EXPECTATION, EXPERIENCE AND EVALUATION OF PARTICIPATION IN A GENOMICS RESEARCH PROJECT IN AFRICA

BY

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BEING A RESEARCH PROJECT SUBMITTED TO THE DEPARTMENT OF SURGERY, UNIVERSITY OF IBADAN, IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE AWARD OF MASTER OF SCIENCE DEGREE (M.SC) IN BIOETHICS.

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DEDICATION

This project is dedicated to my beloved parents, Mr. and Mrs. Robert Kayode Gbadamosi, for their love, care and prayers over me

And

To the West African Bioethics (WAB), for counting me worthy to be a beneficiary of their scholarship, and for selecting me as one of the qualified candidates to undergo the rigorous academic training in Bioethics.

ABSTRACT

The ultimate goal in any genetic research is to reduce the risk for the disease and to facilitate strategies for prevention. As we approach the period of personalized medicine, studies have shown that it is important to investigate diverse populations in the study of complex diseases. The African populations serve as the ancestral population to humans around the world and the African genome has accumulated the greatest genetic variations; and the genomic era is witnessing the large scale sequencing of many personal genomes to understand disease etiology, mechanisms and diagnosis.

On this backdrop, therefore, this study examined, analysed and presents, in a scientific format, the "Expectations, Experience and Evaluation" of certain group of research participants who participated in a Genomics research project in Africa. Data were collected by the use of qualitative research method at Adeoyo Hospital, located at Ring road, Ibadan, Oyo state. We conducted 32 In-depth-Interview (IDI) for 32 research participants, out of which we had 4 adult males, 4 adult females, 4 young males and 4 young females who were categorized as the case group because they actually had ailments including high sugar levels (Diabetes) and blood complications. The total number of participants for the case group amounts to sixteen participants.

We had another set of participants who were categorized as the control group, who never had any ailment whatsoever as it pertains to the Genomics research. They were 4 adult males, 4 adult females, 4 young males and 4 young females, which summed up to sixteen participants.

Analysis of the result showed that most of the respondents in the In-depth- Interview showed positive attitude towards the Genomics research even though they had a very little knowledge about what Genomics research entails.

The overall assessment of the participants' view as regards their "expectations" in the research shows that they were overly optimistic that the research would be beneficial to them as it relates to the diabetics issues many of them had. With regard to their "experiences" with the research process, available statistics shows that majority of them never had any form of issues with the research process and the research team. This implies that it was a nice experience to have

participated in the study. The overall “evaluation” of the research process was that the research participants look forward to attending similar study when called upon in the future.

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Gbadamosi, Raymond Ojo.

CERTIFICATION

We certify that this work was carried out by Gbadamosi, Raymond Ojo under our supervision and submitted to the Department of Surgery, Faculty of Clinical sciences, University of Ibadan, Ibadan, Oyo state.

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1.0 CHAPTER ONE

INTRODUCTION

As we gradually and deliberately move towards the era of personalized medicine, it is important to understand the diversity that exists in the human genome. Emerging technologies and tools have made it possible to understand the molecular mechanisms underlying disease progression. Scientists are now able to interrogate the genome in order to determine the role of functional loci in coding and non-coding regions (Lienert A. et al 2014). Clearly, scientists have made tremendous progress in the quest to use the knowledge of the genome to treat and prevent human diseases. Genomic studies in Africa is witnessing the best of times with the establishment of the Human , Hereditary and Health Africa (H3A) initiative supported by the NIH and Welcome Trust. The H3A was established to develop and support a continent-wide network of scientists and laboratories that will use "state of the art" approaches and technologies to the study of the complex interaction between environmental and genetic factors in disease etiology and pathogenicity.

The negative economic and social impact of infectious diseases in Africa cannot be overemphasized; they are leading causes of death and economic losses in the continent. One of the major challenges in the control of infectious diseases in Africa is inadequate knowledge and understanding of the pathogens and their various hosts. However, as genomic technologies have become available, and the sequencing of both the human genome and the genomes of many pathogens has been completed, we are witnessing a revolution in the way infectious disease research is approached and conducted. This progress has also brought about enormous health, scientific and economic benefits. (Lander, 2011).

The availability of sequencing data from infectious pathogens represents a unique opportunity for the identification of new drug and vaccine targets, which potentially have value for disease management and control. These data have, however, been predominantly benefiting

researchers, institutions and laboratories in North America, Australia, Europe and Asia, contributing to the increasing economic, scientific and genomics knowledge gap between these geographic regions and Africa. This is partly due to the fact that while governments in countries such as the US and UK have increased their investment in genomics research, there is a paucity of governmental, regional political or economic organizational funding in Africa for genomics researchers to address the burden of infectious diseases. Despite the technological advances and significant reductions in the cost of genomic research, African scientists are yet to use genomics-based knowledge and tools to provide novel insights into disease etiology, diagnosis, and therapy for some of the most intractable and devastating diseases on the continent, including malaria, HIV-AIDS and tuberculosis. If the dearth of genomics research involving Africans persists, the potential health and economic benefits emanating from genomics may elude the entire continent. (Lombart, 2007)

There is therefore an important and urgent need to facilitate the establishment of a vibrant research and academic environment that is free of outside influences, that transcends national boundaries, and that ensures the conduct of relevant, responsive, ethical and high-quality translational genomics-based research on infectious diseases in Africa. This will depend, in part, on the ability of African scientists to acquire the expertise and facilities necessary to lead high-quality genomics-based research aimed at understanding infectious diseases relevant to African populations; and become internationally competitive in genomics science and its applications. (Lander, 2011).

The genomics research project on “Diabetics and Breast Cancer’ currently being done in Nigeria is a step in the right direction as it aims to bring medical solution to the different ailments

currently affecting a good number of Nigerians participating in the research and the entire Continent of Africa in general.

This research project explored a qualitative research method in conducting an In-depth Interview (IDI) on 32 individuals who participated in a genomics study in order to elicit information from them as regards their "expectations, experience and evaluation" on the overall genomics research project.

1.1 STATEMENT OF PROBLEM

Available literature indicates that most studies of human genomic variation and the genetic architecture of complex traits have focused on non-African populations. However, Africa is a critical region to study since it is the site of modern human origins, contains the greatest levels of human genetic variation, and is the source of the worldwide range expansion of modern humans in the past 100,000 years. Africa also has a high prevalence of several infectious diseases including HIV, malaria, and TB, resulting in millions of deaths per year. Additionally, several common complex diseases occur at higher frequency in African Americans, and are rapidly on the rise in urban regions of Africa, including hypertension, obesity, and type II diabetes. Differences in diet, climate, and exposure to pathogens among ethnically and geographically diverse African populations are likely to have produced distinct selection pressures, resulting in local genetic adaptation. (Campbell M. etal, 2007.) However, some new initiatives have recently been put in place to empower African researchers to overcome some challenges and to unlock the potential for infectious diseases control through genomics-based approaches. These are the H3Africa consortium, which is funded by the National Institute of Health (NIH) and the Welcome Trust, and the African Center of Excellence for Genomics of Infectious Diseases-ACEGID, which is funded

by the World Bank. Both initiatives are focused on capacity building, as well as on specific scientific goals. (Hirbo A. etal, 2009). The H3Africa initiative focuses on both non-communicable and infectious diseases, and has a major objective to award research grants directly to African institutions in which principal investigators are based. This allows African scientists to develop and direct their independent research agendas. The program also encourages the formation of intra-continental collaborations, and the development of specific infrastructural elements, such as African-based bio-repositories and a pan-African bioinformatics network (H3ABio-Net). Furthermore, the H3Africa initiative also includes training programs aimed at retaining African scientists on the continent to help build a sustainable critical mass of genomics-based researchers.(Scheinfeldt L, 2010). However, there remains the problem and question regarding research participants' "expectation, experience and evaluation" of participation in African genomics research projects. In the light of this gap in knowledge, this project used a qualitative and scientific methodology in examining and analysing the "expectation, experience and evaluation" of participation in genomics research in Africa.

1.2 RESEARCH QUESTIONS

Several genomics research had been previously conducted in Africa by various groups of researchers, but none of such studies has explored the "expectations, experience and evaluation" of the research participants. The major concern of this research work, therefore, is to find answers to the following questions from the participants of a genomics project currently going on in Africa. The research questions are:

1. What are the Expectations of participation in a genomics research in Africa?
2. What are the Experiences of participation in a genomics research in Africa?

3. What are the Evaluations of participation in a genomics research in Africa?

1.3 RESEACRH OBJECTIVE

The objective of this research project is to interview and find out from research participants in a Genomics research in Africa, their opinion on their Expectations, Experience and Evaluation of participation in the research project.

1.4 SIGNIFICANCE OF THE STUDY

Scientists and researchers as well as the general public would appreciate and welcome such research findings that help to explain possible changes that could occur in the research and thereby help in remodeling and reshaping future African genomics research projects.

2.0 CHAPTER TWO

LITERATURE REVIEW

Recent years have seen an explosion of scientific interest in the use of human genomic variation to study common complex diseases. The hypothesis is that human genetic diversity can be used as a tool to study the causal mechanisms of disease. Examples include Genome-Wide Association studies (GWAS) and, more recently, projects that make use of next-generation sequencing. Over the past 5 years, GWAS have proven very valuable in identifying regions of the genome that affect resistance or susceptibility to a wide range of common diseases, although the method provides simply a starting point, and a range of other approaches will be required in future to fully characterize and understand the complex genetic determinants of human health and disease. To date, whilst many such studies have taken place focusing on a wide range of conditions, hardly any of these have been applied to diseases that primarily affect people in lower income countries, especially in African countries. (Rosenberg et al, 2010).

There are good reasons for encouraging medical research on diseases affecting populations with lower average income and literacy levels. Substantial global inequalities exist in health measures such as mortality, quality of life and disease incidence. These persist despite increasing levels of overall wealth (Berlinguer G., 2004). Even today, only a small proportion of medical research focuses on the problems primarily affecting the world's poorest people (Resnik, 2004). Applying the methods of genomics research to these diseases is one way to address this imbalance.

The gene could be regarded as a “cultural icon” and quite apart from its biological and medical contexts, the gene has become “a symbol, a metaphor, a convenient way to define personhood, identity, and relationships in socially meaningful ways” (Nelkin and Lindee 1995, p. 16). Hardly a week goes by when we do not hear about a newly discovered gene for one thing or another. “Geneticization” is a term used to describe this phenomenon marked by an increasing

tendency to reduce human differences to genetic ones (Lippman 1991). This tendency is accompanied by worries of critics that embracing a reductionist approach to medicine that conceives of human health and disease in wholly molecular or genetic terms individualizes these and detracts attention from our shared social and physical environments and the role of toxins, fast food, poverty, lack of access to health care, etc. (Nelkin and Tancredi 1989; Hubbard and Wald 1993). One of the justifications for spending several billion dollars on human genome research is the belief that genes are key determinants of not only rare Mendelian diseases like Huntington's disease or cystic fibrosis but common multi-factorial conditions like cancer, depression, and heart disease. In Watson's words: “Some call New Jersey the Cancer State because of all the chemical companies there, but in fact, the major factor is probably your genetic constitution” (in Cooper 1994, p. 326).

According to Evelyne Keller, an early critic of the Human Genome Project: “Without question, it was the technical prowess that molecular biology had achieved by the early 1980s that made it possible even to imagine a task as formidable as that of sequencing what has come to be called ‘the human genome.’ But it was the concept of genetic disease that created the climate in which such a project could appear both reasonable and desirable” (Keller 1992, p. 293). Given that the development of any trait involves the interaction of both genetic and nongenetic factors, on what bases can genes be privileged as causes in order to claim that a particular disease or nondisease trait is “genetic” or caused by a “genetic susceptibility” or “genetic predisposition”? Does it make sense for HGP proponents like Bodmer, (Bodmer 2004), to characterize even smoking-induced forms of cancer as genetic? “Cancer, scientists have discovered, is a genetic condition in which cells spread uncontrollably, and cigarette smoke contains chemicals which stimulate those molecular changes” (Bodmer and McKie 1994, p. 89). From the outset, we need

to distinguish between genes conceived as causes of a trait's appearance in a given individual ("*x* is a *gene for* trait *y* in organism *z*" or "My three-pack-a-day Aunt Viv must have the gene that causes cancer") and genes as causes of differences in traits among individuals ("*x* is a *gene for* trait *y* in population *z*" or "Lots of people in my family smoke, but only Aunt Viv and Cousin Sal seem to have inherited the gene for cancer"). The logical interrelatedness of cause and effect—that is, whether a condition is necessary and/or sufficient for a given event to occur—is the approach taken to defining what makes a condition "genetic" in individuals. A strong sense of "genetic disease" is recognized when the genetic factor is both necessary and sufficient for the disease to arise "regardless of environment" (Wulff 1984), or when the genetic factor is sufficient for the disease to present "in all known environments" (Kitcher 1996)—this latter definition recognizes that, in some cases, a disease may have nongenetic as well as genetic origins (since the genetic factor is sufficient but not necessary). "Genetic susceptibility" is defined as an increased probability of disease in all known (strong sense) or some (weak sense) environments (Kitcher 1996). Note that *ceteris paribus* clauses referring to an assumed background of necessary, though not sufficient, genetic and environment factors are required by these definitions. Just as striking a match causes it to ignite only if it is dry and in the presence of oxygen, as we saw in the previous section, genes don't do anything alone. This is the first of three ways in which genetic explanations are context-dependent.

Adopting a population-based approach to genetic causation, where differences in genes are understood to explain differences in traits and not traits themselves, replaces the need for *ceteris paribus* clauses because they rely on the actual distribution of the necessary genetic and nongenetic background factors in specific populations. The case can be made that the first approach is indebted to the second, and that one never explains a property of an object *tout court* but only in relation to

a reference class of an object or objects that lack the property (but share the necessary background factors). Writes Germund Hesslow (1983), "all explanations of individual facts of the form *Fa*—that is, where an object *a* has a certain property *F*—involve a comparison with other objects which lack the property in question" (p. 91). No trait can be labeled "genetic" in any absolute sense, but only relative to a specific population. For example, lactose intolerance is considered to be a genetic condition in northern European populations where ingestion of milk products is common and lactase deficiency rare, whereas in African populations, where ingestion of milk products is rare and lactase deficiency common, it is considered to be an environmental condition (Hesslow 1984). This is the second way in which genetic explanations are context-dependent.

The third, and final, way in which genetic explanations are context-dependent is that they are a function of the present state of knowledge. Huntington's disease is deemed a genetic condition on both the individual and population accounts: a single mutant gene is necessary, and arguably sufficient given necessary (and standard) background conditions, for symptoms to appear in a given person; the presence and absence of disease symptoms in members of the population is accounted for in terms of the presence and absence of the mutation. This is nevertheless an epistemically relative claim. Once the relevant gene is mapped and sequenced, the mechanisms by which genetic and nongenetic factors interact to produce symptoms of the disease remain to be understood. Such causal knowledge is often obtained through the experimental manipulation of conditions beyond "normal" limits, and what conditions are exploited as possible causes in the laboratory and what conditions are kept constant as necessary background, along with pragmatic decisions about how research efforts should be expended more generally, are influenced by clinical and social, as well as scientific, contexts (Gannett 1999).

Behind philosophical attempts to seek objective, nonevaluative foundations for designations of diseases as “genetic” or “environmental” lie positivist assumptions that theoretical understanding furnishes the basis for rational action. One concern with geneticization and the trend to label an increasing number of diseases and conditions “genetic” is that this provides normative support for directing future research and therapeutic interventions in particular ways, that is, at the level of the genome (Cranor 1994). Watson's (1992) colorful metaphor makes this normative support explicit: “Ignoring genes is like trying to solve a murder without finding the murderer. All we have are victims” (p. 167). But this is fallacious reasoning, as the context-dependence of genetic explanations shows. We might instead understand geneticization to be the consequence of an increased capacity to manipulate DNA in the laboratory and (potentially) the clinic and not an advancement in theoretical understanding. Genetic explanations, on such a view, are pragmatic: there is a practical context in which genes are singled out as causes not only because they are amenable to technological control but because they are increasingly perceived to be more tractable than their nongenetic counterparts and therefore the best means to a variety of ends (Gannett 1999).

2.1 THEORETICAL FRAMEWORK

Genomics is defined as the study of genes and their functions, and related techniques (World Health Assembly, 2004). (WHO Geneva, 2002). The human genome project – an international, collaborative research programme, has provided a complete map and understanding

of the human genome (Collins F. et al. 1993). (Collins F.S et al, 2003). With the analysis of the human genome comes the opportunity to study biomedical research at a more finite level than has been previously possible. Advancements in technology have made it possible to rapidly analyse genetic information and elucidate its research and clinical relevance. This has given way to predictions that vaccines, drugs and other interventions will eventually be tailored according to an individual's genetic make-up (Guttmacher AE et al, 2003). The potential of genomics research to improve health outcomes of populations cannot be underestimated, and it is therefore important to determine the best way to progress quickly (Lyon GF et al, 2013). However, there remains scepticism regarding the added value of genomics in disease prevention, with the notion that, rather, reinforcing population-based approaches to prevention, especially for diseases with known environmental causes, is more beneficial (Willet WC et al, 2002). Khoury et al, argue that applied genomic research is as important for conditions with environmental causes as for those without known environmental determinants.

Genome-wide association studies are among the genomic tools being used to identify the genetic contributors of common disorders such as diabetes, cardiovascular disease, and prostate cancer (McCarthy et al, 2008). To date, only seven such studies have been documented to have been conducted exclusively on African participants (Hindorff LA et al, 2015). (Morgan M et al, 2003), and a few other studies have included some African participants (Cook MB et al, 2014).

The potential health benefits of genomic research are not always immediately tangible (Green SJ et al, 2010). Genetic counselling and testing for hereditary syndromes are some of the few evidence-based applications that have become part of routine healthcare (Kang SJ et al, 2011). Therefore, a comprehensive genomic research agenda must be adopted in order to aid the

translation of genomic research findings into healthcare in a way that maximizes health benefits and minimizes harm to individuals and populations.

Khoury et al. (2005), in their review paper, provide a four-phase continuum framework for the translation of genomic research into healthcare and prevention that revolves around the development of evidence-based guidelines. The Clinical and Translational Research Institute in San Diego has implemented a model adapted from this framework. However, (Pawson et al, 2005), suggest an alternative approach; their method focuses on context and external validity, and seeks to answer the questions: which intervention, for which problem, which set of patients is the intervention most effective for, and what outcome does it produce? Genomic research is both an opportunity and a challenge for all stakeholders, ranging from legislators, policymakers, researchers, ethics committees, and research participants, as there is an urgent need to balance the obligations to respect and protect research participants with social interest in advancing beneficial research (McGuire et al, 2010).

In Zambia, for instance, genomic research, although rare, is an evolving science and the studies conducted so far have mainly focused on the key genetic determinants of the responses to HIV infection in a cohort of discordant couples (Trask et al, 2002) and on the sequencing of *Bacillus anthracis* outbreak strain CZC5 during the Chama district Anthrax outbreak of 2011 (Ohnishi e tal, 2011); both these studies being important for the advancement of health service provision, health promotion, research and, subsequently, disease elimination. However, the cardinal issue is to ensure there is adequate regulation, an enabling environment and consensus on what constitutes genomics and informatics as argued by Lyon and Segal (Lyon and Segel, 2013).

CHAPTER 3

METHODOLOGY

3.1 Research Design

A Qualitative-Exploratory research design was employed for the study. An In-depth interview (IDI) was the main method of data collection. This is because the data collection techniques involve the identification and exploration of a number of often mutually related variables that give insight into the “expectation, experience and evaluation” of the research participants.

3.2 Research Setting

The study was carried out at the West African Bioethics Center (WAB) office at Bashorun, Ibaban. Ibadan is located in Oyo State (one of the 36 states that make up Nigeria), near the forest grass-land boundary of south-western Nigeria. It lies approximately on longitude 30051 East of the Green-wich Meridian and Latitude 70231 North of the equator at a distance of about 2145 km Northwest of Lagos State, the former capital of the Federal Republic of Nigeria. Part of the study also took place at Adeoyo Hospital, Ring road, Ibadan, Oyo state.

3.3 Study Population

The study was done among certain African genomics researchers currently conducting a genomics research in Ibadan. An in-depth interview will be conducted with the research participants. The research participants could either be Christians or Muslims. This project aims to carry out an in-depth interview on 32 participants, categorized into two groups; four (4) young males, four (4) young females, four (4) adult males and four (4) adult females who fall under the case group and another group, comprising of four (4) young males, four (4) young females, four (4) adult males and four (4) adult females as the control group.

3.4 Description of Research Instruments

An In-depth interview, which is the main research method of data collection involve the use of a tape recorder, a pen and a booklet for making short notes from the In-depth Interview. Informed Consent Form was given to each of the respondents, which was freely and voluntarily signed by them before the commencement of the Interviews. The moderator made occasional modifications and probing to elicit more information on the questions and answers given by the respondents. Hence, it will be possible to exceed the initial questions as a result of new unanticipated clues unveiled through the interview.

3.5 Method of Data Collection

Data collection was done by gathering some qualitative data via In-depth Interviews (IDI). The study involved participants from both genders by meeting them individually and appealing to them for participation.

3.6 Data Management

In order to ensure proper handling of data received, all tapes were reviewed at the end of each session to ensure that the recording is good. Notes taken were also be reviewed after every interview to be sure that correct responses were recorded by going through some of the questions randomly with the respondents or participants. All tapes will be transcribed verbatim. Data collected are being properly filed and kept by the researcher to ensure that information bothering on the respondents are not seen or used by unwanted persons, as the confidentiality and privacy of the respondents must be well respected in line with ethical principle of 'respect for autonomy'.

3.7 Data Analysis Procedure

Analysis of the data using the issues raised on the "expectation, experience and evaluation" identified as themes was done. Reflection and identification of action for change then followed. By using a small number of participants for the In-depth interview, the sample size can be criticized as difficult to generalize from; this is conducive with the research as it involves a small number of participants willing to participate in the research.

3.8 Ethical Considerations.

In line with UI/UCH Ethics regulations, some ethical considerations of this study are centered on informed consent, voluntary participation and confidentiality. Hence, I ensured that the consent of each respondent was obtained before the In-depth interview was arranged. Voluntary participation of the respondents of the In-depth interview was ensured. Confidentiality of the identification details of the respondents was maintained from the starting point for the study to the completion of the study and it will go even further than that.

3.9 Expected Outcome

Findings of this study may be valuable in understanding and appreciating the personal opinions of research participants in a genomics research project in Africa as it relates to the issues

on “expectations, experience and participation” in the research. This research project sets a standard for future genomics researchers to learn from.

4.0 CHAPTER FOUR

DATA PRESENTATION AND ANALYSIS

The main kernel of this chapter is the presentation and analysis of the qualitative data gathered from the In-depth interview of 32 sampled genomics research participants. The data were categorized based on similar responses of the interviewed genomics research participants and presented in the frequency tables below. Bar chart presentations were made on some socio-demographic characteristics of respondents based on gender. Excerpts from the qualitative data gathered were also included in this chapter to further reflect the position of the respondents.

4.2. Socio-Demographic Characteristics of Respondents

Fig. 4.1: Bar chart showing the age distribution of the sampled genomics research participants

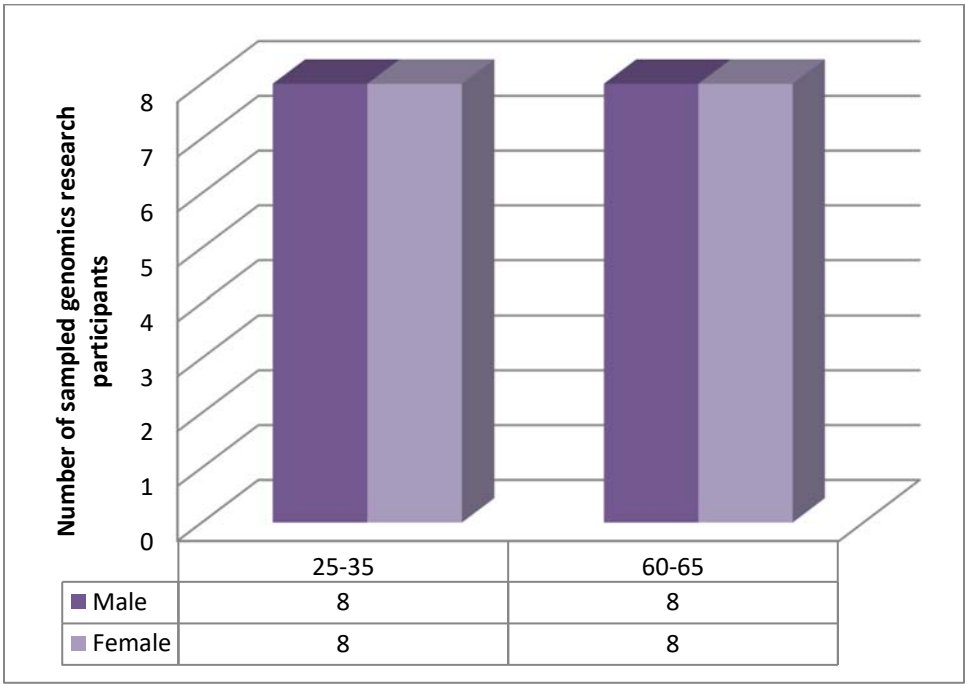

Fig 4.1 above shows the age distribution of sampled genomics research participants. As seen in the bar chart, 16 (50%) of the sampled genomics research participants are between 25-35 years of age. Also, 16 (50%) of the sampled genomics research participants are between 60-65 years of age. This shows that young and adult genomics research participants were equally selected.

Fig. 4.2: Bar chart showing the marital status of the sampled genomics research participants

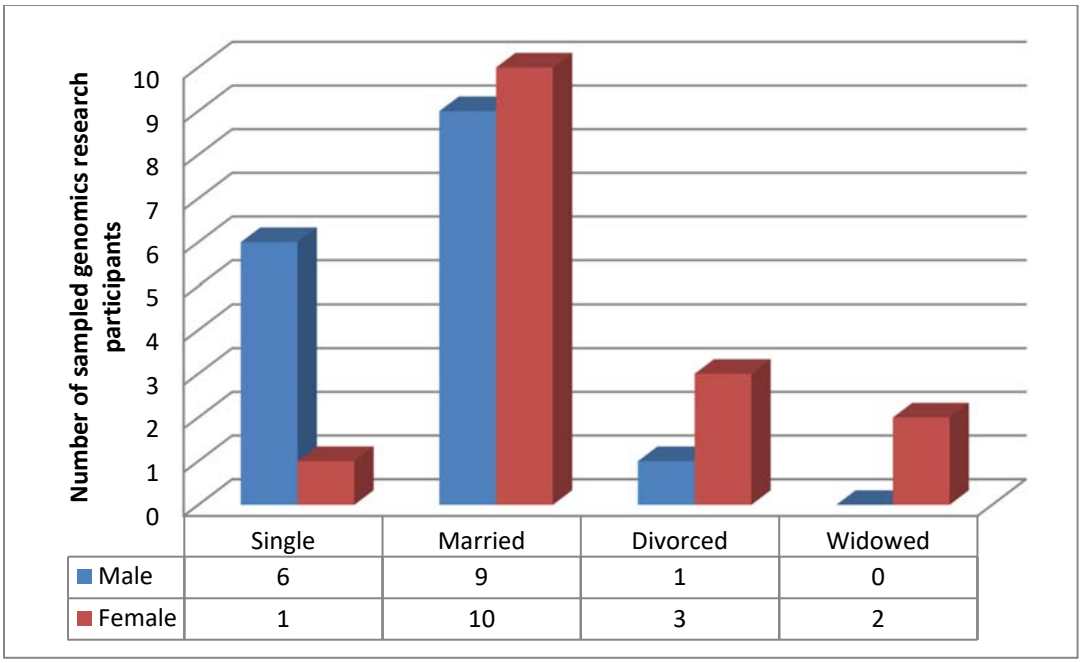

Fig 4.2 is a bar chart showing the marital status of the sampled genomics research participants. From the bar chart, 7 (21.9%) of the sampled genomics research participants are single. 19 (59.4%) of the sampled genomics research participants are married. 4 (12.5%) of the sampled genomics research participants are divorced and 2 (6.2%) of the genomics research participants are widowed.

Fig 4.3: Bar chart showing the occupation of sampled genomics research participants.

Fig. 4.3 above is a bar chart showing the occupation distribution of sampled genomics research participants. As seen in the bar chart, 9 (28.1%) of sampled genomics research participants are civil servants. 15 (46.9%) of the sampled genomics research participants are traders. 5 (15.6%) of the sampled genomics research participants are farmers, while 3 (9.4%) of the sampled genomics research participants are involved in other occupations.

4.3. OBJECTIVE 1: TO EXAMINE THE EXPECTATION OF THE RESEARCH PARTICIPANTS ABOUT GENOMICS RESEARCH.

Table 4.1: What are your reasons for participating in this ongoing genomics research?

Genomics Research Participants' Response Category	Frequency	Percentage
To know my health status	15	46.9
To know whether or not I have Diabetes	2	6.2
To get cured of diabetes	6	18.8

Other Reasons	9	28.1
Total	32	100.0

Table 4.1 above reveals genomics research participants' reasons for participating in the genomics research. As seen in the table, majority (46.9%) of the sampled genomics research participants, held that they participated in the genomics research to know their health status. 62% of the sampled genomics research participants opined that they participated in the genomics research to know whether or not they have diabetes. 18.8% of the sampled respondents participated in the genomics research to get cured of diabetes and 28.1% of the respondents participated in the genomics research for others reasons.

Table 4.2: Are you optimistic that the outcome of the ongoing genomics research would be beneficial to you and to the society as a whole?

Genomics Research Participants' Response Category	Frequency	Percentage
Yes	32	100
No	0	0
Total	32	100

From table 4.2, all of the sampled participants of the genomics research opined that the outcome of the research would be beneficial to them and the society as a whole. This shows that there is a positive

Table 4.3: Do you have any idea as to what genomics research entails?

Genomics Research Participants' Response Category	Frequency	Percentage
Testing for Diabetes	10	31.2
Treatment of Diabetes	6	18.8
To discover potential causes of diabetes	4	12.5
I do not know	2	6.2
Others	10	31.2
Total	32	100.0

Table 4.3 above reveals information about the knowledge of the sampled participants on the genomics research. As observed in the table, 31.2% of the respondents revealed that what the genomics research entails is testing for diabetes among the participants of the research. 18.8% of them opined that what the genomics research entails is the treatment of research participants that have diabetes. 12.5% of the sampled genomics research participants said that what the genomics research entails is to discover potential causes of diabetes. Only 6.2% of the sampled participants have no idea of what the genomics research entails and the remaining 31.2% of the sampled respondents have different ideas of what genomics research entails.

Table 4.4: Are there other expectations you envisage that you would like to share with us as regards this ongoing genomics research?

Genomics Research Participants' Response Category	Frequency	Percentage
That the research should allow for more participants	4	12.5

That drugs should be provided for participants having diabetes	3	9.4
There should be more public enlightenment about this genomics research	4	12.5
That the objectives of the research is achieved in its outcome	3	9.4
That the outcome of the research is communicated to the research participants	3	9.4
Other expectations	9	28.1
I do not have any expectation	6	18.8
Total	32	100.0

Table 4.4 shows others expectations the sampled research participants envisage as regards the genomics research they participated in. As observed in table…, 12.5% of the sampled participants of the genomics research envisage that the ongoing genomics research should allow for more participants, so that more people in the society can enjoy the benefits available to participants of the research. 9.4% of the sampled genomics research participants envisage that drugs should be provided for the genomics research participants having diabetes. 12.5% of the sampled participants of the genomics research envisage for more public enlightenment about genomics research. 9.4% of the sampled genomics research participants envisage that the objectives of the research are achieved in the outcome of the research. Also, 9.4% of the sampled genomics research participants envisage that the outcome of the research is communicated to the research participants. 28.1% of the sampled genomics research participants envisage other expectations and 18.8% of the respondents have no expectation they envisage as regards the genomics research they are participating in.

4.4. OBJECTIVE 2: TO EXAMINE THE EXPERIENCE OF THE RESEARCH PARTICIPANTS ABOUT THE GENOMICS RESEARCH.

Table 4.5: Have you participated in a similar genomics research before now? If yes, what are your experiences?

Genomics Research Participants' Response Category	Frequency	Percentage
Yes	0	0
No	32	100.0
Total	32	100.0

From table 4.5, none of the sampled genomics research participants have participated in a similar genomics research before. This is therefore the first genomics research that all sampled respondents are participating in.

Table 4.6: What can you say are your experiences so far in participating in this genomics research?

Genomics Research Participants' Response Category	Frequency	Percentage
The researchers are friendly and accommodating	6	18.8
All medical tests were carried out free of charged	2	6.2
My health condition has improved since I started participating in this research	5	15.6
I now have a good knowledge of my health condition	4	12.5
My experience has been a good one	6	18.8

Others	9	28.1
Total	32	100.0

Table 4.6 reveals the experiences the sampled genomics research participants have had since the research began. As seen in the table, 18.8% of the sampled respondents said that there experience is that the genomics researchers are friendly and accommodating. 6.2% of the sampled respondents said that their experience so far is that all medicals tests for the genomics research participants were carried out free of charge. 15.6% of the sampled respondents held that their health condition has improved since they started participating in the genomics research. 12.5% of the sampled genomics research participants expressed that they have a good knowledge of their condition. 18.8% of the sampled respondents opined that their experience has been a good one. 28.1% of the sampled respondents shared their differing experiences about the genomics research they participated in.

Table 4.7: Are you pleased or comfortable with the way or manner the research is progressing? Give reasons for your answer.

Genomics Research Participants' Response Category	Frequency	Percentage
Yes	31	96.9
No	1	3.1
Total	32	100.0

As seen in table 4.7 above, all the sampled genomics research participants opined that they are pleased with the way and manner the research is progressing. Various differing reasons were given

by the respondents to support their claim. Excerpts from the qualitative data gathered reveal some of these reasons:

"Yes, I am pleased with the way and manner the research is progressing. The researchers are always here on time and they attend to each one of us in an orderly manner. That is a wonderful display on the part of the researchers."

(29 year old Male, young genomics research participant)

"Yes, I am pleased with the way and manner this research is progressing. I believe the researchers are still on the right track and things are progressing as they planned."

(33 year old Female, young genomics research participant)

"I am not so pleased with the way and manner this research is progressing. This is because there are a lot of people in the rural areas who are not able to benefit from this research because this location where the research is being carried out is not accessible for them. I recommend to the researchers to embark on public awareness on radio in Yoruba language so that more people can benefit from this ongoing research."

(62 year old Male, adult genomics research participant)

"Yes, I am pleased with the way and manner this research is progressing. Carrying out a research is not an easy task. The researchers have put in a lot of efforts which one should appreciate."

(60 year old Female, adult genomics research participant)

Table 4.8: Do you think that there are some things that should have been put in place or done by the researchers which is left undone?

Genomics Research Participants' Response Category	Frequency	Percentage
Drugs should be provided for the research participants free of charge	2	6.2
There should be more public awareness about this genomics research	5	15.6
More hands should be employed to assist the researchers	3	9.4
Nothing is left out undone	16	50.0
I do not know	2	6.2
Others	4	12.5
Total	32	100.0

From table 4.8, 6.2% of the sampled genomics research participants opined that drugs should be provided for the research participants free of charge. 15.6% of the sampled genomics research participants contended that there should be more public awareness about genomics research. 9.4% of the sampled respondents held that more hands should be employed to assist the researchers. Exactly half (50%) of the sampled respondents opined that nothing is left undone by the researchers. 6.2% of the sampled respondents do not know of what could have been done or put in place by the researchers which is left undone. 12.5% of the sampled respondents pointed out other differing things that should have been put in place or done by the researchers which are left undone.

Table 4.9: Are you pleased with the attitude and behavior of the researchers in this ongoing genomics research?

Genomics Research Participants' Response Category	Frequency	Percentage
Yes	31	96.9
No	1	3.1
Total	32	100.0

As seen in table 4.9, a vast majority of the sampled respondents, taking a population of 96.6% of the total sampled genomics research participants are pleased with the attitude and behavior of the researchers. Only 1(3.1%) of the sampled respondents is not pleased with the attitude and behavior of the researchers. This reveals therefore that almost all the respondents are pleased with the attitude and behavior of the researchers.

Table 4.10: Was there a time that you contemplated quitting in this research? If yes, kindly give your reasons.

Genomics Research Participants' Response Category	Frequency	Percentage
I didn't at anytime contemplate quitting in this research	31	96.9
I contemplated quitting in this research	1	3.1
Total	32	100.0

From table 4.10, 31(96.9%) of the sampled genomics research participants didn't contemplate quitting in the genomics research. 1(3.1) of the sampled genomics research participant contemplated quitting in the genomics research. With this information, it can be inferred that

almost all the sampled genomics research participants didn't give quitting in the genomics research a thought. Excerpts from the qualitative data gathered regarding respondents' reasons for either contemplating or not, quitting in the genomics research are as follows:

"I didn't at any time contemplate quitting in this research. Since I know it is for my own benefit."

(34year old Female, young genomics research participant)

"I didn't at anytime contemplate quitting in this research. Why would I quit in a research that will be beneficial to me and the society at large?"

(29 year old Male, young genomics research participant)

4.4. OBJECTIVE 3: TO EXAMINE THE EVALUATION OF THE RESEARCH PARTICIPANTS OF THE GENOMICS RESEARCH.

Table 4.11: Having participated in this genomics research, how would you access the overall research process?

Genomics Research Participants' Response Category	Frequency	Percentage
Very good	22	68.8
Good	7	21.9
Fair	3	9.4
Total	32	100.0

Table 4.11 shows genomics research participants' assessment of the overall research process. As seen in table 4.11 above, majority of the sampled respondents taking a population of 68.8% rated the overall research process as being 'very good'. 21.9% of the sampled respondents rated the research process as being 'good' and only 9.4% of the sampled respondents rated the research process as being 'fair'. From this statistics, it can be observed that more than two-third of the sampled genomics research participants gave a good assessment of the research process.

Table 4.12: What possible assessment can you give about the research as a whole?

Genomics Research Participants' Response Category	Frequency	Percentage
Very good	20	62.5
Good	10	31.2
Fair	2	6.2
Total	32	100.0

Table 4.12 reveals genomics research participants' assessment of the overall research process. As presented in table above, 62.5% of the sampled respondents rated the research as a whole as being 'very good'. 31.2% of the sample respondents rated the research as a whole as being 'good' and only 6.2% of the sampled genomics research participants rated the research as a whole as being 'fair'. This reveals that majority of the sampled genomics research participants gave a good assessment of the genomics research as a whole.

Table 4.13: If called another time in the future to participate in a research like this, would you be willing to volunteer, based on your experience with the ongoing genomics research?

Genomics Research Participants' Response Category	Frequency	Percentage
Yes	32	100.0
No	0	0
Total	32	100.0

From table 4.13, all the sampled genomics research participants expressed that based on their experience of the genomics research; they will volunteer to participate in a research like this in future if called upon.

Table 4.14: What recommendation, based on your experience can you possibly give future genomics researchers?

Genomics Research Participants' Response Category	Frequency	Percentage
They should be committed to achieving the goal of the research	12	37.5
They should extend the grid of the research to cover rural areas	4	12.5
They should be friendly and accommodating to the research participants	4	12.5
Other recommendations	11	34.4
I have no recommendation to give	1	3.1
Total	32	100.0

Table 4.14 reveals the recommendations that the sampled genomics research participants gave to future researchers. As seen in the table, 37.5% of the respondents recommended that the future researchers should be committed to achieving the goal of the research. 12.5% of the sampled

genomics research participants recommended to the future researchers to extend the grid of their research to cover rural areas. Also, 12.5% of the sampled respondents recommended to the future researchers that they should be friendly and accommodating to the research participants. 34.4% of the sampled respondents gave other recommendations to future researchers.

Table 4.15: What recommendation, based on your experience, can you possibly give future genomics research participants?

Genomics Research Participants' Response Category	Frequency	Percentage
They should give the researchers their maximum cooperation	8	25.0
They should avail themselves of the opportunities of participating in the research	10	31.2
I have no recommendation to give	1	3.1
Other recommendations	13	40.6
Total	32	100.0

Table 4.15 above reveals recommendations that the sampled genomics research participants gave to future research participants. A quarter (25%) of the sampled genomics research participants recommended to the future research participants that they should give research participants their maximum cooperation. 31.2% of the sampled respondents recommended to future research participants that they should avail themselves of the opportunities of participating in the research. One (3.1%) of the sampled genomics research participants didn't give any recommendation to the future research participants, while 40.6% of the sampled respondents gave other recommendations to future research participants.

Table 4.16: Do you think this study was worth participating in? Kindly give reasons for your answer.

Genomics Research Participants' Response Category	Frequency	Percentage
Yes, the research was worth participating in	32	100.0
No, the research was not worth participating in	0	0
Total	32	100.0

As seen in table 4.16 above, all the sampled genomics research participants held that the genomics research was worth participating in. Respondents' reasons for their positions differ.

DISCUSSION

The crux of this research work has to do with eliciting information from 32 study participants in a genomics research project in Africa using a qualitative research method. Out of the 32 participants in the study, 8 eight were young males and another eight young females between

the ages of 25_35. The other group of the participants was eight adult males and eight adult females between the ages of 60-65. A number of mutually related questions were formulated under the headings: Expectation, Experience and Evaluation.

As it concerns the respondents' Expectations in the research project, findings, as revealed on the Bar chat, Fig 4.1, indicate genomics research participants' reasons for participating in the genomics research. As seen in the table, majority (46.9%) of the sampled genomics research participants, held that they participated in the genomics research to know their health status. 62% of the sampled genomics research participants opined that they participated in the genomics research to know whether or not they have diabetes. 18.8% of the sampled respondents participated in the genomics research to get cured of diabetes and 28.1% of the respondents participated in the genomics research for others reasons. Some of these other reasons include monetary gains, free medical treatment and drugs.

As often expected for a sample of individuals who have agreed to participate in a genomics research, the majority of the participants interviewed for the Genomics project were positive or very positive about genomics research and described themselves as somewhat or very likely to participate in future studies. The interviews revealed a number of positive opinions about genomics research for these study participants. They included the potential to discover the causes of disease, and the value of awareness and information, which might lead to prevention strategies even without a cure. Society would benefit as well, especially if medical progress ultimately resulted in cost savings associated with a healthier population. More than half of the qualitative sample of respondents gave no negative opinions of the genomics research. Those who gave negative opinions mentioned loss of confidentiality, abuse of information, and possible discrimination. It is

important to note that many of those who felt quite positive about genomics research were also able to list some of these negative consequences.

We found that respondents were more likely to be positive about genomics research if they were, more educated, more knowledgeable about genomics research, and more trusting of medical researchers. The findings revealed that those who are not religious are also more positive about genomics research, compared with those who are very religious, indicates the need for more attention to the role of religion in attitudes toward genomics research. However, because these respondents represented only 5% of the total sample, this particular finding should be interpreted with caution.

It is also worthy of note that few of the participants expressed distrust of medical researchers, and less than half had heard little about genomics research, and a good number of respondents reported a complete lack of knowledge about genomics research. Those expressing this distrust or having little knowledge were much less likely to be willing to participate in future studies. The study participants expressed “enormous expectations” about genomics research studies and the promise of medical progress. These expectations coincide with positive attitudes that the participants hold regarding the potential of the genomics studies to address their major health conditions. Yet, findings of this study demonstrate that positive responses may also be associated with overly high expectations, and that good will toward medical research may not persist without results, that is, the outcome of the study. It is important that researchers and scientific leaders address such “expectations, experience and evaluation” through careful explanation of the goals, potential benefits, and limitations of genomics research for participants.

5.0 CHAPTER FIVE

5.1 CONCLUSION

The majority of genomic studies conducted to date have been on populations of European descent (Need & Goldstein, 2009). Only a fraction has included populations from Africa (Rosenberg et al., 2010). The exclusion of African populations from genomic studies may promote or prolong existing global health inequalities, in particular if such research leads to knowledge that is of clinical relevance (Coloma & Harris, 2009; Newport & Rotimi, 2009). It is therefore very important that genomics research methods are also used for the investigation of diseases primarily affecting patients on the African continent.

The genomics research project currently progressing in Africa, Nigeria, to be precise, is a step in the right direction, as it avails people of African descent, the opportunity to participate in the research, which eventually, will be beneficial to them and to the continent of Africa at large.

Available literature indicates that African people are genetically very diverse (Rosenberg et al., 2010), and this diversity causes considerable methodological challenges in expanding GWA studies to the African continent (Teo, Small, & Kwiatkowski, 2010). Population substructure – i.e. when members of a population have a shared genetic background – has the potential to confound GWA analyses and lead to false positive associations between disease and clinical outcome.

This project employed a qualitative research method in eliciting information from a group of 32 research participants who participated in a genomics research project. The overall assessment of their responses indicates they had positive disposition toward the research and the researchers.

5.2 LIMITATION OF THE STUDY

It must be stated that this study has some limitations. First, because the participants of the study were mostly people of Yoruba ethnic group residing in Oyo State, South-West of Nigeria. The study population from this ethnic extraction accounts for 80% of the entire study population. The geographical location of the study site could be seen as the obvious reason why this happened. Based on this reason, the generalizability of its findings is limited to a large extent, to the people of Yoruba ethnic extraction in Nigeria. This means that those who have not participated in such study may have different and potentially less positive attitudes toward such research participation. Additionally, although the study participants' response was quite awesome and impressive (90%), the fact that the sample size is under powered further limit its generalizability.

Despite these limitations, the contributions of the study findings are highly relevant to current goals of recruiting genomics study participants. It is also good to mention that the study participants were very positive about the promise of genomics research. Moreso, the participants also demonstrate concerns about genomics research studies like the issues of accessibility of research site, lack of adequate knowledge about genomics studies, the need to improve on the communication frequency between genomics researchers and the research participants. These issues, if put in proper perspectives, would facilitate voluntary participation in genomics research in the future. Awareness of the barriers and difficulties gained or gathered from this study would provide a roadmap to improve public understanding and acceptance of genomics studies.

5.3 RECOMMENDATION

It is worthy to recommend to researchers on the need to organize seminars and workshops on genomics to people, especially the people of African origin, on the meaning of genomics and genomics research so as to help educate potential study participants about genomics research and efforts to demonstrate that the trustworthiness of the research team might help encourage future study participation. If this enlightenment process is repeated from time to time, I believe so tenaciously that it will give future genomics participants a better attitude and disposition in participating in future studies. As at today, the level of awareness of what genomics is all about is very limited in African. This is the situation even amongst the educated class.

The attitudes of genomics research team towards participants must be encouraging, as this has a lot of influence on the disposition of participants during and after genomics studies. If researchers become too harsh on participants, there is every possibility that it will influence the kind of responses the participants will give when asked certain questions during genomics research process.

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