Ethical, Legal, Social, and Financial Implications of Human Genome Research in Developing and the Least-Developing Nations

E. William Ebomoyi, Ph.D.

Professor, Department of Health Studies College of Health Sciences, Chicago State University
Chicago, Illinois 60628-1598

ABSTRACT

This project investigated the introduction of genomic research into the developing and the least developed nations. Initially, the basic demographic and epidemiological characteristics of these two geographical areas were provided. The enormous economic impact and medical benefits of genomics in the industrialized nations were outlined to exemplify the innovative applications of genomics. Efforts were made to compare the diffusion of genomic scientific interventions into the progressive developing nations such as Brazil, Russia, India, China and Southern Africa (The BRICS) and the least developing nations as Angola, Bangladesh, Benin, Burkina-Faso, Cambodia, Chad, Gambia, Haiti, Rwanda, Senegal and Uganda among others. The ethical implications of introducing innovative genomic research into these two sets of nations were summarized. The researcher also compared the legal implications of introducing human genome sequencing research in the two distinct group of nations and a contrast was provided about the key social implications of the genomic research project. Finally, the financial capital required to implement genomics research interventions in the two characteristic groups of nations was discussed.

KEY WORDS: Ethical, legal, social and financial implications, Human genome sequencing research, Biotechnology, Patenting of DNA, Genomics, Genetics, Sub-Saharan Patenting office Intellectual properties, Exclusive marketing rights, The BRICS, Brazil, Russia, China, and South Africa, Least developed countries, Sub-Saharan African nations, Innovative Genomic interventions, Gene therapy and Bone Marrow Transplantation polymerase chain reaction, H3African genome Guideline; the prevalence of communicable and non-communicable diseases.

INTRODUCTION

Genomics as an innovative technological science has been accorded international prominence owing to the applications of this scientific discipline in the realm of medicine, public health, agricultural discipline, and numerous other economic ventures. Besides, there are several international economic developments derived from genomics which have the potential for emancipating hitherto under-developed nations, if the initiatives are judiciously and ingeniously applied. From molecular biological perspective, genomics is defined as “the comparative analysis of complete genome sequences from different organisms and the determination of global patterns of gene expression; used to assess evolutionary relations among species and the prediction of the frequencies and general types of RNAs produced by an organism. Genome is the total number of genetic information carried by a cell or an organism [1].

In genomics and the public’s health in the 21st century, the United States Institute of Medicine (IOM) [2] defined genomics as “the study of the entire human genome. The Expert Committee at IOM also emphasized the potential benefits of genomics in improving the health of the public by differentiating genomics from genetics. The latter focuses on the study of functions and effects of single genes while the former explores not only the actions of single genes, but also the interactions of multiple genes with each other and with the environment [2]. A detailed account about the inception of human genome sequencing project was provided elsewhere [3]. However, we must emphasize that the accomplishment of human genome sequencing, mapping and declassification is practically incomplete without the imaginative vision of The Nobel laureate Dr. James D. Watson and his colleagues. Even recently, resources from the Dolan DNA Learning center funded by the National Science Foundation were invested from Cold Spring Harbor Laboratory to train committed research scientists of all ethnic groups across United States. The intent was to train these scientists so that their knowledge of genomics can be used to enhance the scientific and genomic background of their students.

In 1986, Dr Watson organized a special session to discuss the full ramifications of the human genome project, during that meeting at Cold Spring Harbor Laboratory, the idea was raised by Wally Gilbert that the project could

*Corresponding Author: E. William Ebomoyi, Ph.D., Professor, Department of Health Studies College of Health Sciences, Chicago State University, Chicago, Illinois 60628-1598, eebo moyi@csu.edu
consume a colossal sum of money to the tune of “3 billion base pairs, 3 billion dollars”. This was perceived as an extremely expensive project that could only succeed with public funding. The role of Dr. Watson and his associates [4] in involving political leaders and soliciting funding for the accomplishment of the HGP can hardly be overemphasized. As the first biologist to serve as the director of the human genome unit at the National Institutes of Health, he cautioned both administrators and scientists about the enforcement of sanctimonious ethical principles in the practical implementation of genomics; discouraging the slightest elements of the nefarious components of eugenics in the existing guidelines and protocol of conducting genomic research nationwide and internationally[3,4]. Currently even the comprehensive data on human genome are completely declassified and placed under public domain.

James D. Watson [5] has encouraged genomic researchers to be prudent in the applications of the knowledge derived from genomics and to eschew from the application of knowledge derived from genomics to further widen the existing inequalities among nations. But by far most important, he has provided cautionary safeguards about eugenics policies:

Early in the twentieth century, eugenics had almost had the ring of a prospective movement attracting the support of many prominent Americans, the horror of these later Nazi aspects has to make us fear that eugenic arguments might again in the future be used to promote the elimination of supposed genetically unfit political philosophies or ethics group. Such worries come not only from minority groups who fear for their futures, but also, in particular from many Germans whose revulsion of their own history leads them to oppose any aspect of genetic engineering, believing the technologies so developed provide a slippery slope for rekindling of Nazi-type eugenics actions[5-pg175].

Current Trends

Just ten years after the accomplishment of the human genome sequencing project by April25, 2003; resounding economic benefits derived from genomics have been reported by Battelle Technology Partnership Practice for Medical Research (UMR). In United States alone, the federal research investment in genomics has contributed to medical science; improved public health, enhanced technological development, efficient drug development, improved agricultural yields and improved precision in crime-scene-DNA finger print detection. The BTTP [6] has emphatically revealed the creation of numerous American employment opportunities. These estimated benefits have contributed nearly $1trillion in economic benefits to the United States alone among the G-8 nations. Besides, United States, the other industrialized nations where highly sophisticated genome-related infrastructures existed even before the successful sequencing of the human genome; comparative economic and public health benefits have been realized in their improved life expectancy and efficient management of their communicable and non-communicable diseases, environmental remediation, through the application of microbial genomics and the identification of their domestic and international criminals.

Recent findings reported by the world Health organization [6] have revealed the extent to which life expectancy gap has been growing between women in affluent nations compared to their counterparts in poverty-stricken developing and least-developed nations. WHO further emphasized life-expectancy for women at 50 years of Age has improved but the disparity between the poor and rich nations is growing and could worsen without better detection and treatment of cardiovascular diseases and cancer. In the G-8 nations, the initial step in applying genomics to enhance molecular medicine was the sequencing of the gene chromosomes that code for stroke, myocardial infarctions and the application of precision medicine in the identification of BRCA1 and BRCA2 and ATM gene chromosomes and the application of chemo-preventive techniques to protect women from dyeing from these complex diseases. Additional studies reported by WHO have shown that the etiological agents which are the underlying cause of death which included colon, breast and cervical cancers in older women from these affluent nations have been drastically reduced. Whereas women who are over 50 in the impoverished nations encounter increased death rate from the following diseases: diabetes, cardiovascular diseases, and cancer[7] Dr. John Beard[8] director of the WHO’s department of ageing echoed his concerns about this glaring disparities: “More women can expect to live longer and not just survive child birth and childhood. But what we found is that improvement is much stronger in the rich nations than in the in the poor countries. The disparities between the two are increasing.”

It seems self-evident that genomics and improved sanitary conditions continue to confer immense economic, medical, and public health benefits on the health status of women in the affluent, industrialized nations compared to their poverty-stricken counterparts in the least developed nations.

Advantageous Impact of precision Medicine

Powerful and highly sensitive genomic technologies have created hitherto unknown innovative diagnostic medical infrastructures in molecular medicine. Besides, numerous value-added medical benefits derived from
genomics have revolutionized the treatment of women who suffer from various types of cancer. Regarding cardiovascular diseases, the significant breakthrough in genomic medicine has been empirically demonstrated in the use of anti-blood clotting agents such as Coumadin. This drug which has ubiquitous applications in the management of atria fibrillation, blood clot associated with artificial heart valve replacement and recurrent myocardial infarction has saved the lives of both males and females in the industrialized nations. In contrast, the use molecular techniques to precisely sequence the gene-chromosomes that code for various complex diseases have not been efficiently introduced into the clinical practice in most of the least developed nations of the world hence the needless mortality of health care consumers who suffer from cancers and cardiovascular diseases. As a result of this increasing gaps in life-expectancies between health care consumers in the affluent nations and their counterparts in the developing and least developing nations it is morally imperative that genomic medicine is introduced to the developing nations. In an effort to introduce genomics and molecular medicine to impoverished countries without compromising human ethical principles; the study described here was designed to:

- Compare the ethical implications of introducing genomic research into developing and the least developed nations
- Compare the legal implications of introducing human genome sequencing research in selected developing nations and the least developing nations
- Compare and contrast the key social implications of introducing genomic research in selected developing nations and the least developing nations
- Discuss the financial implications of conducting genomics research between selected developing nations and the least developing nations

Developing and least developing nations

In comparison with the developing and least developing nations, the G-8 nations, the practical value-added impact of genomics are being realized in agriculture, forensics, identification science, and microbial ecology, toxic waste management, and the mysteries of evolution, anthropology, sociology, and human migration patterns. The predictions by the international scientific community is that genomics and biotechnology will continue to have a profound impact on engineering, computer science, mathematics, ethics, religion, law, agriculture education, pharmaceuticals, instrumentation, nuclear medicine, forensic science, bioremediation, bio-fuels, and journalism.

The developing nations

A list of some developing nations is summarized in Figure 1. These nations have demonstrated steady economic growth in terms of the Gross Domestic Products (GDP) life expectancy, and literacy level and ability to reduce their infant mortality rates. Figure 1 presents the G20 nations which consist of the leading developing countries as China, Russia, Brazil, Mexico, Turkey, India, Poland, Ukraine and South Africa and their quality of life indices. The B.R.I.C.S. have even created an alliance to enable them to maximize and diffuse the innovative technologies without diplomatic and political impediments.

As a result of inadequate economic growth in many of the developing nations, the funding of science and technological projects is usually accorded low priority. Owing to the comparatively low literacy level particularly among the females, the scientific workforce is not comprehensive enough to undertaken a gigantic scientific project such as the human genome sequencing. The effective coordination of multidimensional federal science institutes, the universities, the commercial and start-up enterprises are just being meticulously designed and implemented in many progressive developing nations such as Brazil, China, India, Cuba and a few other developing nations.

Quality of life indicators

The Physical Quality of Life Index (PQLI) recommended by M.D. Morris [9] of the Overseas Development Council which includes life expectancy low infant mortality and adult literacy rates, which are obviously high. The G20 nations consist of the G8 and other emerging nations such as Brazil, China, India, Indonesia, Mexico, Saudi Arabia, South Africa, South Korea and Turkey. Characteristically low infant mortality rate, but higher life expectancy and literacy rate are quite high in the G8 nations compared to the developing nations. Therefore Brazil, China and India have become very committed in developing viable technological infrastructure to implement genomic programs.
The least developing nations such as Angola, Bangladesh, Benin, Burkina Faso Chad and Niger among others have very high female illiteracy rate, low-life expectancies, high death rates and very low per capital GDP. In the least developing nations, demographic transition which involves a decline in death rate with a corresponding decline in birth rate has not been achieved. The tendency is a high fertility and high death rate, weak technological infrastructural development and low life-expectancy aggravated by the human immune-deficiency virus and the existence low physical quality of life (PQLI) indices.[9 ]

Ethical Issues in Developing and Least Developing Nations

The ethical implications of research on genomic medicine are rather similar but unidentical in the developing and least developing nations. The similarities are the intent and medical imperatives to adopt genomic medicine for the clinical management of single gene diseases and complex diseases in both developing and the least developing nations. The key areas of genomic applications among Brazil, India, China, Cuba, and South Africa are the management of endemic malaria, cardiovascular diseases, diabetes and cancer. With time, the list of endemic, and non-communicable and communicable diseases will surge to include Alzheimer’s disease, cerebro-vascular and kidney failures among other chronic diseases.

In the relatively affluent developing nations, efficient management of endemic parasitic diseases and the construction of efficient drainage systems mostly in the urban areas have enhanced the statistics of human life expectancy for people in the developing area. The existing moderately equipped institutions of higher learning and their technologically-oriented trained scientists facilitate the diffusion of genomic technology and molecular medicine in the selected developing nations. Whereas in the least developing nations replete with inter ethnic and incessant religious and political uprisings, the introduction of genomic science is hampered by these surreptitious interventions. To a large extent, it is among these least developing areas of the world that demographers have observed the lowest life expectancy rate, lowest literacy rate, worst Gross Domestic Product (GDP), highest infant mortality rate, and highest female illiteracy rate.

Cognizant of the grave public health disease burden of parasitic diseases, in 1976, the World Health Organization (WHO), the United Nations Development Programme (UNDP), and the World Bank launched a special programme of Research and Training in Tropical Diseases (10). The targeted six diseases are malaria, schistosomiasis, filariasis, trypanosomiasis (African and American sleeping sickness), Leishmaniasis and Leprosy.
Even now these diseases are not only widespread but they affect every facet of human health in the endemic foci [10]. In most of the tropical countries, effective methods of controlling parasitic diseases particularly malaria and onchocerciasis have neither been successfully designed nor perfected and they impede socio-economic development of rural dwellers.[10]

Although concerted research efforts were directed at the control of tropical parasitic diseases in the nineteenth and early part of the twentieth century, the financial resources budgeted for such activities in the twenty-first century have dwindled due to the decline of resources and the economic meltdown in many European nations and their complaint of donor fatigue. Previously, efforts devoted to control parasitic diseases focused on the application of biomedical techniques which encompass the development of vaccines and formulation of various chemotherapies. Policy makers in the developing nations invested vast sums of money in the construction of large-scale hydroelectric projects which inadvertently led to the spread of parasitic diseases. The relevance of socio-economic research was neither appreciated nor adopted to explore the attendant public health implications of gigantic water resource scheme.

It was only in 1979 that the UNDP/World Bank/WHO established a programme on Social and Economic Research as a component of its biomedical resources to combat the six selected parasitic diseases. As estimated by UNDP/World Bank/WHO, over a quarter of the world’s 4.5 billion people in 1978, were infected with one or more of these six diseases [9, 10]. However by 2013 the global population had increased to 7.2 billion people. These parasitic diseases not only complicate the health status of women during pregnancy but also impede their physiological potential to bear children. Owing to the social and cultural deprivation of women in rural areas of developing nations, the impact of parasitic infections is more severe in women than their male counterparts. Additionally, they constitute the most vulnerable group in the society.

Specific Ethical Implications

As an international gesture of goodwill, the intent to introduce genomic research and innovative molecular medicine to both the developing and the least developing nations, scientists will be trained to efficiently diagnose, treat, and cure both single gene and complex diseases. Medical administrators and public health scientists in both developing and the least developed nations must prioritize the training of their medical and scientific workforce in these low-income nations. Secondly, the appropriate infrastructures, sensitive technologies and the inexhaustible supply of electric energy are required to facilitate efficient implementation of genomic medicine in the developing and least developed nations. An eclectic team of medical scientists, epidemiologists and behavioral scientists can then characterize the broad spectrum of the leading causes of death in these nations which should be targeted because of the limited financial-capital investment using expensive genomic intervention.

A comprehensive list of these sophisticated genomic technologies which include genome analyzer, high performance computing equipment and biotech and life sciences bioinformatics and among others has been published by Ebomoyi and Srinivasan elsewhere [11]. In fact, Hilary Burton, director of the Cambridge-based Public Health Genomics (PHG) Foundation has observed that genomics is absolutely changing the way we deal with public health issues and as this sophisticated technologies involved become relatively less expensive, there will be massive shift in diagnostic techniques toward molecular medicine [12]. About ten years after the accomplishment of the Human Genome Sequencing initiatives; many companies in United States and other industrialized nations invested colossal sums of financial capital in developing their pharmaceutical and diagnostic tests focusing on the broad spectrum of diseases in their nations to satisfy and gain credibility from the public, most especially, the predominant tax payers.

Between 2003 and 2013, the gene-chromosomes that code for diabetes which were sequenced had increased from seven in 2007 to well over twenty by 2013. In the same vein, the genes isolated which code for various cardiovascular diseases, Alzheimer’s disease had increased and therefore biotechnological companies had the financial incentive to invest in the development of appropriated drugs based on the tenets of pharmacogenomic techniques. In the industrialized and progressive developing nations, biotechnological and pharmaceutical companies develop drugs for the management of various cardiovascular diseases, diabetes and other chronic and degenerative diseases because over 500 million people worldwide suffer from these diseases but not the vector-borne parasitic diseases of the impoverished least developing nations.

The United States Department of Energy [13] has emphasized how the ultimate goal of genomics is to use pertinent scientific information to develop innovative strategies to diagnose, treat, cure or even prevent the incipient stages of thousand of diseases which afflict the global human community. In spite of the scientific and technological challenges involved, biotechnological companies continue to make phenomenal progress with commercialization, by designing diagnostic tests to detect errant genes in people suspected of having particular disease or at risk of developing them based on their family history and other genetic or phenotypic expression [13].
Among the BRICS, the registry of diabetes type 2 (DT2) patients and other chronic and degenerative diseases has been established. Even the efficient management of single gene and complex diseases which exist in their communities has been accorded priority in their specialist hospitals. To illustrate, knowledge derived from genomics has revealed that gene therapy and bone marrow transplant are the only two known mechanisms of curing intractable dehumanizing diseases as sickle cell anemia and other hemoglobinopathies. The progressive developing nations which currently have sophisticated medical facilities and technology for managing these genetic diseases include: University of Campinas, San Paola, Brazil, Mexico, Jordan, turkey, India, and South Korea. These nations currently have the state of the art comprehensive medical facilities for the management of these diseases. Whereas in the least developing nations hardly do we find any of their medical centers in which effective and safe BMT can be successfully performed.

Among the BRICS and the people of the least developing nations, trained bioethicists and those medical and behavioral scientists with expertise in developing culturally-succinct regulatory infrastructures to address genomic research as very scanty. An enormous financial investment has been made by the US National Institutes of Health and the U.S Department of Energy to ensure that human genome sequencing was accomplished. Many of the pharmaceutical companies and biotechnological companies are now inundated with donor fatigue therefore most of their interventions regarding drug development focus on those health problems in high-income industrialized nations.

The ethical issues of informed consent have not been comprehensively developed in the developing and the least developed nations for economic and social cultural reasons. To avoid the mistakes of history such as inhuman eugenics, forced sterilization and other ethical issues, genetic screening should require informed consent owing to the potential sensitivity and harmfulness to specific individual and certain ethnic groups in geographically isolated villages where consanguineous marriages are tolerated. They wish genomic science could be practiced within the context of their cultural nuances.

In many isolated villages of West Africa, we have observed situations whereby research from Europe and United States obtained biopsy and blood sample for patients suffering from river blindness (onchocerciasis) and schistosomiasis and never returned to Bangalaku, Olomibobo, Paku and Elemere and Babanan isolated villages West Africa[14]. Then we were led to surmise that outside researcher who visit developing and least developing nations periods could have research agendas which are quite different from the assessment of health needs of the community and the provision of evidence based interventions such as the hand-pump and the provision of safe water supply to these villages. This international kind gesture was spearheaded by President Jimmy Carter in the late 1980s and 2000[14].

The impact of the vector-borne parasitic diseases and the high prevalence of genetic diseases create enormous economic drain, political, cognitive, and socio-psychological drain of people in the least developing nations. The needless mortality attributed to hemoglobinopathies the parasitic diseases combined with the onset of cardiovascular diseases and cancer constitutes an enormous burden that is extremely expensive to incur owing to ignorance, social ineptitude and unbride corruption. Among the BRICS and the least developing nations pertinent ethical issues are bound to evolve; this includes the gradualonset of genomic disparities triggered by income and educational inequalities in access to molecular medicine which are being provided to the affluent cohort and the wanton neglect of the impoverished people of these low-income nations. The other ethical issues pertain to the serendipitous finding from most DNA testing. The possibility, periodically exists whereby clinicians could have access to unintended medical information about the unsuspecting patients carrying lethal genes chromosomes such as Brugada disease among other life-threatening conditions.

The Legal Implications

Many of the eugenic doctrines which were exposed and denounced by the twenty-first century geneticists, genomic epidemiologists, and medical sociologists were designed to sterilize mental retardates, and those that the Germany Aarons characterized as “social misfit and undesirable.” In fact, Ebomoyi et al[14] discovered that it was the emergence of Francis Galton before the turn of the twentieth century that gave birth to the term eugenics, now defined as “the study and control of procreation as a means of improving hereditary characteristics of future generation”[15] Galton was interested particularly in the heredity of quantitative traits such as “intelligence.” The emphasis of the early eugenicists was on health maintenance and they were also interested in the development of specific human traits. Under Hitler’s reign the Germans advanced the notion of racial health. “Eugenic Law” was promulgated, with the Germans establishing themselves as the master race in 1930. Under this law, a German Aryan could not marry a non-Aryan. The law was upheld supposedly to preserve genetic fitness. What became transparently obvious were the underlying motives in advancing the practice of eugenic law. Millions of Jews, gypsies, disabled people, gays and others were sent to “Death Camps.” In both developed and developing nations, Bioethicists, Human Rights advocates must remain vigilant to critically monitor the application of genomics and
research derived from this innovative science to ensure the dignity of everyone participating in such research is upheld and never jeopardized [16].

It is quite prudent to realize that Participation in genomic research involves taking predictive genetic tests that are most likely to reveal an individual that is likely to become victim of cancer, Alzheimer’s disease, stroke melanoma, Huntington disease and numerous other late-onset diseases such neurofibromatosis and Brugada diseases among others.

However, James D. Watson [17] has not only denounced the use of research derived from genomics for inappropriate scientific ventures but emphasized that “The principal goal of the human genome project is to assist biomedical researchers in their assault on disease. The main benefit of genome research will be to provide tools to better understand the afflictions that exact an enormous toll of human suffering on every culture and in every geographical region.”[17]

In accentuating the benefits of modern day genomic innovative science, Stickberger [18] and other geneticists attempted to explain the beneficial aspects of eugenics. They argued that, when stripped of ignoble racism and parochial prejudice, eugenics may be considered as a mechanism to diminish human suffering. Eugenics can be utilized to actually improve the human gene pool. This positive eugenics entails increasing the frequency of beneficial traits rather than merely decreasing the frequency of deleterious genes.

Presented in Table 1 is a list of numerous single gene and complex diseases. Today when physicians and geneticists are able to manage the complexities of cystic fibrosis, specifically, the pain and suffering associated with this genetic disease. However, diseases such as Tay-Sachs disease and the doubly homozygous variants of sickle cell anemia confer on patients severe pain and agony from these life-threatening diseases.

In the twenty-first century, as the new generation of scientifically trained journalists saturate the telecommunication airways about health education and primary preventive mechanisms to prevent the onset of these genetic diseases; parents who know that they are carriers of these lethal genes and they decide to marry women who are also heterozygous for these lethal genes only to expose their unborn babies to the psychological, physical and emotional agony associated with diseases such as Tay-Sachs, sickle cell anemia, cystic fibrosis, and hemophilia among others, laws should enacted worldwide to permit children of such parents to sue their fathers because they have deliberately exposed their children to life-threatening diseases and low quality of human existance.

Social Implications of Genomics Research

Genomics has enhanced the ability of most clinical geneticists and several gynecologists to quickly detect the onset of genetic diseases in the unborn fetus. Many of the single gene diseases which follow Mendelian pattern of inheritance include sickle cell anemia, cystic fibrosis, hemochromatosis, hemophilia, neurofibromatosis, Duchenne muscular dystrophy, Tay-Sachs disease, phenylketonuria (PKU) and Huntington diseases among others. The complex genetic diseases are the congenital heart disease, neural tube defects, cleft lip/palate, and congenital primary hypothyroidism. The chromosomal aberrations include: Down syndrome, fragile-x syndrome, klinefelter syndrome and trisomy13 among others. Although the technology for screening and detecting these diseases were developed quite a few years ago, the high precision liquid chromatography and hemoglobin electrophoresis are found to be quite effective. DNA-based test used in many prenatal services has been modified with the improved knowledge of many medical scientists and molecular biologists. These gene tests can be used to diagnose, and confirm genetic diseases, even before the symptoms of the disease begin to appear. DNA test can effectively predict or provide relevant information about the progression or prognosis of a disease. It can also predict the risk of future onset of specific diseases in apparently healthy individuals [18].

Genetic Screening of Pregnant Mothers

The expressed intent of prenatal screening of expectant mothers is to ensure that the unborn fetus is not only developing in a healthy intra-uterine environment, but also has an acceptable chance of survival during and after birth. Clinical epidemiologists must be able to ascertain that an inexpensive test is available with acceptable sensitivity and specificity. Sensitivity is when the technology indicates that the genetic disease is present when it is actually present, whereas specificity is when the technology indicates that the genetic disease is absent when in fact the disease is not present in the unborn baby. Reproductive option must be available for the couple. The best example is that of Tay-Sachs disease, because this disease is autosomal recessive disorder and because of the attendant neurological defects and the possibility of death at the age of two and four years, and no known therapy; this disease is most appropriate for prenatal screening.

With advances in genomic medicine, many of the genetic diseases can routinely be managed to ensure that the child with many of these diseases can still enjoy improved quality of life. Specifically, the guidelines recommended
by the World Health Organization WHO [19] for most genetic screening must meet a number of requirements before implementation:

- The condition in question should portray high prevalence
- The condition in question should impose a significant health and economic burden on the population
- The gene in question should be easily and inexpensively tested, the analytic validity of the test should be justified
- Genetic counseling and prenatal diagnosis should be available and termination of affected pregnancies, for women who voluntarily choose to use this service should be a feasible option
- For many of the genetic diseases presented in Table 1, these conditions are squarely met[19].

Inappropriate applications of Genomics-Fetal Abortion and Sex Selection

Abortion refers to the termination of pregnancy which follows pre-natal diagnosis of an abnormality which constitutes health risk either for the unborn baby or the expectant mother or both. Termination of pregnancy routinely is sometimes accepted for Tay-Sachs among Ashkenazi Jews and abortion on account of thalassemia, is religiously allowed in Saudi Arabia and Pakistan even up to 17 weeks of pregnancy. Whereas abortion under any circumstances is not tolerated in Chile, this practice is universal in most of the Latin American states and the Caribbean with the exception of Cuba, Ecuador and the isolated jurisdiction of Mexico City. Among the BRICS, particularly in China and India; Boughton [20] has observed that genomics and other innovative technologies such as “ultrasound and CT scan and X-ray machines are being used not only for the determination of the gender for the fetus, but also to selectively about female fetuses.” Boughton[20] further emphasized the rationale for sex selection among some BRICS nations:

In China the one child law combined with a preference for male children has led to female feticide, along with the laws to prohibit use of technology to determine the sex of the fetus before birth. Apparently, the law is difficult to enforce and so sex specific feticide continues there. In India conservative estimates of the number of female fetuses aborted was about 250,000 per year. There are campaigns by the government to encourage valuing female children, but the economic and social reasons that the problem exists in the first place are at the very basis of the issue.[20].

The one child policy adopted by the Chinese government further exacerbates gender disparity and female infanticide. The current male: female birth ratio of 58.8% reveals glaring evidence of male preference in China. The concomitant effect of this policy is the high incidence of obesity in adolescent males in the areas with the attendant medical complications.

Social Implications of genomics and consanguinity

In many cultures where the social system does not treat men and females equally and where there is strict gender roles, the scope for discrimination against women exit, and the females who give birth to children with recessive genes is tainted with ill luck and this could create the potential for discrimination, because they are stigmatized as carrier of recessive genes. In many developing nations such as the BRICS and the least developing nations in South Saharan Africa, endogamy and consanguineous marriages occur. The former is encouraged while the latter is tolerated. Many epidemiologists and geneticists who advise against these socio-cultural practices have been advised to introduce and practice genomics with the culturally accepted practices of the people.

The practice of sex-selective abortion not only occurs but also in such communities, there are strong social and cultural and economic structures that strongly favor the birth of male children. Sex selection for medical reasons could involve the selection of specific gender to avoid reproducing children affected by sex-linked recessive genes. In many developing nations, “sex selection almost exclusively involves the abortion female fetuses”

Commercialization of personalized medical services has led to the development of very sophisticated genetic diagnostic tools capable of identifying with relative ease, the sex of the fetus. Even before the upsurge of genomic technology, ultrasound machine, which is relatively inexpensive, was used worldwide to identify fetal gender.

Social implications of genetic screening for sickle hemoglobinopathies

The major social implications of neonatal screening for hemoglobinopathies among the BRICS and in many of the least developing nations in Sub-Saharan Africa, are the social stigmatization status of the young children with doubly recessive autosomal genes for sickle cell anemia and other similar genetic diseases. To a large extent, the inheritance of recessive autosomal genes coupled with living in an environment that is replete with malaria, bacterial and viral infections can further worsen the health status of infants. Some of the psychosocial health problems experienced by patients with sickle cell anemia are low self image, lack of self-confidence and fear of socio-stigmatization not only by family members but also by society and the health care workers. In the northern region of
Cameroon, the child with sickle cell is labeled as “Akwombeu’ which means “one who has died and returns.” The disease itself is characterized as “that ailment which eats the bone.” Among the English speaking areas in The Cameroon, babies born with sickle cell are labeled as Ogbanje. This derogatory term is also commonly used by the Ibos in the Eastern region in Nigeria[21].

Among the Hausa ethnic group in Sub-Saharan African nations, there is the superstitious belief about the rebirth of the child with sickle cell anemia as a mysterious baby who dies and reoccurs to merely tantalize its parents with sadistic regularity. The Hausas ostracize and nickname such children as “Danwabi.” Among the Yoruba ethnic group in of Sub-Saharan Africa, such mysterious child with doubly homozygous recessives genes are nicknamed as “Abikus.” Abikus are the superstitiously conceived to be sadists who reincarnate to tantalize their parents by dying in early infancy after birth. The Edo ethnic group describes such children with sickle cell anemia as “Igbakhuan.” In Ghana, among the Akan ethnic group, children with sickle cell are derided as “Ahotutuo.” This tantalizing nickname means the children who always have with high fever [22].

The source of this erroneous notion derives from the misunderstanding by parents who are carriers who without premarital screening inadvertently marry others who are also heterozygous for the sickle cell genes. Although our knowledge of Mendelian genetics and pedigree illustrate a probability of HbAs versus HbAs to indicate a ratio of 1 normal birth, 2 carriers and 1 doubly homozygous autosomal recessive birth; based on human fecundity, all four children could be born with full-blown sickle cell anemia or all four babies with sickle cell trait or with the desired statistical combination presented. Among rural illiterate dwellers without the scientific knowledge about genetics, it becomes a mysterious situation that every pregnancy and birth outcome, carriers the lethal sickle cell anemia genes [23]. This phenomenal experience makes it imperative that the BMT technology needs to be adopted to permanently cure sickle cell anemia.

In many of the BRICS states and countries in the least developing nations with very high illiteracy rate the psychosocial impact of stigmatization and discrimination which are associated with genomics and genetic screening in reproductive behaviors must be addressed as these innovative technologies are introduced to developing nations

**Phenomenology and Cultural Contributions to Gender Disparities**

The lived-experiences of people, their culture, religious and ritual observances constitute their phenomenological experience. The cultural nuance which contributes to gender disparities in prenatal abortion of the fetus is associated with gender specific role in societies. In the developing nations, and the Least Developing nations, the domineering role of males by ascribing to them leadership functions regarding religious observances, burial rights, military functions, and political leadership activities accentuate their perceived advantageous social functions compared to their female counterparts.

The roles of females in these societies include enhanced fecundity, child-upbringing, domestic type duties which further relegate their functions to non-aggressive less risk-taking status. Whereas, the inherent biological genes of female with their XX chromosomes confer better longevity and improved quality of life as universal advantage. However, in developing nations, their male counterparts develop and modify human cultural attributes just to compensate for their biological disadvantages.

From the innovative human genome project, and the commercialization of sophisticated sequencing techniques, numerous genetic diseases will be diagnosed, and the incriminated alleles will be characterized so as to pinpoint the litany of advantages and plausible disadvantages of consanguineous and endogamous marriages. In the twenty first century, the physical agony, the psychosocial pain associated with single genes, and those involving multi-factorial etiological agents have out-spaced existing curative medical sciences worldwide. The implementation of prudent public health and innovative medical sciences can mitigate the impact of these single gene and complex diseases worldwide.

**Financial Implications**

The United Nations Office of the High Representative for the Least Developing nations(LDN) applied the income per capital GDP to characterize the nations that make up the LDN. This United Nation’s Team echoed, in spite of the three successive programmes of Action and notwithstanding the positive development recorded, in recent times, the LDC still confront massive developmental challenges. The UN reported how progress in economic growth has not made any significant impact on existing poverty, and income disparities. It was observed that hunger and malnutrition are not only widespread but also they create severe consequences on the vulnerable cohort. The list of those nations that face massive deprivations include 34 of them in Africa, with majority of the nations in Sub-Saharan Africa, 14 in Asia and one in Latin America and the Caribbean[24].
In these financially challenged nations with massive indebtedness to the international monetary Fund (IMF), and other G-8 nations and China, the implementation of expensive genomics research programmes is bound to involve economic challenges.

As summarized in Table 2, the Gross National Income of these Nations and per capital income are among the lowest worldwide.

<table>
<thead>
<tr>
<th>Nations</th>
<th>GNI (in bil.)</th>
<th>Capital in USS</th>
<th>2009 Data</th>
<th>2012 Data</th>
<th>International Ranking</th>
</tr>
</thead>
<tbody>
<tr>
<td>South Africa</td>
<td>$283.3</td>
<td>$930m</td>
<td>9.2</td>
<td>67</td>
<td></td>
</tr>
<tr>
<td>Gabon</td>
<td>$10.49</td>
<td>$511</td>
<td>3.6</td>
<td>91</td>
<td></td>
</tr>
<tr>
<td>Namibia</td>
<td>$8.8</td>
<td>$488</td>
<td>7.2</td>
<td>101</td>
<td></td>
</tr>
<tr>
<td>Nigeria</td>
<td>$175.62</td>
<td>$136</td>
<td>6.1</td>
<td>136</td>
<td></td>
</tr>
<tr>
<td>Cameroon</td>
<td>$21.8</td>
<td>$111</td>
<td>10.1</td>
<td>151</td>
<td></td>
</tr>
<tr>
<td>Senegal</td>
<td>$11.83</td>
<td>$106</td>
<td>5.7</td>
<td>156</td>
<td></td>
</tr>
<tr>
<td>Burkina Faso</td>
<td>$7.27</td>
<td>$86</td>
<td>3.7</td>
<td>163</td>
<td></td>
</tr>
<tr>
<td>Benin</td>
<td>$5.95</td>
<td>$69</td>
<td>4.3</td>
<td>172</td>
<td></td>
</tr>
<tr>
<td>Liberia</td>
<td>$645m</td>
<td>$50</td>
<td>12.1</td>
<td>180</td>
<td></td>
</tr>
<tr>
<td>Ethiopia</td>
<td>$19.12</td>
<td>$42</td>
<td>4.4</td>
<td>184</td>
<td></td>
</tr>
<tr>
<td>Eritrea</td>
<td>$14.9</td>
<td>$16</td>
<td>2.8</td>
<td>191</td>
<td></td>
</tr>
</tbody>
</table>


As the technologies for the implementation become relatively inexpensive, the component of genomic research which should be implemented in these nations must focus primarily on the relevance of family history approach, and health education activities regarding participatory medicine. The application of evidence –based health education to prevent single gene diseases and complex diseases can be implemented without colossal financial investments. Besides, the development of national genomic workforce and the revision of the existing medical and public health curricula which should include specific components of genomics must be accorded priority.

The recruitment of epidemiologists, medical sociologists, health educators, physicians to educate the society about the relevance of premarital counseling will sensitize the public about the lethal impact of many single gene diseases and other chronic and degenerative diseases.

Conclusion

The introduction of genomics research into the developing and the least developing nations should occur through gradual evolution and by the active involvement of local scientists and genomic programmes must be implemented at a cost that the nations in the Least Developing Countries can afford and not through further indebtedness to IMF. By far most important the culture of those in the DC and LDC should be recognized and taken into consideration as this innovative scientific breakthrough is being introduced to the nations.

REFERENCES

1 Lodish H, Berk, A, Krieger M Bretscher, A etal Molecular Biology W.H Freeman and Company 2013 pg G.10
2 Institute of Medicine(IOM) implications of genomics for public health Washington DC National academy Press 2005
3 Ebomoyi E.W Establishing genome sequencing centers, the thematic units in the developing nations and the potential medical, public health and economic implications. Drug Metabolism and Toxicology 2011vol2:1pp1-11
4 Watson, JD Apassion for DNA genes, genomes, and society Cold Spring Harbor, New York 2000
5 Watson JD pp175
6 Battelle United for Medical Research Technology Partnership Practice for Medical Research (UMR) Impact of genomics on the U.S. economy pp 1-6 June 2013 USA, Advocates for NIH and life sciences Research pp1-8
7 Beard J Director of the WHO department of Aging on glaring disparities WHO, 2013
8 Beard J Ibid
10 Ibid
11 Ebomoyi, W and Srinivasan, S Genomic technology and the imminent setbacks in developing nations International Journal of Medical Engineering and Informatics 2011 20 Vol 3, no 4 pg 369-380
12 Burton, H Director of the Cambridge-based Public Health Genomics (PHG)
19 World Health organization Medical genetic services in developing countries WHO human genetics chronic diseases and health promotion Geneva, Switzerland WHO pp1-234
24 United Nations United Nations Classification of the developing and the Least developing nations Unistats un.org/unsd. methods/m49/m49 reginhtm Retrieved September 23, 2013 least developing nations

<table>
<thead>
<tr>
<th>Disorder Name</th>
<th>Description</th>
<th>Genetics Link</th>
<th>Incidence of Prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Congenital Heart Defects</td>
<td>Defects in heart function or structure</td>
<td>Multifactorial</td>
<td>5700</td>
</tr>
<tr>
<td>2. Colon Cancer</td>
<td>Inherited predisposition to colon cancer</td>
<td>Single gene</td>
<td>5000</td>
</tr>
<tr>
<td>3. (Familial Adenomatous Polyposis)</td>
<td>Kidney cysts resulting in death in infant, or another version resulting in varying effects on mid-life adults</td>
<td>Single gene</td>
<td>4000</td>
</tr>
<tr>
<td>4. Hemochromatosis</td>
<td>Treatable metabolic disorder of excessive iron accumulation in the body; varying degrees of severity</td>
<td>Single gene</td>
<td>2500</td>
</tr>
<tr>
<td>5. Neural Tube Defects</td>
<td>Neural tube fails to close, resulting in anencephaly, hydrocephalus, or spina bifida</td>
<td>Multifactorial</td>
<td>2000</td>
</tr>
<tr>
<td>6. Hypercholesterolemia</td>
<td>Hereditary high cholesterol</td>
<td></td>
<td>2000</td>
</tr>
<tr>
<td>7. Diabetes, Type 1</td>
<td>Insulin-dependent diabetes</td>
<td>Single gene</td>
<td>2000</td>
</tr>
<tr>
<td>8. Breast/ovarian Cancer</td>
<td>An inherited form of cancer in breasts and/or ovaries found in 270 women over 50 in U.S.</td>
<td>Multifactorial</td>
<td>1850</td>
</tr>
<tr>
<td>10. Cleft lip/palate</td>
<td>Lack of closure in the upper lip and/or palate</td>
<td>Chromosomal</td>
<td>1000</td>
</tr>
<tr>
<td>11. Down Syndrome</td>
<td>Disorder resulting in mild to severe mental retardation</td>
<td>Single gene</td>
<td>1000</td>
</tr>
<tr>
<td>12. Noonan Syndrome</td>
<td>Heart defects, mental retardation, hypogonadism</td>
<td>Chromosomal</td>
<td>700</td>
</tr>
<tr>
<td>13. Fragile-X Syndrome</td>
<td>Disorders resulting in mild to severe mental retardation</td>
<td>Single gene</td>
<td>680</td>
</tr>
<tr>
<td>14. Sickling and related blood disorders</td>
<td>Including Sickle-cell anemia, Thalassemia, and others</td>
<td>Chromosomal</td>
<td>500</td>
</tr>
<tr>
<td>No.</td>
<td>Disease Description</td>
<td>Genetic Disorder Type</td>
<td>Chromosome/Diagnosis</td>
</tr>
<tr>
<td>-----</td>
<td>---------------------</td>
<td>-----------------------</td>
<td>----------------------</td>
</tr>
<tr>
<td>15.</td>
<td>Cystic Fibrosis</td>
<td>Lung disorder usually resulting in death by late twenties</td>
<td>Single gene</td>
</tr>
<tr>
<td>16.</td>
<td>Alpha 1-Antitrypsin Deficiency</td>
<td>Metabolic disorder which may result in liver cirrhosis and emphysema</td>
<td>Single gene</td>
</tr>
<tr>
<td>17.</td>
<td>Trisomy 18</td>
<td>Extra #13 chromosome results in abnormal brain and heart, deafness, with death in first year for over 80 percent</td>
<td>Chromosomal</td>
</tr>
<tr>
<td>18.</td>
<td>Neurofibromatosis (Type 1)</td>
<td>Disorder resulting in varying degrees of deforming tumors</td>
<td>Single gene</td>
</tr>
<tr>
<td>19.</td>
<td>Waardenburg Syndrome</td>
<td>Results in deafness and other features</td>
<td>Single gene</td>
</tr>
<tr>
<td>20.</td>
<td>Congenital Primary Hypothyroidism</td>
<td>Mental, skeletal and growth retardation, sluggishness</td>
<td>Multifactorial</td>
</tr>
<tr>
<td>21.</td>
<td>Turner Syndrome</td>
<td>Results in short stature, sexual immaturity in females</td>
<td>Chromosomal</td>
</tr>
<tr>
<td>22.</td>
<td>Ichthyosis</td>
<td>Multiple forms of scaling skin disease</td>
<td>Single gene</td>
</tr>
<tr>
<td>23.</td>
<td>Trisomy 13</td>
<td>Extra #13 chromosome results in abnormal brain and heart, deafness, with death in first year for over 80 percent</td>
<td>Chromosomal</td>
</tr>
<tr>
<td>24.</td>
<td>Duchenne Muscular Dystrophy</td>
<td>Very disabling muscle loss in male children; results in death by age 20 for most</td>
<td>Single gene</td>
</tr>
<tr>
<td>25.</td>
<td>Hemophilia A</td>
<td>Blood disorder resulting in excessive bleeding</td>
<td>Single gene</td>
</tr>
<tr>
<td>26.</td>
<td>Achondroplasia</td>
<td>Short-limbed dwarfism</td>
<td>Single gene</td>
</tr>
<tr>
<td>27.</td>
<td>Marfan Syndrome</td>
<td>Connective tissue disorder with varying degrees of severity</td>
<td>Single gene</td>
</tr>
<tr>
<td>28.</td>
<td>Tubercous Sclerosis</td>
<td>Epilepsy, mental retardation, and features</td>
<td>Single gene</td>
</tr>
<tr>
<td>29.</td>
<td>Congenital Adrenal Hyperplasia</td>
<td>Dehydration and weight loss, virilization, many die in infancy</td>
<td>Single gene</td>
</tr>
<tr>
<td>30.</td>
<td>PKU (phenylketonuria)</td>
<td>Metabolic disorder which may cause mental retardation if untreated</td>
<td>Single gene</td>
</tr>
<tr>
<td>31.</td>
<td>Huntington Disease</td>
<td>Results in severe mental and physical incapacities in midlife</td>
<td>Single gene</td>
</tr>
</tbody>
</table>

Table 1-A List of genetic diseases

Biographical Notes

E. William Ebomoyi is a professor in the Department of Health Studies, College of Health Sciences, Chicago State University, Chicago Illinois. He holds a post-doctoral certificate in Epidemiological science from the National Institutes of Health, MD, USA and a Ph.D. in community health and statistics from the University of Illinois, Urbana-Champaign, Illinois USA. He serves as a Consultant in International Health for the American Public Health Association (APHA) and he is a pioneer member of the US National Children Study Advisory Committee. He has published extensively in epidemiologic science, genomics, HIV/AIDS pandemics, WHO-sponsored primary health care services programs, and sustainable development. He is the current Chief Editor of The International Journal of Tropical Diseases and Health and Associate Editor of the Journal of Scientific Research and Reports; and the Journal of Applied Global Health