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Genomics, Insurance and Human Rights: Is there a Place for Regulatory Frameworks in Africa?

Vincent O. Nmehielle†

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Abstract

This article examines the human rights dimension of genetic discrimination in Africa, exploring the place of regulatory frameworks while taking into account the disadvantaged position of the average African. This is in response to the tendency of insurance companies toward making health insurance decisions on the basis of individual genetic information, which could result in genetic discrimination or health insurance discrimination based on a person's genetic profile. The author considers such questions as the intersection between human rights (right to life, health, privacy, human dignity and against genetic discrimination) in relation to the insurance industry, as well as the obligations of state and non-state actors to promote, respect, and protect the enjoyment of these rights. The article argues that African nations should not stand aloof in trying to balance the competing interests (scientific, economic and social) presented by the use of genetic information in the health care context and that ultimately it is the responsibility of states to develop domestic policies to protect their most vulnerable citizens and to prevent entrenched private discrimination based on an individual's genes.

†Associate Professor of Law, University of the Witwatersrand School of Law, Johannesburg, South Africa. Professor Nmehielle is currently on leave to the Special Court for Sierra Leone where he is the Principal Defender of the Special Court. He specializes in international human rights and comparative law.

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I. Introduction

The human genome project has been described as among the few scientific achievements that "are so momentous that they mark turning points in history."[1] The turning point in this regard is the capacity that human beings have acquired "to document, and eventually alter, our own genetic blueprint" through science and technology.[2] There is also agreement that the science and technology that this achievement will make possible in the near future will affect the health and well-being of every person and could possibly result in deliberate control over the future evolution of the species.[3] Scientific development in genomics will aid society in countless ways, but the fear remains as to its effect in ordinary social life, especially regarding insurance, with particular emphasis on health insurance. The tendency would be for insurance companies to make health insurance decisions on the basis of individual genetic information, which could result in genetic discrimination or health insurance discrimination based on a person's genetic profile.

This article examines the human rights dimension of the genetic discrimination conundrum in an African context with a view to exploring the place of regulatory frameworks, having in mind the disadvantaged position of the average African. The paper will consider such broad questions as the intersection between aspects of human rights – such as the right to life, health, privacy, human dignity and against genetic discrimination in relation to the insurance industry – as well as the horizontal obligations of insurance companies as non-state actors, and the vertical obligations of states to promote, respect, and protect the enjoyment of those rights.

II. Background to the Human Genome Initiative

"The Human Genome Initiative is an international research program for the creation of detailed genetic and physical maps for each of the twenty four different human chromosomes and the elucidation of the complete deoxyribonucleic acid (DNA) sequence of the human genome",[4] resulting in the Human Genome Project (HGP). The HGP is said to be at the forefront of the biology movement in the 21st Century – a century which scientists have predicted will be the "biology century."[5] This is as a result of the fundamental change that biology has undergone in the last fifty years, which has been compared to the industrial revolution of the 19th Century and the advances in quantum physics of the 20th Century.[6] The term "genome" originated in 1930 and was used to "denote the totality of genes on all chromosomes in the nucleus

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[1] Jie Chen, 'Ethics and the Genome in World Health: WHO's deliberations and a Global Plan of Work' < http://south.genomics.org.cn/unsceo/documents/abstr/001.htm> accessed 15 March 2003.
[2] Ibid.
[3] Ibid.
[4] John L Houle, Wanda Cadigan, Sylvain Henry, Anu Pinnamaneni and Sonny Lundahl, 'Database Mining in the Human Genome Initiative' (White Paper).
<http://www.biodatabases.com/whitepaper01.html> accessed 10 April 2003.
[5] US Department of Energy Office of Science, 'The Science Behind the Genome Project: Basic Genetics, Genome Draft Sequence, and Post-Genome Science'.
<www.ornl.gov/TechResources/Human_Genome/project/info.html> accessed 15 March 2003
[6] UC Davis Genome Center, 'What is Genomics? The Emergence of Genomics as a Discipline'
<http://www.genomics.ucdavis.edu/what.html> accessed 15 March 2003 (extract on file with the author).

of a cell."[7] It is thus "the master blueprint for a person's lifetime and contains the complete list of instructions for making an organism."[8] It has been observed that "DNA was not identified as the genetic material of all living organisms until 1944" and that "the genetic code was elucidated in 1961", making it possible to contemplate the concept that biological organisms had a blueprint that consists of a finite number of genes.[9] "The sequence of these genes encoded all of the information required to specify the reproduction, development and adult function of an individual organism", resulting in the new discipline referred to as genomics.[10]

Scientists hold that "the complete sequencing of the human genome was proposed in 1986, and the resulting large scale initiatives collectively known as the human genome project were begun in 1990 with joint support from the [US] National Institutes of Health and the [US] Department of Energy."[11] Since then, researchers from various parts of the world, particularly the United States, the United Kingdom, Germany, Japan and France have been engaged in reconstructing DNA sequencing to produce detailed physical maps of the human genome.[12] A genetic map "depicts the linear arrangement of genes or genetic marker sites along a chromosome"[13] and "two types of genetic maps are identified: genetic linkage maps and physical maps. Genetic linkage maps are based on the frequency with which genetic markers are coinherited"[14] while "physical maps determine actual distances between genes on a chromosome."[15]

It has been observed that while the first genomics initiatives were publicly funded as distributed research projects, many governments as well as private sector firms involved in biological research also mounted substantial efforts in genomics.[16] This enormous interest and commitment of resources in both the public and private sectors is said to

> flow from the generally held perception that genomics will be the single most fruitful approach to the acquisition of new information in basic and applied biology in the next several decades but that if genomics were only to be a tool

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[7] UC Davis (n 6).
[8] Natalie E Zindorf, 'Discrimination in the 21st Century: Protecting the Privacy of Genetic Information in Employment and Insurance' (2001) 36 Tulsa Law Journal 703.
[9] UC Davis (n 6).
[10] Genomics has been operationally defined as "investigations into the structure and function of very large numbers of genes undertaken in a simultaneous fashion." See Ibid.
[11] Ibid.
[12] Zindorf (n 8) 704, citing Division of Extramural Research (DER), 'HGP, The Human Genome Project: Human Genome Project Goals: 1998-2003' < http://www.nhgri.nih.gov/HGP> accessed 11 March 2006. According to Pearson and Soll, the Human Genome Initiative has six scientific objectives: (1) construction of a high-resolution genetic map of the human genome; (2) production of a variety of physical maps of the human genome; (3) determination of the complete sequence of human DNA; (4) parallel analysis of the genomes of a selected number of well-characterized nonhuman model organisms; (5) creation of instrumentation technologies to automate genetic mapping, physical mapping and DNA sequencing for the large-scale analysis of complete genomes; and (6) development of computational tools such as algorithms, software and databases for the collection, interpretation and dissemination of the vast quantities of complex mapping and sequencing data that are generated by human genome research. See Houle et al (n 4), citing ML Pearson and D Soll, 'The Human Genome Project: A paradigm for information management in the life sciences' (1991) FASEB J 5, 35-39.
[13] Zindorf (n 8) 704.
[14] Ibid.
[15] Ibid.
[16] UC Davis (n 6).

> for the basic biologist, the benefit of this approach would be staggering, yielding new insights into fundamental processes such as cell division, differentiation, transformation, the development and reproduction of organisms and the diversity of populations.[17]

In fact, for scientific and medical purposes, the advent of a high-resolution genetic map of the human genome will generate advances in six areas of medicine, namely: genetic counseling, prediction of genetic disease susceptibility, diagnostic tests, gene therapy, rational drug design, and pharmacogenomic drug customization.[18] While these areas of medical advance are scientifically and medically rewarding, the rewards have, however, attracted the private sector and public interest. Among others, "these include the promise of facile new approaches for drug discovery, new understanding of how cancers form, new approaches for the treatment of diseases, genetic engineering of plants for disease resistance and improved nutrient content".[19] Thus, Genomics is generating a lot of excitement not only in the research institutes and pharmaceutical companies but also in the financial and insurance world. The excitement that genomics brings to the insurance world is one of the primary concerns of this paper, particularly in the area of health, in relation to the human rights dimension of the application of genetic science.

III. Genomics, Insurance and Human Rights

The insurance industry's attraction to genetic science raises suspicion among the general public and various scholars around the globe who point to the dangers of possible discriminatory practices resulting from genetic testing and/or the use of genetic information. Even though systematic testing does not currently seem to take place and the use of genetic information by insurance companies and other institutions is quite limited as expressed by some scholars,[20] the fear remains that in the future, as genetic research develops and test kits become cheaper, the capacity to conduct such tests quickly and inexpensively will boost demand, commercial production and distribution of the tests, making it potentially cost effective to introduce genetic screening in a variety of non-medical settings such as in the provision of insurance policies and in the workplace, among others.[21] Despite the fact that most genetic findings have not presently been integrated into underwriting procedures because of lack of clear data, scholars point out that there have been quite a number of population-based studies to establish risk predictions that are quite precise in the context of many hereditary diseases, such as cancer and the like.[22] Thus, "in the future, more and more reliable risk information will become available on a variety of diseases. Increased accuracy of genetic risk calculations combined with cheaper and faster genetic detection of mutations will constitute a

[17] UC Davis (n 6).
[18] Houle et al (n 4).
[19] Ibid.
[20] J Beckwith and JS Alper, 'Reconsidering Genetic Antidiscrimination Legislation' (1998) JL Med & Ethics 26, 206.
[21] T Lemmens, 'Selective Justice, Genetic Discrimination, and Insurance: Should We Single Out Genes in Our Laws?' (2000) McGill L J 45, 352.
[22] Ibid, citing Shattuck-Eidens et al, 'BRCA1 Sequence Analysis in Women at High Risk for Susceptibility Mutations' *(1997)* J Am Med Assoc 27, 1242; BL Webber, 'Update on Breast Cancer Susceptibility Genes' (1998) Recent Result Cancer Res 152, 49.

significant incentive to conduct genetic testing outside the medical context."[23] This is because the commercial interests in the booming technology made possible by genomics is enormous and, as a result, "notwithstanding ethical concerns about the premature introduction of new genetic tests, increased pressures will inevitably be created for faster integration of genetic testing into daily clinical practice."[24] The expectation, therefore, is that there will be a tendency toward the predictive value of genetic tests in determining insurance premiums, which will lead to an increased individualization in underwriting.[25]

A. Actuarial considerations

From the insurance point of view on the possible use of genetic testing and information as part of health information, the argument hinges on underwriting, which is based on what Lemmens refers to as both "economic" and "moral" considerations. The economic factor is based on "adverse selection"[26] to the effect that if insureds were allowed to hide health factors, insurers would in no time be confronted with a disproportionate number of people at risk applying for extended coverage. Lemmens posits that "this is because insurance applicants who know that they are at risk and know that they can hide the information have an incentive to obtain insurance" and as a result, "insurers will have to pay out more claims; extra costs will result in higher insurance premiums and people who are low risk will gradually lose interest in obtaining insurance."[27] Accordingly, "the proportion of high risk individuals will thus systematically increase; insurance will enter a spiral of price increases and eventually, the industry will collapse."[28] While the extent of underwriting required for insurance may be controversial, there is agreement that it is normal that some exchange of information and some assessment of risk remain the basis for private insurance[29] and as such, insurers would be justified in their attempts to minimize their risks.

On the moral angle, the ethical concept of equity or fairness is invoked to the effect that insurers have to distinguish people on the basis of individual risk for reasons of fairness to policyholders.[30] Lemmens criticizes Pokorsky's view that "the fundamental goal of the underwriting process is equity: policyholders with the same or similar expected risk of loss are charged the same" and "an insurer may – and must – discriminate to achieve equity, insofar as the discrimination remains fair."[31] She maintains that the statement begs the question "since the criterion for deciding

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[23] Lemmens (n 21) 352.
[24] Ibid, citing T Caulfield, 'Genetic Testing in the Biotech Century: Are Physicians Ready?' (1999) Med Assoc J, 161C, 1122.
[25] Ibid 351.
[26] Ibid 383.
[27] Ibid.
[28] T Lemmens and P Bahamain, 'Genetics in Life, Disability and Additional Health Insurance in Canada: A Comparative Legal and Ethical Analysis' in BM Knoppers (ed), *Socio-Ethical Issues in Human* Genetics (Yvon Blais, Quebec 1998) 122-23; "Genetic Testing and Insurance," *Health Which Magazine* June 2001, p. 18.
[29] Lemmens (n 21) 383.
[30] Ibid.
[31] Ibid, referring to RJ Pokorski, 'Use of Genetic Information by Private Insurers' in TF Murphy and MA Lappe (eds), *Justice and the Human Genome Project* (University of California Press, Berkeley 1994) 92-93.

whether equity is achieved is whether the means to achieve it are fair."[32] The statement indicates that in insurance terms, an insurance scheme is equitable if it respects actuarial rules, which presupposes that "the use of actuarial rules itself is neutral and not questionable from the standpoint of equity."[33] This author agrees with the position that this kind of equity is "at best actuarial equity – fairness according to existing insurance practices, based on actuarially accurate determination of risk."[34]

According to Lemmens, actuarial equity says nothing about the fairness of the premise that access to insurance, and in this particular context health insurance, "should always be based on presumptions of contractual liberty."[35] She goes on to ask the question whether contractual liberty has any limits – a question that goes to the heart of the matter when considering issues of distributive justice in healthcare and other areas such as social security.[36] One would agree with her observation that the "equity invoked by insurers is valid for those who accept the premise on which the insurance game is based", and that the "more important issue as to how insurance fits into the human vision of a just society calls into question the premise upon which claims of fairness are made."[37] Thus, it is important that the role of insurance in society must be discussed in this new era, having in mind questions about the fairness of the effects of genetics on insurance, particularly health insurance. This is because the choices regarding insurance systems impact on the way a community defines itself. According to Deborah Hellman, "a way of understanding the disagreement over the justifiability of insurance rating is as much a discussion about what kind of a community we want to be."[38] Similarly, she argues, "the debate about whether the actuarial fairness principle ought to govern health insurance pricing is a debate about whether ours is a community that is committed to the provision of aid to those who are sick or disabled."[39]

The relevance of the above discussion is apt in the African context where there is more poverty than in any other part of the world, which in turn has a drastic effect on access to healthcare. Access to healthcare, it can be argued, is a defining feature of society and in our contemporary society, according to a view credited to Walzer, "medical care has become a socially recognized need so that a deprivation [of it] is a double loss – to one's health and to one's standing."[40]

B. Human rights considerations

A discussion of the human rights dimension of insurance in its relationship to genomics forms part of the ethical, social and legal implications of genomics, which in turn impacts on the desirability of regulatory frameworks. We must understand

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[32] Lemmens (n 21) 384.
[33] Ibid.
[34] Ibid, citing N Daniels, 'Insurability and the HIV Epidemic: Ethical Issues in Underwriting' (1990) Milbank Q 68, 500.
[35] Lemmens (n 21) 385.
[36] Ibid.
[37] Ibid.
[38] D Hellman, 'Is Actuarially Fair insurance Pricing Actually Fair? A Case Study in Insuring Battered Women' (1997) Harv CR – CL L Rev 32, 355.
[39] Lemmens (n 21) 355.
[40] Ibid 388, citing M Walzer, *Spheres of Justice: A Defense of Pluralism and Equality* (Basic Books, New York 1983) 89.

that although human rights obligations are primarily those of nation states, they bear on transactions conducted by and with private or non-state actors like corporations. For the purpose of this discussion, states promote the human rights of their citizenry by, among other things, creating a culture of awareness with respect to these rights. States respect these rights first of all by not directly infringing them, but they also safeguard these rights by preventing other entities from violating them. According to the World Health Organization (WHO), several key human rights lie at the heart of the ethical, legal and social implications of genomics, including the right to "equality and nondiscrimination; education, information and participation; privacy, individual autonomy and physical integrity; the highest attainable standard of health; and to life, to benefit from scientific progress, to social security, and to an adequate standard of living, including food, water, clothing and housing."[41] For the benefit of the human rights implications of insurance based on genomics, this paper limits the implicated rights to the right against discrimination (genetic discrimination), the right of access to healthcare/human dignity/right to life, and the right to privacy.

Genetic discrimination

Virtually all human rights instruments and constitutions from around the world prohibit discrimination. Genetic discrimination is, however, quite a new concept that emerged from the fear of exclusionary practices based on genetic susceptibility. The concept, which has become firmly established in legal and bioethics literature, has been defined in various ways. It has been described in general terms as any form of differentiation based on genetic information. Mark Rothstein sees it as "differential treatment based on genetic status."[42] Larry Gostin defines the term as "the denial of rights, privileges or opportunities on the basis of information obtained from genetically-based diagnostic and prognostic tests."[43] The United States Equal Opportunity Commission describes genetic discrimination as "using genetic information to judge an individual with predisposition to a certain disease or condition based on the possibility that he or she might one day develop that disease or condition."[44] Without arguing which of the above definitions is the best, it is important to note that they all emphasize differentiation in granting a benefit based on genetic makeup. In the context of this paper, genetic discrimination thus involves making health insurance decisions about an individual on the basis of genetic information. Genetic information itself is not easily defined and has prompted a heated debate as to its precise meaning. Some groups narrowly define it "as the

[41] World Health Organization, 'Genomics and World Health' (briefing at the 57th Session of the United Nations Commission on Human Rights, Agenda Item 17d, Promotion and Protection of Human Rights: Science and Environment; The Advisory Committee on Health Research) (WHO, Geneva 2002) 147 (Genomics and World Health).

[42] MA Rothstein, 'Genetic Discrimination in Employment: Ethics, Policy and Comparative Law' in *Human Genetic Analysis and the Protection of Personality and Privacy* (Swiss Institute of Comparative Law, Geneva 1994) 129, reprinted in Lemmens (n 21) 355.

[43] L Gostin, 'Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers' (1991) Am J L & Med 17, 109, reprinted in Lemmens (n 21) 355.

[44] Zindorf (n 8) 708 citing The United States Equal Employment Opportunity Commission, 'Policy Guidance on Executive Order 13145 Prohibiting Discrimination in Federal Employment Based on Genetic Information' <http://www.eeoc.gov/policy/docs/guidance-genetic.html> accessed 16 March 2003.

results of DNA and related gene testing and other groups broadly interpreting it to include family medical history."[45]

Genetic testing or genetic screening involves "detecting alterations or errors in an individual's genetic composition that indicates a person's susceptibility to developing a particular disorder."[46] One must agree with the observation that the results of such tests contain information of a highly personal nature, and that the thought that an insurer or employer could have access to such private health details is quite threatening to those who, in this case, may be termed "genetic test subjects" as well as their family members.[47] An example of the inherent danger of genetic information falling into the wrong hands is the fact that it could prevent a mother from undergoing prenatal or fetal screening that ordinarily would be beneficial to her and her child.[48] It becomes very important, therefore, that confidentiality is protected by law. Despite criticism that it is speculation whether or not genetic information will be misused, there is agreement that in the eyes of society the threat is real and there is a need for protective laws "if genetic science is to continue advancing and accomplishing goals to benefit the public."[49]

One is reminded of two real-life cases, among many such examples in the United States, concerning the threat of genetic discrimination in health insurance related situations, as told by Congresswoman Louise Slaughter:[50]

> A woman took a genetic test for breast cancer based on numerous cases among her family members and learned that she carried the gene. She decided to have a prophylactic double mastectomy and petitioned her insurer to cover the procedure without sharing the genetic information. When her insurance company denied her request, she revealed to them that she had the breast cancer gene. Upon learning this information, the insurer not only denied her request for coverage, but canceled her policy as well. The other case involved Terri who had received outstanding job evaluations and regular generous salary increases for years. Upon going to the doctor for allergy problems, she was diagnosed with ALPHA1, a disease that had killed her brother. She began a regimen of treatments that would keep her healthy and functional, carefully scheduling her appointments on evenings, weekends, and vacation time. When her self-insured employer learnt about her condition, she was told that her services were no longer needed and was asked to leave.[51]

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[45] Zindorf (n 8) 708.
[46] Ibid, citing Tara L Rachinsky, 'Genetic Testing: Toward a Comprehensive Policy to Prevent Genetic Discrimination in the Workplace' (2000) U Pa L Rev 2, 578.
[47] Ibid 709, citing Lawrence Gostin and James Hodge Jr, 'Genetic Privacy and the Law: An End to Genetic Exceptionalism' (1999) Jurimetrics J 40, 40-41.
[48] Ibid.
[49] Ibid 710.
[50] Louise Slaughter, 'Personal Genetic Information: Implications for the Workplace and Criminal Justice. The Genetic Nondiscrimination in Health Insurance and Employment Act: H.R. 602' (2001) NYL Sch J Hum Rts 18, 5, citing US Senator Tom Daschle Press Release, 'Daschle Remarks Prepared for Delivery by the Senate Democratic Leader on the Introduction of the Genetic Nondiscrimination in Health Insurance and Employment Bill'.
[51] Ibid citing 'Genetic Information in the Workplace: Hearing of the US Senate Committee on Health, Education, Labor and Pensions' (2000) 106th Cong 80-81 (Statement of Terri Seargent). Slaughter also refers to a case where the Equal Employment Opportunity Commission for genetic discrimination sued the Burlington Northern Santa Fe Railroad in the United States. Here, workers who filed disability

The significance of the above cases for Africa is enormous. If that could happen in the United States where there is a claim of respect for human rights and long history of anti-discrimination laws and policy, the dangers are that it could routinely happen in Africa with impunity. This is more so the case in this era of globalization where multinational corporations continue to expand and exert their influence on developing countries in the guise of foreign investment, without a commensurate policy of social corporate responsibility and without adequate home-grown regulatory frameworks to keep them in line. The shift from public sector provision of healthcare to the private sector in many countries where private insurers make use of ratings for health insurance will only exacerbate the fears of genetic discrimination, which in turn could lead to stigmatization. According to the WHO:

> The stigmatization of people carrying genes creating risks for serious disease can often have serious psychological consequences, not just social consequences with respect to labeling as diseased or unhealthy an individual who remains healthy and who has not yet developed, and may never develop, the disease in question. Being labeled as having "bad" genes can have a variety of serious social and psychological consequences for individuals, and this stigmatization may be stronger and more common where levels of education and understanding about genetics is low.[52]

There is no doubt that stigmatization fuels discrimination and that this can be carried out with impunity in developing countries, the majority of which are in Africa where there are few effective non-discrimination laws and regulations and where adverse societal and cultural labels are not easily erased in the minds of many, including corporate entities. The example of HIV/AIDS is a glaring one and has impacted peoples' ability to obtain health and other necessary insurance policies.

Access to healthcare/human dignity/right to life

Without getting into the long drawn debate about the appropriateness of the right to health or the right of access to healthcare as a human right – a right classified under economic, social and cultural rights – there is an important connection between access to healthcare, human dignity and the right to life, which is a civil and political right, in our modern society. The use or misuse of genetic information in a manner that adversely impacts on a person's ability to access healthcare has a direct effect on the person's right to human dignity and life. The foundation of human rights is anchored in the age-long and universal notion of the intrinsic worth of human beings.

The WHO defines health as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity."[53] In the

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claims related to carpal tunnel syndrome were being tested without their knowledge or consent for an extremely rare genetic condition that may predispose some individuals to the disorder. The company evidently hoped to avoid paying disability claims for workers found to have the gene.

[52] Genomics and World Health (n 41) 158.

[53] Constitution of the World Health Organization, *Basic Documents*, Official Document No. 240 (Washington 1991). The WHO Constitution was adopted in New York in 1946 at the International Health Conference and was signed by representatives from 61 states.

implementation of human rights treaties, states have the obligation to ensure the human right to health by *inter alia*, guaranteeing access to quality health care services without any form of discrimination. Article 25 of the Universal Declaration of Human Rights (Universal Declaration) emphasizes recognition of the right of all persons to an adequate standard of living, including guarantees for health and well-being. It acknowledges the relationship between health and well-being, its link with other rights such as the right to food and the right to housing, as well as medical and social services.[54] In Article 12 of the International Covenant on Economic, Social and Cultural Rights, state parties recognize the right of every one to the enjoyment of the highest attainable standard of physical and mental health.[55] Various other international and regional treaties include similar provisions.[56] In the same vein, some national constitutions recognize the right to health care.[57] The obligation of states under these instruments is to ensure the existence of good health standards and to protect groups within the population that are especially vulnerable. Among measures that states must adopt are those aimed at reducing maternal mortality – preventing, treating and controlling epidemics and illnesses – as well as creating conditions that ensure that medical attention and services are available for all in the event of illness.

The WHO had long joined the various other international and national bodies to agree that access to at least a basic level of healthcare is a human right and a requirement of equity and justice. Thus

> basic health care services should be available to all people and not just to those with the ability to pay for them. Since the health care services are often expensive, with individuals' needs highly variable and unpredictable, they are difficult to budget for and so are typically provided through some form of insurance; usually social insurance within a national health system, but increasingly in many countries, at least in part, by private health insurance. If individuals are subject to risk rating for health insurance, and increasing amounts of information become available to insurers about genetic risks, many people will face large differences in their health insurance costs from genetic risks; they will be denied health insurance, or be unable to afford it at all. This will seriously undermine the universal provision of health care.[58]

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[54] Universal Declaration of Human Rights (adopted 10 December 1948) UNGA Resolution 217 A (III) (UDHR) art 25.

[55] International Covenant on Economic, Social and Cultural Rights (adopted 16 December 1966) 993 UNTS 3 art 12.

[56] See generally the Convention on the Rights of the Child (adopted 20 November 1989, entered into force 2 September 1990) UNGA Res 44/25 art 23-24; the Convention on the Elimination of All Forms of Discrimination Against Women (adopted 20 December 1979, entered into force 3 September 1981) (CEDAW) UNGA Res 34/180 art 12(2); Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights (Protocol of San Salvador) (entered into force 16 November 1999) OAS Treaty Series 69 (1988) art 10; European Social Charter, art 11; and the African Charter on Human and Peoples' Rights (adopted 27 June 1981, entered into force 21 October 1986) (1982) 21 ILM 58 art 16.

[57] The Constitution of the Republic of South Africa, Act No 108 of 1996. Section 27 provides for access to adequate health care.

[58] Genomics and World Health (n 41) 158.

It has been argued, and rightly so, that "we must understand that heath and well-being are deeply personal matters"[59] but that it is

> when we or those close to us face illness or chronic suffering that we perceive that health is in reality a very public issue. Policies which dictate what level of health care provision is guaranteed, what kinds of service will be offered, how priorities are established between competing claims, where resources are concentrated, and what alternatives are available all become far more immediate when they affect us or our loved ones. Facing a particular health related condition, and then being on the receiving end of the decisions or prejudices of others – be they health professionals, religious authorities, family members, neighbours, employers or insurance companies – is something that often gives us a new awareness of how limited is our capacity to control some of the most central aspects of our lives. It gives us an insight into what exclusion feels like.
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> Disempowerment and exclusion are caused by a similar combination of personal experience and circumstances on the one hand and the social and political context on the other. At the one end of the spectrum, we see the importance of the macroeconomic and ideological settings. Economic policies that result in the under-funding of public services and fragmentation of the regulatory role of government tend to reduce the threshold of what is considered an acceptable minimum standard of healthcare provision for the population at large. Access to healthcare becomes dependent on the individual's capacity to pay; patients are turned from citizens who have rights and responsibilities into clients and customers. The question of financing healthcare may thus be posed as a pseudo-technical one: what kinds of cost recovery and insurance mechanisms "work" and in what circumstances?[60]

The interrelatedness of the right to health, human dignity and the right to life cannot be overemphasized. While the right to life is usually considered to be offering protection against arbitrary killing by state actors, the United Nations Human Rights Committee considers it linked to a state obligation to adopt all measures to reduce infant mortality and to foster life expectancy, especially by adopting measures to eliminate malnutrition and epidemics.[61] Thus, the right to health is an essential component of the right to life, which itself is based on the right of human dignity. It follows, therefore, that as Walzer emphasized earlier, "medical care has become a socially recognized need so that deprivation of it is a double loss to one's health and

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[59] International Human Rights Internship Program, 'Circle of Rights: Economic, Social and Cultural Rights Activism: A Training Resource – Module 14: The Right to Health' <http://www1.umn.edu/humanrts/edumat/IHRIP/circle/modules/module14.htm> accessed 16 March 2003 (Circle of Rights).

[60] Ibid.

[61] Human Rights Committee, General Comment 6, art 6 (Sixteenth Session 1982) Compilation of General Comments and General Recommendations Adopted by Human Rights Treaty Bodies, UN Doc HRI/GEN/1/Rev.1 at 6 (1994) para 5.

social standing" and "doctors and hospitals have become such massively important features of contemporary life that to be cut off from the help they provide is not only dangerous but also degrading."[62] In other words, people's dignity is at stake when they do not have access to healthcare, and insurance roadblocks based on genetic considerations may just result in debased human beings.

Privacy

In human rights, privacy is central to personal autonomy[63] and ought to be respected, primarily by the state and its agents but also by non-state actors at the insistence of the state through some form of regulation. Accordingly, the growing concern over the handling of genetic information includes the question of privacy – in this sense, genetic privacy. What is not clear is whether the general human rights principle that recognizes an individual's right to privacy would apply *mutatis mutandis* to genetic privacy, or whether a specific genetic privacy principle should be developed due to the importance attached to this issue.

Be that as it may, the argument surrounding genetic privacy has been reduced to how existing and known genetic information, on the one hand, and unknown information, on the other, should be treated. According to Graeme Laurie, it is legitimate to permit the insurance industry to have access to existing genetic information, no matter how defined, in keeping with full disclosure, since the general principle of *uberrima fides* (utmost good faith) governs insurance contracts.[64] This is especially so, since the decision to seek such information through testing is likely to be taken by the individual unfettered by other considerations and free from coercive forces, meaning it would have been a free choice and exercise of individual autonomy.[65] On the other hand, Laurie argues that it would be illegal to request genetic testing for insurance purposes because such a request would interfere too greatly with "the core set of interests which individuals have in their selves and the control to which they are entitled over their private lives."[66] Laurie maintains that unlike the request for information, which already exists, the request to undergo testing generates new information, which is not necessarily for the benefit of the individual concerned. He agrees that it is largely to further the financial interests of the insurance industry, and that once the information is known, it can never be unknown, but "becomes and remains a part of the individual's life and has the tendency to affect his or her future" and that of his or her progeny.[67]

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[62] Lemmens (n 21) 388.

[63] Most constitutions of the world protect personal privacy, though principally against the state and state actors. That protection, in appropriate circumstances, could be extended to private actors, especially where the state refuses to prevent private actors' violation of people's privacy. Similarly, several international and regional human rights instruments protect privacy. See Convention for the Protection of Human Rights and Fundamental Freedoms (European Convention for Human Rights, as amended) art 8 and the American Convention on Human Rights, art 11.

[64] Graeme Laurie, "Genetics and insurance: is it 'in the public interest' to involve the law?" <http://www.law.ed.ac.uk/ahrb/publications/online/GLGene.htm > accessed 15 March 2003

[65] Ibid.

[66] Ibid.

[67] Ibid. This view is in furtherance of what Laurie calls the right not to know in that "knowing has the tendency to significantly impact the psychological integrity of the individuals, by burdening them with information which forces them into a period of self-reflection and self-reassessment which they would not otherwise have experienced, and could lead to morbidification and ill-treatment of asymptomatic individuals."

While Laurie's advocacy for the right not to know in promotion of privacy is innovative, it restricts the promotion of privacy to unknown genetic information, while known information would easily be available for insurance purposes without a commensurate obligation as to its privacy and use as it affects an individual's access to health care. What about where the known information is misused to the detriment of the individual due to lack of adequate exercise of privacy caution by the insurance company or by other entities for the benefit of insurance companies? An example is information known through medical or scientific research and meant for databases. The question then becomes whether such genetic information can be used for other purposes beyond that for which consent was originally given without obtaining additional consent for new uses. There is no doubt that utmost good faith is the basis of insurance contracts, but the fact that one has information of a genetic flaw does not automatically mean that one will develop the disease. The misuse of the information in this regard could adversely impact an individual's ability to access health or other necessary insurance.

IV. The Place of Regulatory Frameworks

Considering the concerns raised in the previous sections of this paper on the possible impact of genomics on insurance and consequently, on human rights, the question arises whether there is any need for frameworks that would address those concerns, especially in Africa. If there is agreement that regulation is proper, there is the further question on the form such regulation should take – an outright ban on genetic discrimination in health insurance and possibly in employment, or another form of protection of genetic information? There have been various regulatory initiatives in other parts of the world involving international, regional as well as national action. A review of some of these initiatives is relevant here.

The first universal regulatory instrument to establish an ethical framework in this area was the Universal Declaration on the Human Genome and Human Rights.[68] Article 6 of the Human Genome Declaration provides that no "one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity." It emphasizes the importance of confidentiality of genetic data and the need for informed consent, which embodies the right of individuals to determine whether or not they want to know about their genetic condition.[69] Although the Human Genome Declaration "has no binding force in international law, it is designed to serve as a lasting instrument of reference, primarily for states, which are expected to reflect its principles in their laws" and "the contents of the declaration are essentially a codification of ethical rules that are generally recognized internationally, the purpose of which is to enable each citizen to take advantage of them." [70]

Regionally, the adoption by the Council of Europe of the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the

[68] UNESCO Gen Conf Res 29 C/Res 16, reprinted in Records of the General Conference, UNESCO, 29th Sess 29 C/Resolution 19 at 41 (1997) (UNGA res 152 UN GAOR 53rd Sess UN Doc A/RES/53/152 (1999)) (Human Genome Declaration).
[69] Ibid art 7.
[70] Noelle Lenoir, 'Universal Declaration on the Human Genome and Human Rights: The First Legal and Ethical Framework at the Global Level' (1999) Colum Human Rts L Rev 30, 547.

Application of Biology and Medicine[71] "marked the emergence of specifically European bioethical principles inspired by the general principles of the European Convention on Human Rights."[72] In the same vein, there have been a series of national and provincial or state efforts in the United States,[73] Belgium, Norway, Austria and the Netherlands among others. In these countries, the regulatory frameworks consist of a combination of legislation either prohibiting the use of genetic testing for insurance purposes, banning genetic discrimination, or increasing genetic privacy.

In Africa, apart from the various constitutional provisions and specific statutes that outlaw discrimination generally,[74] there is no known particular legislative initiative that tackles genetic information. The tendency would be to try to interpret existing legislation in ways that would extend their application to genetic discrimination. It appears that such an approach would not go far enough because these statues allow discrimination provided it is not unfair. Based on this standard, it is not clear that the use of genetic information by the insurance industry would qualify as discriminatory since the practice the world over is to allow discrimination based on reasonable actuarial calculations. That would not be very beneficial, as it adds nothing to the current debate in the context of Africa. Alternatively, the only option may be to leave it up to insurers to regulate themselves by say, adopting codes of conduct that would guide their practices with respect to the use of genetic information, as is currently being advocated in South Africa. The danger here is that voluntary codes of conduct have not always worked and will most likely be abused by companies in an African setting in view of the weak economies and lack of effective regulation of multinational corporations.

The whole idea of regulatory frameworks that address genetics in relation to insurance has been criticized as leading to what has been termed "genetic exceptionalism" – singling out genetics for special legislative attention.[75] The argument is that there are other kinds of information that raise the same concerns that genetics evokes, and that specific attention to genetics ignores the importance that should be attached in safeguarding such other information.[76] Despite these criticisms, it is not likely that the various global and national legislative initiatives will go away any time soon. What is surprising, however, is that some of these countries that have legislation outlawing genetic discrimination or promoting genetic privacy have a universal health system, particularly in Europe. It follows, therefore,

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[71] Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine (Convention on Human Rights and Biomedicine).
[72] Lenoir (n 70) 541.
[73] Zindorf (n 8) 719-720 citing Executive Order No 13145, 65 Fed Reg 6877 (8 February 2000) signed by President Clinton prohibiting federal employers from using genetic information to discriminate against employees. "An aggrieved person as a result of a violation of the Executive Order is further protected by the Rehabilitation Act, 29 U.S.C. 701. Similarly, the Health Insurance Portability and Accountability Act of 1996, which applies to employer-based commercially issued group health insurance, prohibits genetic discrimination in health insurance." At the state level, it is reported that nearly half of the states in the US have laws prohibiting discrimination based on genetic information in the workplace, health insurance and other situations.
[74] The example that is often referred to is the South African Constitution with its strong equality provisions under the Promotion of Equality and Prohibition of Unfair Discrimination Act (section 9), the Medical Schemes Act and the country's experience with the HIV/AIDS pandemic in which a strong policy on non-discrimination has been mounted and appears to be widely followed.
[75] Zindorf (n 8) 722; See also Lemmens (n 21) 369-372.
[76] Ibid.

that Africa appears to be the odd continent out in this regard and stands at a disadvantage in the whole discourse. There is currently a lack of access to healthcare on the continent where poverty continues to ravage the people as much as the prevailing diseases and where a culture of rights awareness is absent. There is no doubt that the complexities of genomics in relation to health insurance will impact Africa more in view of the above observations. It is, therefore, high time to consider serious regional African initiatives in this regard to set standards for the various countries on the continent. There is need for an engaging debate regionally and in each individual country on the acceptable contours of genomics in relation to their overall social existence. Similarly, African states should begin to reevaluate their health policies and adopt such measures that have the citizenry at heart. Thus, in view of the poverty that pervades the continent, there is little likelihood that private health insurance will become the major avenue of access to healthcare. It would appear that the adoption of a universal healthcare system would reduce the concern over the effects of genomics on health insurance among other areas of human well-being.

V. Conclusion

Genomics is relevant to Africa and would have an impact on the continent in various ways, including health insurance and human rights. Africa should not stand aloof in the global search to balance the various interests that are implicated by this rather complicated intercourse between scientific, economic and social considerations. The responsibility for this search is primarily that of states, which could be extended to private actors such as insurance companies through regulation and self-realization of their social responsibility to society – a responsibility that should not only be measured on the basis of a healthy financial bottom line.

Alternatively, African states will do well to adopt a universal health stance that guarantees every citizen basic health coverage as a social good irrespective of individual genetic makeup. Though a majority of Africans are poor and private insurance is still limited, there is no disputing the fact that the landscape could drastically change in the future at which point the influence of private insurers would be heavily felt. It becomes the responsibility of the state to at least help those who may not be in a position to adequately help themselves and to prevent entrenched private discrimination based on an individual's genes. In a case from the Canadian Supreme Court, Justice L'Heureux-Dubé wrote instructively that "no human rights legislation could ever attain its objective if discrimination could be justified by the self-serving claim that a practice 'has always been done this way '...[If] this were so, complacency and a history of discrimination would be rewarded at the cost of progress and the recognition of higher societal norms of behaviour."[77]

[77] *Zurich Insurance Co v Ontario (Human Rights Commission)* (1992) 16 CHRR D/255 (SCC) 378, reprinted in Lemmens (n 21) 412. Justice L'Heureux-Dubé wrote in dissent on the question of statutory endorsement of insurance discrimination on *bona fides* grounds.