights that most of the charters did not incorporate; these include Articles 12.2(a) and Article 12.2(c) of the ICESCR where the inclusion of the right to security is vague in some instances, and the freedom of movement is not included at all.

The human rights that are unanimously adhered to are Article 12.2(d) of the ICESCR; namely, the right to dignity; the right to life; the right to equality and non-discrimination; the right to liberty; the right to remedy, and the right to confidentiality. It would seem,

therefore, that these rights are what international standards consider to be the most important for patients to know and understand within the health sector. In terms of the alignment of patient charters to bioethical rights, the right to informed consent, the right to receive information, and distributive justice feature in all the charters.

It is clear that the charters do not differ based on income classifications, as in some cases, namely Uganda and Scotland which have similar charters. However, where differences do exist, this depends on the right and the interpretation of that right. Although South Africa aligns with most human rights, consideration of a stronger emphasis on freedom of movement, justice, security and safety is needed.

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Appendix 1

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

Ref: W-CP-180424-3

24 April 2018

TO WHOM IT MAY CONCERN:

Waiver: This certifies that the following research does not require clearance from the Human Research Ethics Committee (Medical).

Investigator:	**Ms Kelly Kumalo (student no 457759)**
Supervisor:	**Prof Ames Dhai**
Faculty:	Health Sciences
School:	Clinical Medicine
Department:	Steve Biko Centre for Bioethics
Project title:	**A Comparative on Global Patients' Rights Charters and their Alignment to Bioethical Principles and Human Rights**
Reason:	Literature Review

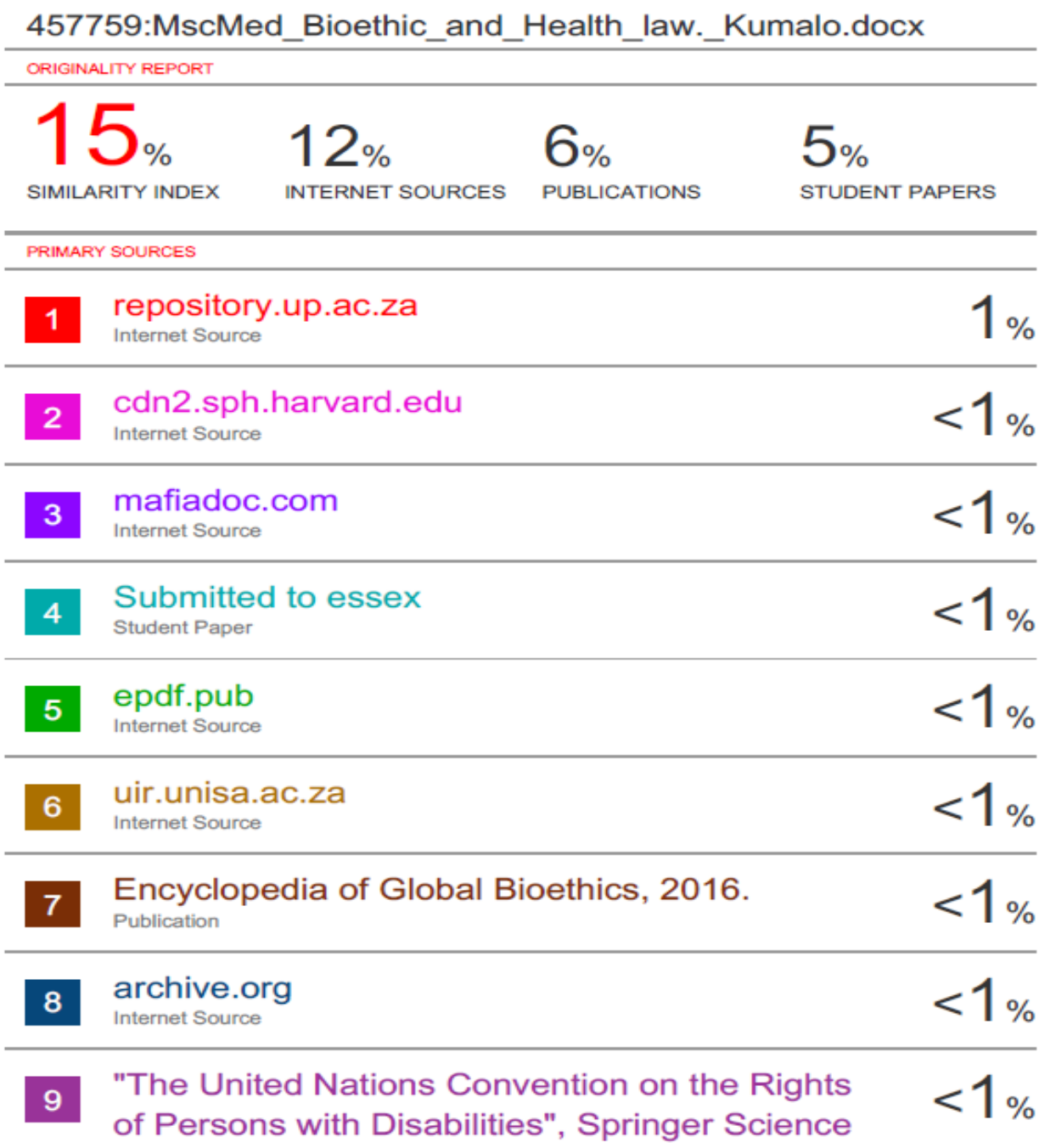
Professor Clement Penny

Chair: Human Research Ethics Committee (Medical)

Copy – HREC (Medical) Secretariat: Zanele Ndlovu, Rhulani Mkansi,Iain Burns

Research Office Secretariat: Faculty of Health Sciences, Phillip Tobias Building, 3rd Floor, Office 301, 29 Princess of Wales Terrace, Parktown, 2193 Tel +27 (0)11-717-1252 /1234/2656/2700 Private Bag 3, Wits 2050, email: zanele.ndlovu@wits.ac.za Office email: hrec-medical.researchoffice@wits.ac.zaWebsite:

Appendix 2



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