PERSPECTIVES OF RESEARCHERS IN NIGERIA ON SHARING SAMPLES AND DATA

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DEDICATION

I dedicate this project to the Almighty God, who makes all grace abound towards me to be sufficient in all things and also abound to every good work.

ABSTRACT

The concept of sharing is seen by some as an obligation and by others as a choice. Sharing of samples and data in research is novel to researchers in developing societies. Therefore, the objectives of this study were to assess the perspectives of researchers in Nigeria on the various aspects of samples/data sharing.

Forty (40) researchers from six universities in southwest Nigeria were recruited by purposive and snowballing sampling methods and information were obtained from the respondents through key informant interviews. The data was analyzed quantitatively with the use of the Statistical Package for Social Sciences (version 16) and qualitatively by Content Analysis.

It was observed that the respondents had varied views on sharing and most were unwilling to share their research samples/data with other researchers. Only 40% were aware of material transfer agreements in Nigeria and all respondents opposed being mandated to share their samples/data. Second authorship position, acknowledgement, refund of the cost of conducting the research, capacity development, donation of research equipments, financial reward, holiday trip abroad and reciprocal sharing were described as adequate compensation by the respondents as a reward for sharing their samples or data. As regards the role of residuality of samples/data, respondents insisted that they will not share their samples/data without having a copy of such in their custody. Most respondents believed that the primary researcher own samples/data shared while a minority (5%) believed ownership is shared between the two parties. Existence of a national database, full involvement of the stakeholders' institutional review boards, legal input and written agreement between parties were suggested to be incorporated in the formulation of Nigeria's policy on samples/data sharing among researchers.

This study has demonstrated that the concept of samples/data sharing is still alien to researchers in Nigeria and efforts to establish it should incorporate awareness/educational programmes for the researchers in Nigeria while giving consideration to peculiar needs.

Keywords: Sample, Data, Nigeria, Researcher, Perspectives.

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CERTIFICATION

I hereby certify that this research was conducted by Fakorede, Omokehinde Olubunmi (Matric No 188993) in the Department of Surgery, Faculty of Clinical Sciences, University of Ibadan under my supervision.

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LIST OF ABBREVIATIONS

CHSOAU:	**College of Health Sciences, Obafemi Awolowo University**
CMUL:	**College of Medicine, University of Lagos**
COMUI:	**College of Medicine, University of Ibadan**
DNA:	**Deoxyribonucleic Acid**
EKSU:	**Ekiti State University**
FMOH:	**Federal Ministry of Health**
HREC:	**Health Research Ethics Committee**
IRB:	**Institutional Review Board**
KII:	**Key Informant Interview**
KJV:	**King James Version**
LASUCOM:	**Lagos State University College of Medicine, Lagos**
LAUTECH:	**Ladoke Akintola University of Technology, Osun**
MTA:	**Material Transfer Agreement**
NAS:	**New American Standard Bible**
NHREC:	**National Health Research Ethics Committee**
NIH:	**National Institute of Health**
NIV:	**New International Version**
RNA:	**Ribonucleic Acid**
UCH:	**University College Hospital, Ibadan**

UCSF: ***University of California, San Francisco***
UI: **University of Ibadan, Ibadan**
UK: **United Kingdom**
US: **United States of America**
USAID: **United States Agency for International Development**
WHO: **World Health Organization**

CHAPTER ONE

INTRODUCTION

1.1 Background to the study

While some people describe ‘sharing’ as a virtue similar to giving and so should be inborn (Erard, 2011), others see it as an act that should be learnt (Raising Children Network, 2015). Whether what is shared is tangible (such as a commodity) or not (such as information), ‘sharing’ has been shown to be instrumental in promoting happiness and prosperity; reducing sufferings; meeting other people’s needs such as the case of receiving an organ transplant or preventing wastage on the part of a giver who appears to have excess (Dawes, 1996; Naagarazan, 2006).

There are several stages during implementation of research projects that may provide opportunities for sharing (Kerner et al., 2005; Goldblatt et al., 2011). Such opportunities include knowledge sharing, cost-sharing, benefit sharing, sample sharing and data sharing. Knowledge sharing is a situation in which skills, expertise and information are shared between researchers and other stakeholders (Tsui et al., 2006). In the process of disseminating research findings, knowledge can be shared by means of writing (Whalen, 2004), speaking at conferences/workshops (Keen and Todres, 2007; de Vries and Pieters, 2007), information technology (Hendriks, 1999; McDermott, 1999) and publication in academic journals (Keen and Todres, 2007). Knowledge sharing helps to provide useful generalizable knowledge which may serve as a basis for future research (Hailey et al., 2008;

Song et al., 2010) or as a template for evidence-based practice apart from its role in promoting dialogue among stakeholders (Tsui et al., 2006).

Costs of research has been broadly categorized into infrastructure/administration cost; standardization cost; cost of human resources as well as opportunity costs (Wilhelm et al., 2014). These costs are usually borne by researchers who collect data (Wilhelm et al., 2014). Cost sharing is a widely embraced means of reducing the cost associated with conducting researches (Mitka, 2011). Mandating research audience to pay subscription fee to access research findings and profit sharing are some of the strategies utilized in cost sharing (Wilhelm et al., 2014).

Benefit sharing describes a concept in which proceeds from the use of genetic resources, monetary or otherwise are apportioned between parties in a research project (Schroeder, 2007). Sharing among relevant stakeholders such as research participants, researchers, research community and the society at large (Lairumbi et al., 2012) is said to be an effort in promoting justice and fairness in research (Simm, 2005; Ballantyne, 2005). Other justifications for benefit sharing are for solidarity and reciprocity reasons (Dauda and Dierickx, 2013).

Sample sharing entails the provision and use of samples obtained from research participants among various parties in a research project (O'Doherty and Hawkins, 2010). Increasingly, researchers are being mandated to share samples in collaborative projects (Renner et al., 2012) and at times as a prerequisite for obtaining research grants (Tenopir et al., 2011). Sharing of samples has been instrumental in improving diagnostes, discovering biomarkers and enhancing treatment options in healthcare (Asslaber and Zatloukal, 2007). In fact, the concept is quite important in researches involving rare diseases (Mascalzoni et al., 2015). Reasons are that in rare conditions, individuals with the diseases are few; there is a shortage of researchers in the relevant field and resources are usually inadequate to conduct such researches at many sites at the same time (Mascalzoni et al., 2015). Also, samples may need to be shared in studies that involve large sample datasets (Chokshi et al., 2006) and in situations where the local institution lack the expertise or technology to work on the samples obtained (Smith et al., 2014).

However, the concept of sample sharing has been a controversial topic in recent times because of the attendant risks to the research participants as well as to the researchers. The participants are at risk of loss of their privacy as well as discrimination against their community when their samples are shared with other individuals/organizations unknown to them (Moodley et al., 2014; Truyers et al., 2010). Despite the benefits discussed above, studies have shown that researchers have not been willing to share their samples with one another due to the risks of poor academic recognition and financial exploitation especially if such researches yield financial benefits (Pereira, 2013).

Increasingly, data sharing has also been gaining renewed attention in research largely due to the fact that funding organizations are requesting that biomedical researchers should plan to share their data with other researchers or organizations (The Wellcome Trust, 2003; Kaye et al., 2009) and biomedical journals are now asking researchers to include statements on data sharing in their manuscripts before such works can be published (Rathi et al., 2012). Data sharing has been useful in studies involving large datasets (Poldrack and Gorgolewski, 2014), where the institutions in which the data was collected do not have the facilities to utilize the data (Cheah et al., 2015; Tangcharoensathien, 2010) and in national public health emergencies (Fidler and Gostin, 2011). Data sharing promotes transparency in research (Kuntz, 2013), prevents duplication of research efforts (Hate et al., 2015), gives room for new discoveries by secondary data users (Pisani and AbouZahr, 2010) and allows for publication of many academic papers from a single data (Pienta et al, 2010).

However, various concerns have been raised by researchers as well as research participants as regards data sharing. Issues of inadequate compensation/authorship (Vickers, 2006), risk of loss of academic credit (Denny et al., 2015), data mishandling (Alter and Vardigan, 2015), non-acknowledgement of the local researcher in secondary publication (Lötter and Zyl, 2015) and financial exploitation in the event of commercial benefits (Alter and Vardigan, 2015) have all been raised by researchers. Concerns of loss of privacy (Jao et al., 2015), breach of informed consent (Merson et al., 2015), stigmatization of local community (Bull et al, 2015) have also been aired by research participants.

Sample and data sharing are indispensable events in genomic research because of the benefits they present (Mailman et al., 2007). When samples are shared, it enables the generation of large and superior-quality data sets (Chasman et al., 2009) which in turn increases the statistical power of such research studies (Kosseim et al., 2014). Similarly, sharing data in genomics has been described as a means of ensuring judicious use of data obtained in publicly-funded studies (Kaye et al., 2009) as well as reducing participants' burden (Trinidad et al., 2010).

Some ethical concerns have arisen in regards to the concepts of samples and data sharing in genomics. These have centered on appropriate recognition of data producers (WTCCC, 2007); incentives to data producers (Kaye et al., 2009) as well as breach of privacy and consent of research participants (Knoppers et al., 2014). Though various policies are being made to address these concerns, they appear not to be fool proof. For instance, as regards the anonymity of the data, it is difficult to guarantee that the privacy of participants have been fully protected knowing fully well that the unit of storage (DNA) is unique to every individual (Karp et al., 2008) and modern genomics research tools can identify individual study participants with a high degree of precision from their DNA. Also, the informed consent obtained from participants as regards sharing their data may not be truly reflective of the many uses the data can be put to (McGuire et al., 2011) and the rights of a participant to withdraw from research might be impossible to implement (Kaye, 2015). In addition, data producers and ethical committees find it difficult to regulate the various uses secondary user puts the samples and data to (Langat, 2005). Despite all these, genomic research has been instrumental in developing resources and policies on the concepts of sharing samples and data (Paltoo et al., 2014; Collins et al, 2003).

While the importance of samples and data sharing cannot be overlooked, there have been few studies on the views of African researchers on samples and data sharing. Review of literature has revealed that researchers share samples and data for different reasons, some of which may yet be unknown. Some researchers may want to share their samples or data but only under special circumstances or to a particular extent. The possibility that the latter group of researchers may desire to have certain measures in place before agreeing to share their research samples or data have not also been explored.

Aside from the concerns noted above on samples and data sharing, there is an issue that has not caught the attention of authors in this field. This is the concept of residuality. Researchers who share samples with other researchers will no longer have access to the samples shared while the one who shares data is still in possession of the data apart from the copy sent to the secondary data user (Pereira, 2013). This concept may have peculiar implications to the researcher in a low and middle income country who shares his samples/data with a researcher who is based in a high income country. A local researcher who shares his research samples in a collaborative research may be at a disadvantage since he no longer has access to the samples but the same cannot be said for data sharing since the local researcher still has a copy of the shared data in his possession. This may suggest the need to see samples and data sharing as entirely different concepts. However, the views of researchers from low and middle income countries, such as Nigeria, on this concept are yet to be explored.

1.2 Statement of the problem

The issue of samples and data sharing is very critical at this moment in the field of research ethics in Nigeria. This is because of the challenges that local researchers may face when an agreement is made to share research samples/data with others. Some of these challenges may include the issues of inadequate compensation (Merson et al., 2015), ownership of the samples/data after sharing (Bull et al, 2015) as well as mechanisms of ensuring strict adherence to the agreement on samples/data sharing (Lötter and Zyl, 2015).

One of the major fears of researchers about samples and data sharing is the possibility of poor or no compensation for all their efforts in obtaining these samples/data (Van et al, 2013). Though various suggestions ranging from financial rewards, acknowledgement in secondary publication and co-authorship have come up in this regard (Koslow, 2002), controversies are still ongoing about the most appropriate way to compensate samples/data providers.

Also, the issue of intellectual rights over the samples and data shared is a subject of concern (Nash, 1993). Prior to samples/data sharing, it is largely believed that the researcher owns the samples/data in individual-level research. After sharing the samples/data, both the primary researcher (samples/data provider) and the secondary researcher (samples/data user) have some of the samples/data in their custody. The issue of who claims ownership of the samples/data has therefore been a subject of debate.

Lastly, there have been efforts in the developed world geared towards developing national guidelines for samples/data sharing (Carlhed and Alfreddson, 2008; Knoppers et al., 2011). Usually an agreement is entered into between the samples/data provider and user. The problem in this situation is how the local researcher can guarantee that the samples/data user agree to the terms of the agreement of sharing samples/data. For instance, if it is agreed that the end user will use the data for a particular duration or for only a specific number of research project(s), how can the data provider guarantee that the data user is adhering strictly to this agreement?

The price to pay if these perspectives are not examined is the risk of apathy for research and sharing by researchers in Nigeria. They may tread this path because they may perceive the issue of samples/data sharing as an exploitative tool in its overall sense. This will contribute to further decline in research output from the country as a whole.

1.3 Research Questions

It is against this backdrop that I proposed the following research questions:

i. How do researchers in Nigeria perceive the concept of samples and data sharing?

ii. What are the views of researchers in Nigeria on the types of samples and data that can and should be shared, extent/level of sharing and regulations on access to the samples and data?

iii. What are the benefits of samples and data sharing to the researcher in Nigeria?

iv. What are the harms of samples and data sharing to the researcher in Nigeria?

v. What are the challenges of samples and data sharing to the researcher in Nigeria?

vi. What does the researcher in Nigeria regard as an adequate compensation for agreeing to share samples and data?

vii. Who should claim ownership of samples and data after it has been shared?

viii. How can the researcher in Nigeria ensure that the samples and data user adhere strictly to the terms of agreement of using the samples and data?

ix. Are researchers in Nigeria aware of the existence of a national policy that guides sharing of samples in Nigeria? Are they aware of the steps that must be taken in the course of sharing samples with other researchers?

x. Which areas do researchers in Nigeria think a national guideline on data sharing should address?

xi. What, if any, has been the experience of Nigerian researchers in sample and data sharing?

xii. Are there differences in expectations for when samples and data are shared with researchers within Nigeria; in other developing countries; in developed countries and with specific countries like UK, US, South Africa and China

1.4 Objectives of the study

The general objective of this study is to assess the perspectives of researchers in Nigeria on samples and data sharing.

The specific objectives of this work are:

i. To assess the views of researchers on the types of samples and data that should be shared, extent/level of sharing as well as benefits, harms and challenges of sharing samples and data with other potential users .
ii. To assess the various ways researchers think they can be adequately compensated for their efforts in providing samples and data for sharing with other researchers in Nigeria, from other developing countries, developed countries and with specific countries like the UK, the US, South Africa and China.
iii. To explore the views of researchers in Nigeria on the ownership of samples and data after it has been shared.
iv. To explore the various aspects of data and sample sharing that a national guideline should address.

1.5 Significance of the study

Most research on data sharing to date focused on the adequacy of consent and protection of participants in sample and data sharing during research. Largely, these studies have approached the issue from the angle of the research participants and not the researchers. Therefore, there is a need to explore the views of the researchers who share their research samples or data with other local or international researchers and organizations.

Studies have shown that the challenges of research development differ in high and low income countries and this has been attributed to the peculiar needs of each setting (Parker and Bull, 2015). As a result, the need to address some pertinent issues on samples and data sharing among researchers in low and middle-income countries is important considering the fact these nations have their own peculiarities (Parker and Bull, 2015).

Unlike his counterpart in the developed world, the average researcher in Nigeria may not have access to the infrastructure which makes samples and data sharing easy nor derive further downstream benefits such as utilization of data and samples for new research grants (Cheah et al., 2015) like their colleagues in developed countries. In fact, researchers sometimes conduct these studies under stressful conditions such as lack of research facilities and sponsorship; inefficient transportation arrangement of materials/persons to study sites;

poor motivation of participants and research assistants as well as epileptic power supply to power computer systems for data management and analyses (Eze et al., 2012). These factors may have a role to play in the way a researcher in Nigeria views the concept of sample and data sharing.

Currently, Nigeria is at a stage in which the awareness of research ethics is just being embraced and regulations governing the conduct of research are being promulgated (Ogunrin et al, 2013). The subsection n of the Section E of the National Code of Health Research Ethics (FMOH, 2007) provides for materials transfer agreement involving the transfer of research materials obtained in Nigeria outside the country. The code states that "The transfer of samples and biological materials such as animals, herbs and plants out of Nigeria shall require a Materials Transfer Agreement (MTA) detailing the type of materials, anticipated, use, location of storage outside Nigeria, duration of such storage, limitations on use, transfer and termination of use of such materials subject to any law, regulations and enactment in Nigeria". The code explains that the MTA is necessary for the protection of the research participants, local researcher and the international collaborators from exploitation. The institutional Health Research Ethics Committee (HREC) and National Research Ethics Committee (NREC) are expected to coordinate the terms of conditions between the local and international investigators as regards the transfer of the materials. The HREC has been given powers to issue provisional and final approval for the research after it must have ascertained that the MTA is in line with the stated objectives and the stakeholders have agreed to the terms. However, the MTA and provisional approval for the research must be filed with the NREC before the final approval for the research can be given by the institutional HREC. Any amendments to the MTA must be brought to the notice of the HREC and NREC before such research can commence.

Similarly, , the Nigeria's National Code of Health Research Ethics also provides for data sharing. The subsection s of Section E of the code addresses the protection of researchers from exploitation. It emphasizes the primary researcher's rights to ownership of and access to data. The code states that "HREC shall protect researchers from exploitation. (i) In certain situations, this will require the submission of an agreement between sponsor(s), institution(s) and researcher(s) indicating rights to, ownership of and rights of access to data, resources, intellectual property and infrastructure generated in the course of the research."

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However, it is hoped that findings from this research may also aid in the development of policies and regulations that will further protect the Nigerian researcher in situations that mandate him or her to share research samples and data.

CHAPTER TWO

LITERATURE REVIEW

2.1 Sharing

"Sharing" means "to have or use (something) with others" or "to let someone else have or use a part of something that belongs to you" (Webster, 2015). The Cambridge dictionary (2015) defines it as "to have or use something at the same time as someone else". Generally, sharing has been understood to be synonymous with altruism or generosity (Kim and Stanton, 2015). From the religious point of view, the Holy Books document events in which men of God gave what they had as a pattern of the way of life of the creator (Al-Isra' 17:29; KJV Luke 6:38). Followers were admonished in various passages of the books to do the same in obedience (Quran 9:60; KJV; Romans 12:6-8). As a result, religious adherents believe that the individual who shares have demonstrated kindness to be willing to give part of what he has (KJV NIV, Romans 12:6-8). The person that refuses to share is misconstrued as being stingy or wicked (KJV NAS, Proverbs 28:27). However, some others have a different posture as regards sharing. The latter believe that willingness should be demonstrated in the process of sharing and people who share should be "willing to" and not forced. In other words, sharing means different things to different people: an attribute human beings are expected to show in obedience to religious injunction and modeling after their creator or an outward expression of one's altruism, the degree of which may vary from one person to another.

Following from above, the meaning this concept has to individuals may influence their attitude towards it (Coleman et al., 2003). Attitude is a measure of one's outlook towards a thing and it is a product of one's thinking or a result of many cognitive processes which reflects in one's behavior (Allport, 1935). Sometimes, an attitude develops from a belief and it may also be modified by experience (Schwarz, 2007). Some authors have classified the attitude to a matter as being either positive or negative in reference to the overall objective (de Liver et al., 2007). Attitude has however been associated with practice (Chaiklin, 2011). In other words, a positive attitude towards an act may explain its frequent practice while a negative attitude on the other hand may hinder it (Federer et al., 2015).

2.2 Sharing in Research

Researchers usually engage in "sharing" at different stages of a research. Sometimes, researchers share research ideas, costs of research, benefits from research, knowledge from research as well as research samples and data obtained from research. Researchers share at these different stages of research for various reasons. Sharing research ideas may lead to better refinement of research ideas and topic (Guzdial et al, 2009). This may also be an attempt to invite other researchers to buy into the worth of a research idea and hence serve as an invitation to collaborate on a research project (Lumbreras and Hernández-Aguado, 2007). The costs of a research are many and could be burdensome for a single individual to bear (Manfredi et al, 1990). The costs range from those incurred in the process of sourcing materials to review, preparing the research proposal and getting it approved, implementing the research and disseminating the research findings (Wilhelm et al, 2014). Sometimes in collaborative research projects, financial rewards (Schroeder, 2007) or other forms of benefits (Dickenson, 2015) result and these are shared among stakeholders. Dissemination of results at conferences or through publication also exemplify the concept of knowledge sharing among researchers in the research community (Wang and Noe, 2010). Some additional costs are incurred in the process of preparing and transporting samples obtained from one researcher to another and the same also applies when data obtained from a research must be curated in preparation to being shared with others (Goodhill, 2014).

Current evolving trend in the research world is the sharing of samples and data especially in the field of genomics (Mailman et al., 2007). However, more frequently than others, sharing at this stage of research involve research support staffs (Federer et al., 2015) who are usually involved in research sample and data collection as well as its preparation to be shared. Though much work has not been done to ascertain the views and attitudes of these staff to samples and data sharing, Denny and colleagues (Denny et al., 2015) reported the view of some research support staff in South Africa. The respondents stated that they will only be willing to share research data with other people out of altruistic motive or if doing so will result in some health benefits or monetary rewards. Similar reasons were noted by the clinical and basic science researchers in the Intramural Research Program at the National Institutes of Health where (Federer et al., 2015). In addition, the respondents in the latter study (Federer et al., 2015) expressed their desire to "assist" a colleague as another motivation for sharing.

From a study conducted on data sharing among health research stakeholders in Vietnam (Merson et al., 2015), some respondents opined that everyone including potential recipients are naturally stingy and suggested that the decision to share should be a voluntary one while some others regarded the request for data provider to share as being disrespectful or insulting (Merson et al., 2015). In another study conducted among public health researchers and research participants in India (Hate et al., 2015), respondents viewed the readiness of individuals to share data from genetic and socio-economic point of view. Some of the interviewees opined that the less affluent and the Indians were more generous and were more likely to share than non-Indians and the affluent (Hate et al., 2015).

2.3 Sample and Sample Sharing

In medical parlance, a sample is a portion of a larger substance (UCSF, 2005). These larger substances are naturally occurring within the body and so are referred to as biological samples (Medical Research Council, 2014). Therefore, biological samples could be components such as DNA or RNA, cells or tissues from any part of the human body, gametes, organs, embryos and fetal tissues, bodily products such as teeth, blood and blood fractions such as plasma and saliva as well as buccal cells (UCSF, 2005). In biomedical research, biological samples are mainly collected for research purposes (Medical Research Council, 2014). These samples are usually analyzed macro- and microscopically for chemical substances of interest which may be naturally occurring, a metabolite of a drug or another chemical compound (UCSF, 2005).

In research, sharing samples with other researchers may be necessary in certain circumstances. A researcher may collect research samples in a region where the facilities to analyze such samples are unavailable (Pereira, 2013). Researchers may also have a need to share the samples obtained from patients in the situation of an epidemic where there is an urgent need to develop therapeutic interventions for the affected (Mascalzoni et al., 2015).

Sharing samples may also be necessary when a research finding is unusual or seemingly interesting to the scientific community and repeat or further analysis on the samples needs to be conducted (Moodley et al., 2014). Doing this will prevent reduplication of research and waste of resources (Mascalzoni et al., 2015). In multi-national collaborative research projects, researchers from different countries may need to exchange the samples obtained in the various countries among one another or submit to a major repository in order to confirm the findings noted by each of the researchers in their various countries (Zhang et al., 2010). In summary, for non-solo research projects, the risk of sharing research samples is more likely.

2.4 Data and Data Sharing

In research, data collected from respondents form the substrates for analysis (Pope et al., 2011). Data can be obtained from the measurement of a biological characteristic such as height or blood pressure; of the concentration of a chemical substance such as drug in the body or derived from responses to questions on a questionnaire (Duriau et al, 2007). Data have been categorized based on the nature of the information obtained. For instance, information that represent views or opinion on a subject are referred to as qualitative data (Polkinghorne, 2005) while information that has to be measured or rated in comparison to a standard before it can be recorded are referred to as quantitative data (Creswell, 2007). Data may need to be shared for reasons similar to that of samples (Mascalzoni et al., 2015). However, in addition, data may need to be shared when the local researcher lacks expertise to further analyze the data obtained (Smith et al., 2014).

2.5 Samples and Data Sharing

Though necessities for samples and data sharing tend to be similar, they are different entities (Mascalzoni et al., 2015). While samples are biological materials collected from human beings and so can be seen and is tangible (UCSF, 2005), data cannot be seen or felt. Samples are collected from part of a larger pool (Medical Research Council, 2014) but data has no extension of a large pool. While a repeat sample can be obtained from the same person from whom it is initially collected almost immediately with a higher likelihood of being identical, the same may not be guaranteed of all types of data (Tworoger and Hankinson, 2015).

Sharing samples and sharing data may be similar from the view that sharing either should require some form of permission from the person from whom it is obtained (Mascalzoni et al., 2015) and either could be altered, lost or destroyed in the process of being transferred from one person to another (Alter and Vardigan, 2015). However, the two differ in some other respects. For instance, one can share part of the sample obtained from one person (e.g 2mls out of 4mls of plasma) but part of the data obtained from that person cannot be shared because it is intangible (e.g sharing part of an individual's blood pressure reading). This is referred to as the concept of residuality (i.e samples have residuality while data do not). Also, data can be obtained from samples but the reverse is impossible (Tworoger and Hankinson, 2015). Despite these differences, authors have noted that the justification, benefits, dangers and concerns for samples and data sharing from low and middle-income are similar (Cheah et al., 2015).

2.6 Sharing Samples from Low and Middle Income Countries

Collecting, storing and using biological samples are not novel practices in developed countries (Goldenberg et al., 2015). In fact, there are sample repositories and biobanks in which such samples are stored for future research purposes (Husedzinovic et al., 2015). As a result, more of the ethical issues arising in developed countries as regards biosamples mainly involve re-consenting participants as regards the future use of the samples in research (Moodley et al., 2014), commodification of the samples (Dickenson, 2015) and sharing of proceeds from the research that such samples are used for (Dickenson, 2015). On the contrary, sample storage and use for research in developing countries is a new development. To buttress this, a Nigerian study that assessed the knowledge and attitude to biobanking among laypersons revealed that most of the respondents were ignorant of what biobanking was (Igbe and Adebamowo, 2012). Another study conducted among researchers from developing and developed countries revealed that most of those from developing countries had never been involved with the use of material transfer agreement (Zhang et al., 2010).

Sharing samples aids the efforts in the understanding and stratification of diseases (Medical Research Council, 2014). A case in point is that of the recent outbreak of Ebola Virus Disease in West Africa (Folayan et al., 2015). As a result of this, medical discoveries of biomarkers or novel treatment as well as improved diagnostics may arise in the process of working on these samples (Mascalzoni et al., 2015). Provision of samples for sharing may also be necessitated in a situation in which the local scientist lacks the expertise to analyze such samples for the substance of interest (Smith et al., 2014). Scarcity of research samples, research participants and researchers are some of the factors that necessitate sample sharing among researchers (Mascalzoni et al., 2015). Of course, this has raised numerous ethical concerns especially if the country of origin is a developing one. Some of these concerns include issues of re-consenting, breach of participant's privacy and potential discrimination of participants (Husedzinovic et al., 2015).

Despite these, authors have noted the relative difficulty in obtaining blood samples for research in developing countries (Pereira, 2013). This finding has been linked to the unwillingness of researchers to share their biological samples (Pereira, 2013). The lack of readiness of these researchers have been attributed to the finiteness of samples and the difficulty in producing a duplicate unlike data which is a lot easier to reproduce (Pereira, 2013). Another limitation to sample sharing from developing countries is the issue of ownership of such samples (Alta Charo, 2006). This difficulty may also be as a result of research participants who also were unwilling to provide samples to be shared with international researchers because they were unsure of the diabolic consequences that could result from such an action. Though this report was from a South-Africa based study, the findings may not be different in other developing countries because of the latter's cultural and religious beliefs (Barrett et al., 2013).

Though there appears to be a paucity of studies on the issue of sharing biological samples from low and middle-income countries, a study conducted by Zhang et al (2010) revealed the views of researchers in three developing (China, India, Egypt) and two developed countries (South Korea and Japan). In this study (Zhang et al., 2010), respondents included researchers who work on samples, individuals who collects samples, ethics committee members and policy makers (as regards the use of stored samples). The study showed that researchers from developing countries were willing to share samples with researchers outside the countries. A high percentage of respondents vehemently opposed the transfer of samples outside their country and the main reason for this was lack of trust. These interviewees however endorsed the transfer of such samples only if the local country lacked the expertise to work on them. Even at that, the respondents insisted that a portion of the samples sent must be retained within the country of origin. These respondents also stated that an agreement must be made between all stakeholders but they had divergent views as regards who should be the custodian of such agreement - World Health Organization, local government or local institution. Most respondents from developing countries were of the opinion that the local scientist must be consulted and be fully involved in the future use of samples collected from host country. Also, they opined that the local researcher should have a veto power over whether the sample collected can be used for a particular research or not and most insisted that the local scientist should be part of the board to approve such study. As regards benefit sharing, most of the respondents stated that the local scientist must partake of any royalty from the research as well as be an author (though most cited being first author) while the local participants must also have access to products from such research (such as vaccines) to which the sample was put into.

2.7 Sharing Data from Low and Middle Income Countries

Compared with high-income countries, data sharing is more justified in low and middle income settings based on the high disease burden (Pisani and AbouZahr, 2010) and inadequate resources (Whitworth, 2010) in the latter. Sharing data in these settings is necessary for ensuring prompt attention to public health emergencies (Sieber, 2015), maximization of such data, (Langat et al., 2011), better interpretation of the data (Mello et al., 2013), prevention of research duplication (Langat et al., 2011), extension of scientific findings (Alter and Vardigan, 2015), promoting new science (Pienta et al., 2010), increasing publication (Piwowar et al., 2007), justifying research gap (Eichler et al., 2013) and reputational benefits to the local researcher or research group (Cheah et al., 2015).

As regards the stakeholders' perspectives on the practice of sharing data obtained from developing countries, there are very few works done in this regard. One of such studies revealed that researchers from developing countries such as Vietnam, Thailand, South Africa, and Kenya share data with one another (Parker and Bull, 2015). However these researchers have suggested that recognition of the value of data sharing (Jao et al., 2015), minimization of harm (Bull et al., 2015), promotion of fairness/reciprocity (Gornall, 1976) and trust are the essential pillars of good data sharing practice (Carr and Littler, 2015). Scholars have stated that trust and confidence are especially important when sharing data with researchers in low and middle-income countries because of the issues of social justice which are more prevalent there (Bull et al. 2015). Hence, in data sharing involving a developing country, the moral aspects should be addressed (Parker and Bull, 2015) with a view of promoting equity between the parties (Tangcharoensathien, 2010).

Another study by Denny and colleagues (Denny et al., 2015) revealed a different understanding on data sharing by researchers in developing countries. Some of the respondents in the study perceived researchers (from developed countries) who asked them to share data as a group of people who were not ready to let go of the independence they had earlier granted these developing countries. In fact, some of the respondents in the study described them as "neo-colonialists", wanting to reap where did not sow.

The dangers of sharing data from low and middle income countries as highlighted by scholars are significant. These include the risk of altering the data (Merson et al., 2015), porosity of data management (Alter and Vardigan, 2015), harming and exploiting research participants (Bull et al., 2015) as well as data sharers and local research institution (Cooper, 2007; Tangcharoensathien et al., 2010); declining research capacity in local researchers (Parker and Bull, 2015) and losing incentive for novel research (Rabesandratana, 2013).

Despite the vast importance enumerated above, this practice is limited in developing countries by non-availability of infrastructure (Manasa et al., 2014), lack of technical know-how (Pisani and AbouZahr, 2010), poor funding to facilitate data curation services, (Denny et al., 2015), lack of resources (Manasa et al., 2014), lack of existing policies to address ethical concerns (Rani and Buckley, 2012; Alter and Vardigan, 2015); lack of adequate incentive to local researchers who go through the rigors of curating data for sharing purposes (Cheah et al., 2015), uncertainty about user agendas (Hate et al., 2015).

A major concern is the issue of ownership of the data. The latter became an issue when a controversy arose on whose consent must be taken or permission obtained before data is shared. Some scholars have said the data was obtained from the research participant and so are the owner while others said it is the research funder who has the intellectual property rights over the research (Harris and Wyndham, 2015).

2.8 Theoretical Framework

The concept of sharing has various meanings to different individuals. Some people may readily want to share what they value because they are naturally concerned about other people’s needs while others may not. For those who share their research samples or data with fellow researchers, they may be rewarded in various forms including acknowledgement, authorship and financial rewards.

Researchers from low income countries lack funds to conduct research and so approach funding bodies. These bodies in return are mandating them to sign agreement to make their research samples and data available for sharing with other researchers or depositing them in central repositories. Failure to comply may lead to denial of future grant application or abrupt stoppage of ongoing sponsorship.

Based on the above, this work rests on the following theories:

Empathy-altruism (Sober, 1991): The prosocial behaviour of sharing may stem out of the concern that other researchers need the requested samples or data for an eventual public good. This may convince a researcher to share what he values (research samples or data) with a fellow colleague.

Reciprocity norm (Croson, 2008): Belief that doing good for others will be a template for others to do the same in the nearest future may also explain why a researcher may share research samples and data.

Agency theory of obedience (Eisenhardt, 1989): Researchers may obey funding organizations to share their research samples and data because the funding organizations are perceived to be legitimate authorities.

CHAPTER THREE

METHODOLGY

The Ethical Approval to conduct the study was obtained from the University of Ibadan/University College Hospital (UI/UCH) Ethics Committee, Ibadan as well as the Research and Ethics Committee of the University Teaching Hospital, Ado-Ekiti, Ekiti. The study was conducted between February and April 2016. The relevant authorities at all but one of the study sites gave verbal and express permission for the lecturers to be interviewed. The exception was the Olabisi Onabanjo University whose requirements could not be met within the time frame allocated for the completion of this project. Hence, this site was excluded.

3.1 Study Design

The design that was utilized in this study was the key informant interview. A key informant is an individual who has an appreciable knowledge on the subject matter of interest (Sherry, 1999). This study design is particularly useful when there is a need to enquire about a new issue and when direct information needs to be obtained from stakeholders (USAID, 1996). Findings from key informant interviews are usually useful for future development of regulations and policies as regards the subject matter (Cuthill, 2002; Taylor et al, 2002).

Therefore, the study entailed interviewing the researchers about their views on sharing their research samples or data with other researchers.

3.2 Study Population

The study population consisted of researchers at the Colleges of Medicine or Health Sciences of the six government-owned universities in southwest Nigeria. The study population was also restricted to researchers in these colleges because they conduct researches pertaining to the health of humans and are so referred to as biomedical researchers. Both purposive and snowballing sampling methods were employed in selecting the key informants. Purposive sampling method was used to deliberately approach specific individuals, who based on their experiences, were in a better position to provide information on the topic of study (Trotter, 2012). Snowball (Referral) sampling was used to identify other potential key informants based on referral from informants that have been interviewed (Trotter, 2012). The interviewer selected participants in a way that ensured broad representation based on age, duration of experience in research, previous participation in samples or data sharing, involvement in multi-institutional collaboration studies and involvement in international collaboration studies. The categories from which the participants were selected are:

i. Age: below 50 years old; 50 years old and above: This is to explore possible variety of opinions between the young and old researchers.
ii. Duration of experience in research: below 10 years; 10 years and above: The role of vast research experience is the underlying factor for this categorization.
iii. Previous experience of samples or data sharing: Yes or No: Researchers with previous sharing experience may have a different perception compared with those with no such history.
iv. Previous involvement in multi-institutional collaboration studies: Yes or No: This also further explores the role of research experience in contributing to perspectives on sharing.

Two key informants were selected from each faculty or institute in the Colleges of Medicine or Health Sciences of the six universities. Summing the number of faculties and institutes in all the colleges described above yielded a figure of twenty (20). Therefore, a total number of 40 key informants were interviewed in this study (See Table 3.1).

3.3 Study Sites

The study was conducted at the Colleges of Medicine/Health Sciences of six government-owned universities in southwest Nigeria. These colleges are:

v. College of Medicine, University of Lagos, Idi-Araba, Lagos State
- College of Medicine, University of Ibadan, Ibadan, Oyo State
- College of Health Sciences, Obafemi Awolowo University, Ile-Ife, Osun State
- Lagos State University College of Medicine, Ikeja, Lagos State

- College of Health Sciences, Ladoke Akintola University of Technology, Osogbo, Osun State
- College of Medicine, Ekiti State University, Ado Ekiti, Ekiti State

The first three are Colleges of Medicine/Health Sciences in federal universities while the remainders are those of state universities. The medical colleges of these universities have been selected because they have a large number of lecturers who are also researchers in biomedical field. These lecturers mandatorily conduct biomedical researches because publishing research papers is a prerequisite for promotion in Nigerian universities (Owuamanam and Owuamanam, 2008; University of Ibadan, 2014).

The College of Medicine, University of Lagos was established in 1952 and it is located at Idi-Araba, an urban cosmopolitan setting that is on latitude 6°31'13.01" and longitude 3°21'13.75" in Lagos State. The college has three faculties which are basic medical sciences, clinical sciences and dental sciences (CMUL, 2015).

The College of Medicine, University of Ibadan began as the faculty of medicine in 1948. It is located within the University College Hospital on Queen Elizabeth Road at latitude **7**°40′64″N and longitude 3°90′24″E in Mokola area of Ibadan, Oyo State. The college has four faculties: basic medical sciences, clinical sciences, public health and dentistry in addition to two research institutes (COMUI, 2015)**.**

The College of Health Sciences, Obafemi Awolowo University, Ile-Ife began as the faculty of health sciences in 1971. It is situated in Ile–Ife in Osun State which is located on latitude 7°31′06″N; longitude 4°31′22″E and about 218km northeast of Lagos state. Currently, the college is composed of three faculties (basic medical, clinical sciences dentistry) and an institute of public health (CHSOAU, 2015).

The Lagos State University College of Medicine was established in 1997 and currently has three faculties: basic medical sciences, clinical sciences and dentistry. It is situated in Ikeja, the capital of Lagos state which is on latitude 6 35' 48" and longitude 3 20' 35" (LASUCOM, 2015).

The College of Health Sciences, Ladoke Akintola University of Technology was established in 1991 and is currently made up of the faculties of basic medical sciences and clinical sciences. The college is situated at the Osogbo campus of the university. Osogbo has a geographical coordinates of 7° 46' 0" North, 4° 34' 0" E in the map of Nigeria (LAUTECH, 2015).

The College of Medicine, Ekiti State University is located at Ado-Ekiti which has a geographical coordinate of 7° 38' 0" North, 5° 13' 0" East. The college is made up of the Faculty of basic and allied medicine as well as the faculty of clinical sciences. It is located in Ekiti State (EKSU, 2015).

Table 3.1: Showing the procedure of sample selection

Name of University	**College of Medicine/ Health Sciences**	**Faculties/Institutes**	**Total Number of Faculties + Research Institutes at the College**	**Number of Participants to be interviewed per Faculty/Research Institute**	**Total Number of participants to be interviewed in the University**
University of Lagos	College of Medicine	Basic Medical Sciences, Clinical Sciences, Dental Sciences	3	2	6
University of Ibadan	College of Medicine	Basic Medical Sciences, Clinical Sciences, Public Health, Dentistry, Institute of Child Health, Institute for Advanced Medical Research and Training	6	2	12
Obafemi Awolowo University	College of Health Sciences	Basic Medical Sciences, Clinical Sciences, Dentistry, Institute Of Public Health	4	2	8
Lagos State University	College of Medicine	Basic Medical Sciences, Clinical Sciences, Dentistry	3	2	6
Ladoke Akintola University of Technology	College of Health Sciences	Basic Medical Sciences, Clinical Sciences	2	2	4
Ekiti State University	College of Medicine	Basic and Allied Medicine, Clinical Sciences	2	2	4
Total			**20**		**40**

3.4 Instrument development and Data collection

3.4.1 Interview Guide

The research instrument employed in this study was the interview guide (Appendix 1a and 1b). This was used to guide the researcher in conducting the key informants' interviews. The interview guide served as a pattern for the questions interviewees responded to. These questions were structured in a way that allowed for the free flow of ideas and information. They were open-ended questions which gave participants the opportunity to respond in their own words. It also gave room for expression of various views about the subject matter and did not give room for a yes or no answer (Sherry, 1999). The interview guide utilized in this study addressed the following:

- Perception and experience of researchers in Nigeria on the concept of samples and data sharing.

v. Views of researchers in Nigeria on the types of samples and data that should be shared, extent/level of sharing and regulations on access to the samples and data.

vi. Researchers' views about the benefit, harms and challenges of sharing their samples and data with other potential users.

vii. Researchers' opinions on how they can be adequately compensated for their efforts in providing samples and data for sharing with other researchers in Nigeria, from other developing countries, developed countries and with specific countries like UK, US, South Africa and China.

viii. Views of researchers in Nigeria on the ownership of samples and data after it had been shared.

ix. Suggestions on aspects of data and sample sharing that a national guideline should address.

3.4.2 Key Informant Interview

Key informant interviews were conducted with each research participant (key informant) on a face-to-face basis at the offices of the key informants. The researcher introduced herself to the key informant and subsequently asked the questions that elicited the knowledge of the participant on the research topics. The key informant interview guide was used to structure the interview and ensure that all relevant areas were covered. When necessary, probing questions were also asked. The responses to the questions were audio taped by a voice recorder and transcribed later. The key issues mentioned as well as the non-verbal communication, interferences, gestures and background events that occurred in the course of the interview were also documented.

The key informant interviews were conducted at the offices of the key informants. The mean duration of interview was 31 minutes (range: 17-57 minutes). Participants were appreciated for their time with two ink-pens. The phone numbers and e-mail addresses of the participants were obtained for possible clarifications after the interview.

3.5 Ethical Considerations

Potential participants who fulfilled the study criteria were approached to participate in the study and the purpose, procedure, risks and benefits of the study was explained to them. Each participant was also informed of his/her right to choose whether to participate in the research or not and even to withdraw at any time during the study.

Consent was obtained using the consent form in Appendix 2 and individuals who gave their informed consent were recruited for the study.

Participants were assigned an identification tag to protect their identity and thereby ensure confidentiality of their responses. The data obtained in this study was kept in the researcher's custody, away from the public and was not tampered with in anyway.

Ethical approval for the study was obtained from the UI/UCH Health Research Ethics Committee as well as the Research and Ethics Committee of the University Teaching Hospital, Ado-Ekiti, Ekiti. Verbal and express permission to interview the respondents was granted at all but one of the study sites. The exception was the Olabisi Onabanjo University whose requirements could not be met within the time frame allocated for the completion of this project. Hence, this site was excluded.

3.6 Data Management

The audio-taped recordings were transcribed after the interviews to minimize risk of loss of information. These transcripts were organized in different files with an appropriate file naming system (site.participant's category.type of document. sequential number.date). All the interviews were saved in their corresponding folders: *ALL.KII.AUDIO.300416* and

ALL.KII.TRANS.280716 meaning the "audio recordings of all the key informant interviews collated on the 30th day of April, 2016" and the "transcripts of all the participants' interviews collated on the 28th day of July, 2016" respectively. A similar approach was adopted for the field notes taken during the interview session.

The field notes taken, audio tapes used and the transcripts obtained in the study were kept in the researcher's custody (as the principal investigator) away from the public and were not tampered with in any way to ensure that the reliability of the data was maintained.

Confidentiality of the data obtained was ensured by conducting the interviews in the offices of the participants. This also helped to reduce interferences from third parties in the course of the interview. In addition, each research participant was also given an identification tag which is an alphanumeric code containing alphabets and numbers. At the beginning of the interview, each research participant was addressed with the identification tag and not the actual name. The reason was also to protect the identity of the interviewee both in the audio-taped recordings as well as the transcribed records. For example, an identification tag of P1 and P2 meant 1st and 2nd participants respectively. The notes taken during the interview also bore the identification tag (and not the name) of the participant.

3.7 Data Analysis Procedure

The raw notes taken during each interview by the researcher was transformed into an expanded field note to capture all the observations made after the interview. The audio recordings of the interviews were also transcribed after the interview.

Content and Thematic analyses were utilized as measure of data analyses. The researcher read and annotated the expanded field notes as well as the transcripts to have a general feel of them and subsequently identified the recurring themes in them. These recurring themes were tallied based on the categories (stated above) of the key informants. Also, the significant differences in the responses of the key informants were noted and analyses of these were also done based on the categories.

3.8 Expected Outcomes

It was expected that the researchers in Nigeria will have different views on when and how samples and data should be shared with fellow researchers in Nigeria, other developing and developed countries. It was also hoped that researchers in Nigeria will make useful suggestions on the issues a national guideline on samples and data sharing should address.

CHAPTER FOUR

RESULTS

4.1 Socio-demographic characteristics of participants

A total of forty (40) lecturers from the six study sites were interviewed (Figure 4.1). The study sites were the Colleges of Medicine/Health Sciences of six government universities in southwest Nigeria:

i. College of Medicine, University of Lagos, Idi-Araba, Lagos State
ii. College of Medicine, University of Ibadan, Ibadan, Oyo State
iii. College of Health Sciences, Obafemi Awolowo University, Ile-Ife, Osun State
iv. Lagos State University College of Medicine, Ikeja, Lagos State
v. College of Health Sciences, Ladoke Akintola University of Technology, Osogbo, Osun State
vi. College of Medicine, Ekiti State University, Ado Ekiti, Ekiti State

Both male and females were equally represented in the sample and the age of participants ranged from 34 to 68 years with a mean (SD) of 47.5 (8.20) years. The respondents have been in active research for a period ranging from 2 to 34 years and and have between 1 and 53 publications in international peer-review journals to their credit. Figure 4.2 shows that most (32.5%) were of Lecturer 1 cadre.

More than four-fifths (85%) of participants had been involved in multi-institutional collaborative research projects with other researchers either within or outside Nigeria (Figure 4.3) and about three-quarters (72.5%) had shared their samples or data in the process (Figure 4.4). Less than half of the participants (42.5%) have had at least a formal training in research ethics (Figure 4.5) and only about one-fifths (22.5%) adjudged themselves as having adequate knowledge of the ethical, legal and social implications of samples and data sharing in research (Figure 4.6).

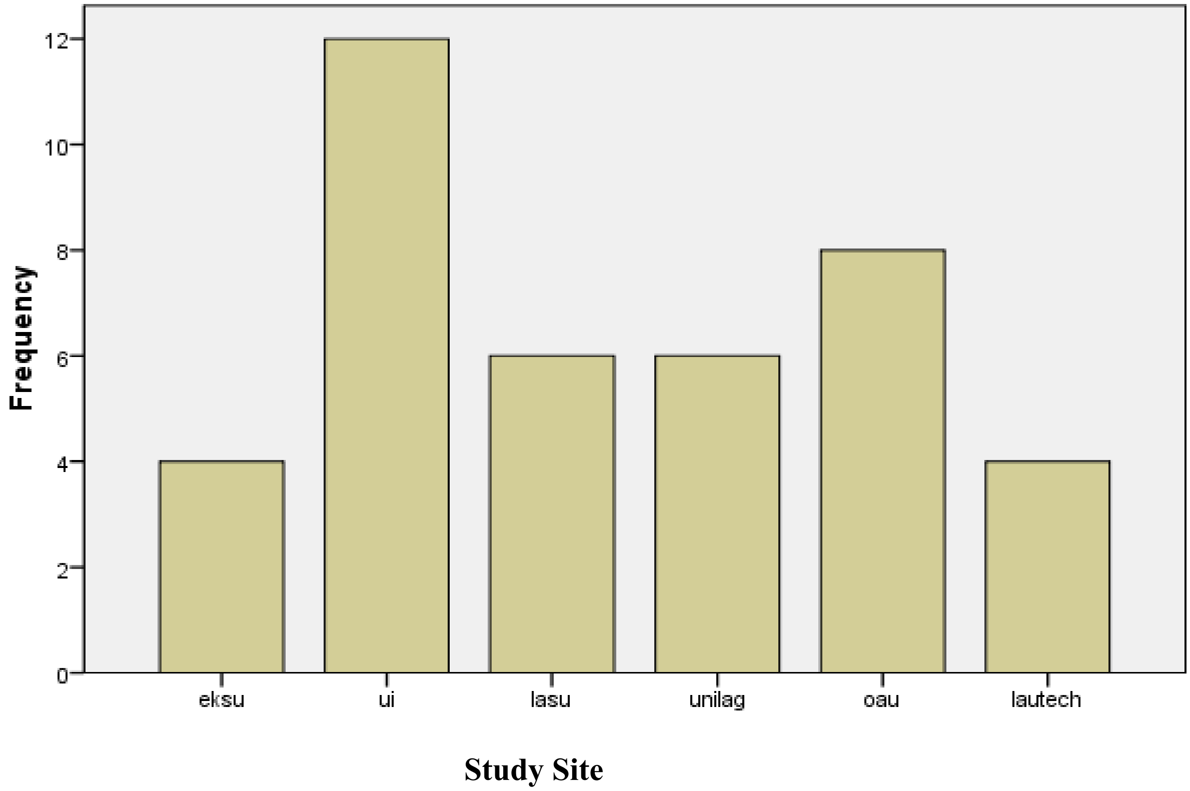
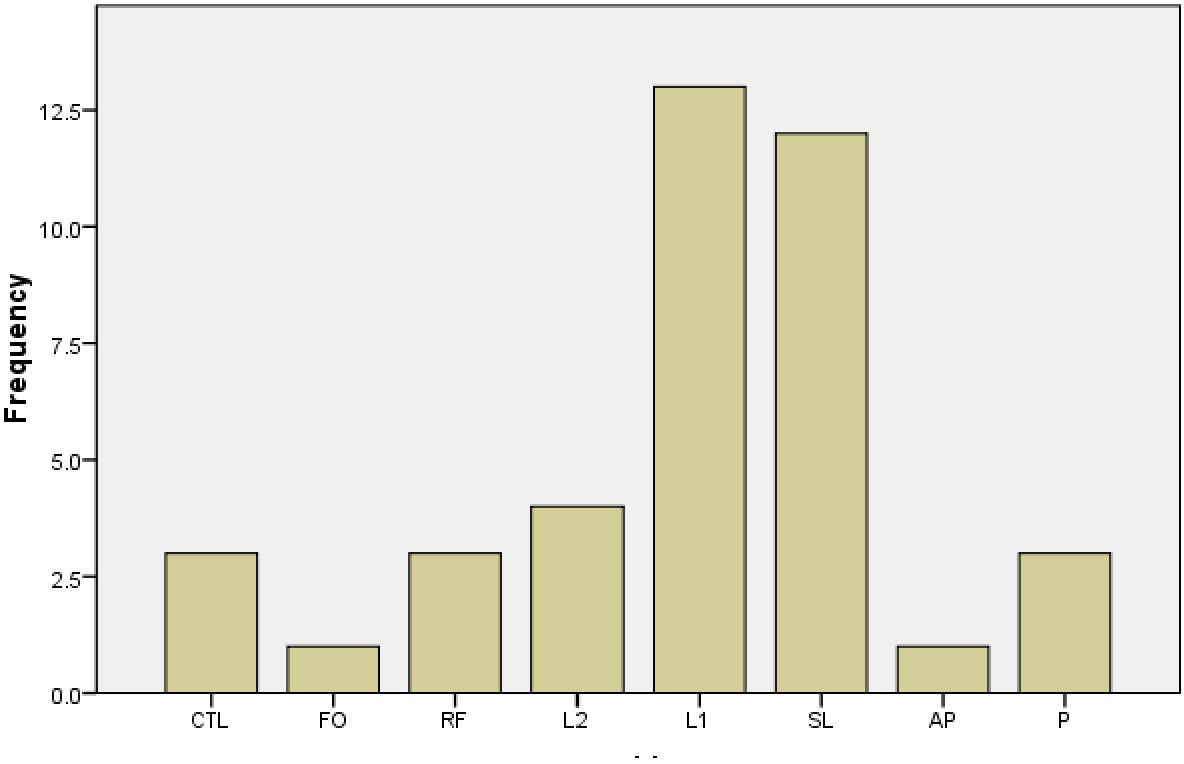


Figure 4.2: Pattern of distribution of respondents at the study sites

Legend:

EKSU: Ekiti State University
UI: University of Ibadan
LASU: Lagos State University
UNILAG: University of Lagos
OAU: Obafemi Awolowo University
LAUTECH: Ladoke Akintola University of Technology



Job Cadre

Figure 4.2 : Job cadres of respondents

Legend:

CTL: Chief Technologist/Chief Laboratory Scientist
FO: Field Officer
RF: Research Fellow
L2: Lecturer 2
L1: Lecturer 1
SL: Senior Lecturer
AP: Associate Professor
P: Professor

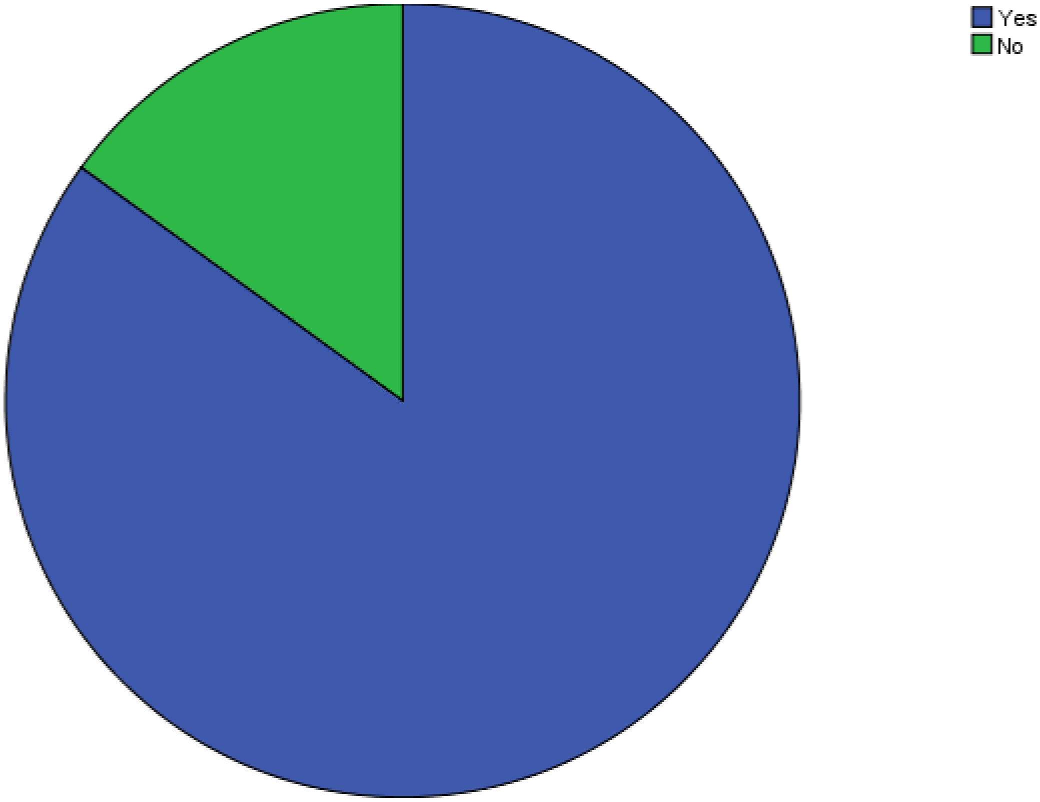


Figure 4.3: Previous/Ongoing Multi-institutional Collaboration with other researchers

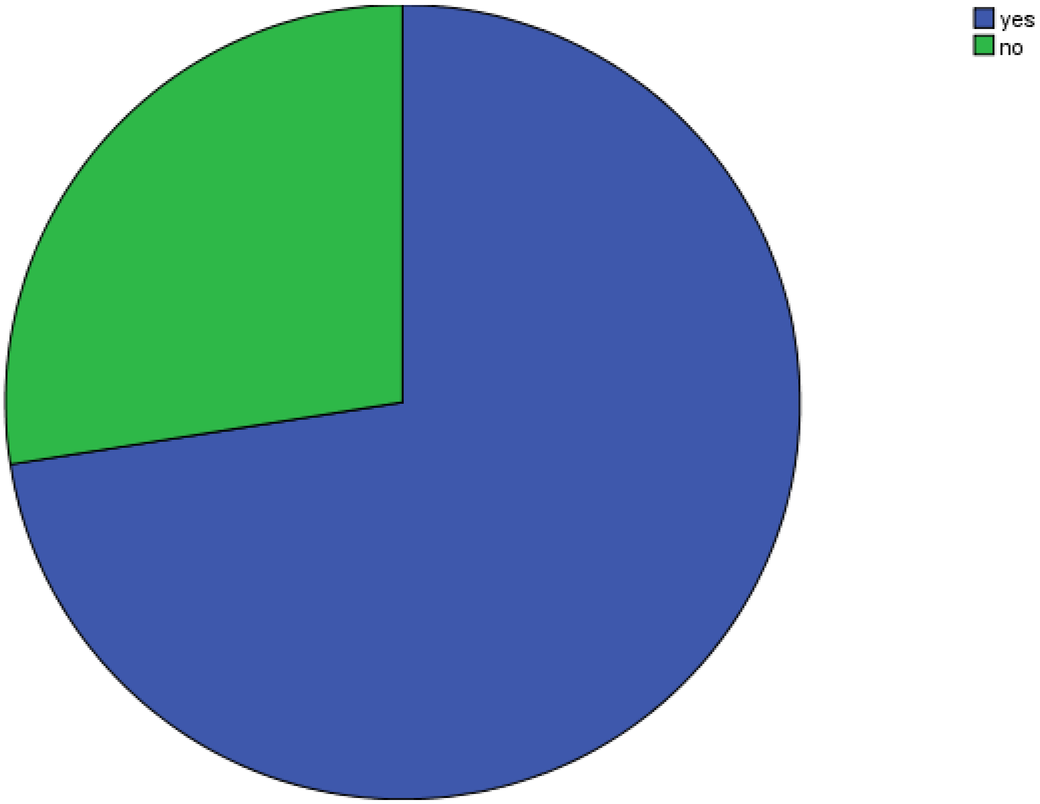


Figure 4.4: Previous or ongoing sharing experience

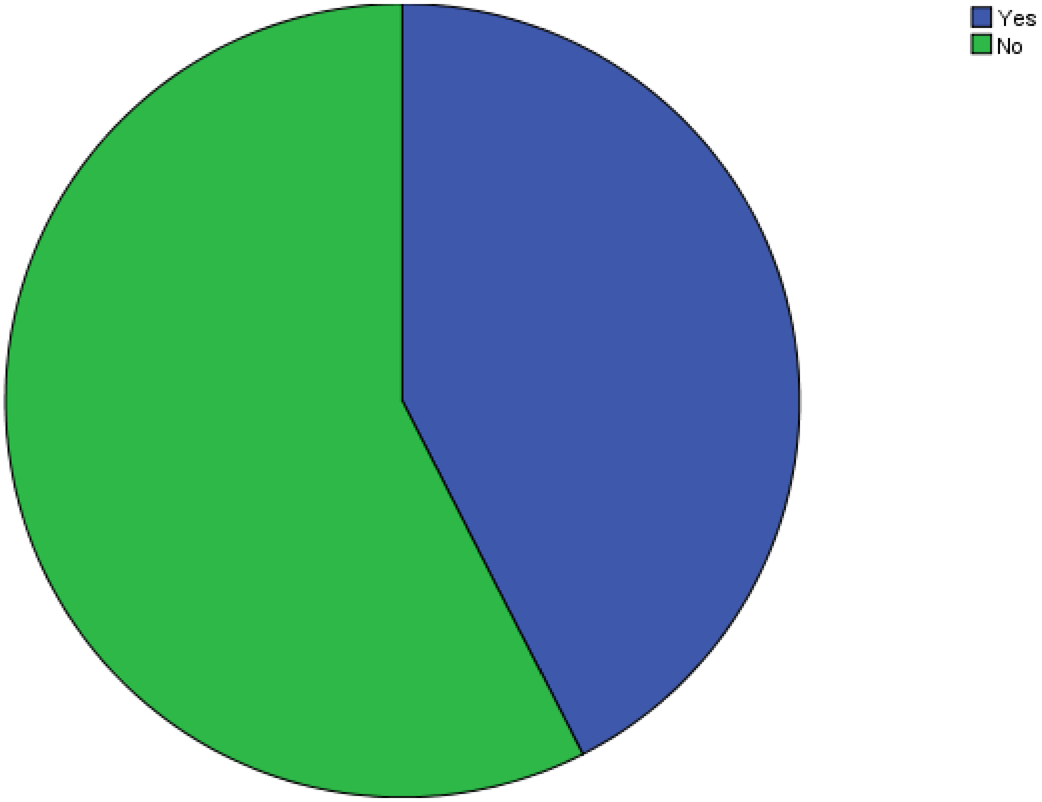


Figure 4.5: Formal training in Research Ethics

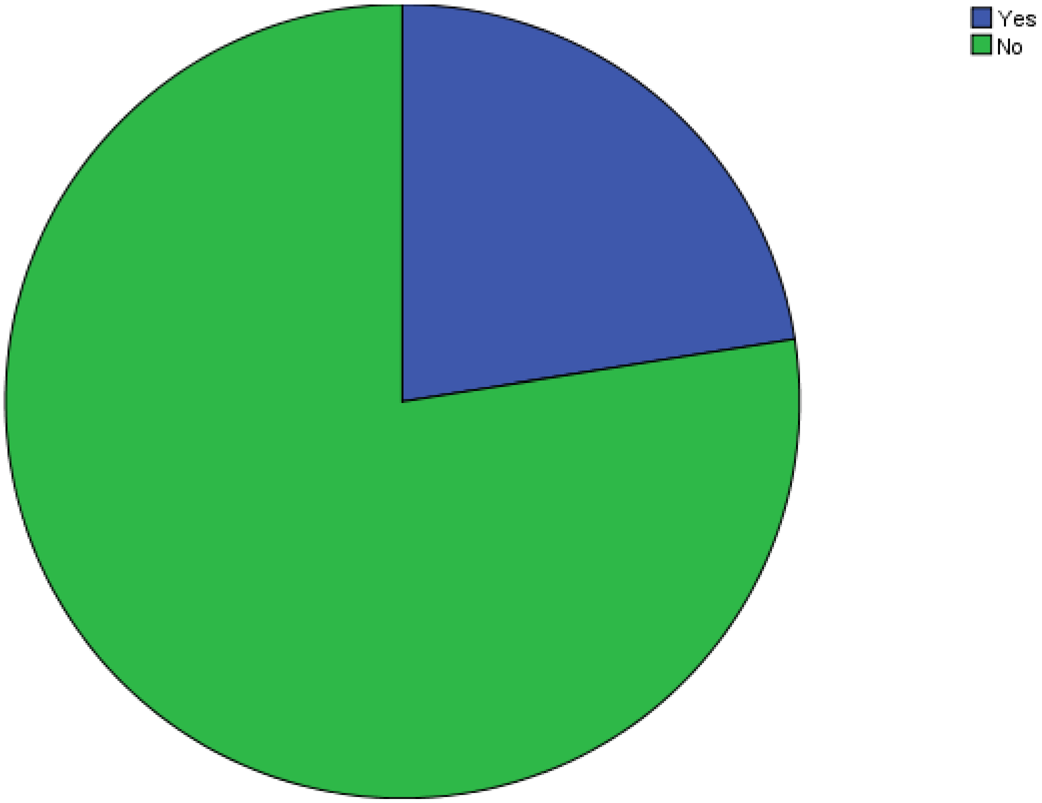


Figure 4.6: Adequacy of knowledge on implications of sharing in research

4.2 Perception on sharing Samples/Data

Respondents had varying views as regarding the concept of sharing research samples or data with other researchers. The views by various respondents were described as “good; okay; ethical; very important for genetic studies and bio-banking; basis for another person’s work and eye-opener”. A pathologist with previous experience of sharing both samples and data within and outside Nigeria noted:

> Sharing is okay if people involved are of repute (sic).

while a medical biochemist with 33 publications to his credit noted that:

> Sharing is good if only for collaboration, corporate interest and development.

However, another category of respondents had opposing views to it. This set of participants saw the act of sharing as being “unethical; bad; improper; not ideal; not appropriate or dangerous”. In fact, a research fellow at a research institute exclaimed:

> Sharing is dangerous especially if it is with a senior colleague. -- It’s very dangerous especially if the person… (is) a senior colleague. If a senior colleague should lay his or her hand on your data and anything happens, there’s no way you can... (unfinished sentence). There was a time I actually wrote a proposal and because of my level, I needed to use a senior person in the university as my PI and when the money eventually came, he bolted and there (was) no way…. I tried talking to friends. It’s like it’s not possible; this man could not have stolen from you. So, if I give my data out (to people I) … don’t know, to a senior colleague and anything happens, people will not.. (unfinished sentence) I don’t think they will find it very easy to believe me- that he has stolen. How can I say a professor has stolen from me? It’s going to look ridiculous.

A professor of Medicine said:

> Why will I share it? No o, no sharing. Sample sharing does not even arise under any condition, be it local or international even with my daughter or my colleagues. Sharing samples, sharing data or samples, how can it be done? It should not be done. No. No. You won’t get my research samples at all. You can get the publication which is open, and usually it is open.

Some respondents were not willing to share their samples or data in the future while some would share only if certain conditions are met. Some of these conditions are sharing with only members of the same research team; participants’ consent has been obtained; if there is refund of the cost of the research by the requesting individual/organization; the intent of exchange is reciprocity or to have journal publication fees waived. In fact, a researcher who also doubles as an anesthetist said:

> I cannot share my data with you without a mutual benefit. When you too have data and I know that you have a data that will benefit, willingly, you should be able to involve me.

Similarly, a female anatomist stated that:

> I believe that he who plays the piper dictates the tune. For this journal, I was going to be publishing free and knowing how much it costs to publish in open access journal, if the payment for that is sending data, then for me, it's a welcome development.

And another female research fellow said:

> So in sharing samples or data, I think there should be some ethical boundaries that are involved and especially… I don't really agree in sharing data with external bodies if they are not within a particular research team.

With regard to why researchers may not be willing to share their samples or data, some of the reasons given were concern about integrity of research partners and the tendency of some to hoard their data. A pediatrician noted:

> So, to me it helps research, it advances the general body of knowledge. So why will I hoard anything? It's just unfortunate. But Nigerians tend to hoard things but I don't know what they gain from it anyway.

Though only four respondents were aware of material transfer agreements, all respondents vehemently opposed the formulation of any policy mandating them to share their samples or data. The reasons adduced ranged from the right to do whatever researchers want to do with their samples or data to the fact that many research projects are self-sponsored. However, while a biochemist was willing to share the samples/data obtained in a sponsored research with the sponsors, a female anatomist insisted that she would prefer not to be sponsored at all if she would have to share the samples/data obtained. In response to views on whether sharing samples/data should become mandatory in the research community, a research fellow said:

> That will have to be for a particular reason or an important reason would have to be stated before you can mandate researchers to share their data. I really don't think there is anywhere globally that you have to mandate researchers to share their data. There has to be a very important reason.
> So I don't think that it's something that researchers or academics will not contest if they are mandated to share their data. I think that that is going to create a lot of confusion in research area especially in publications. You will have a lot of reinventing of wheel, you will have a lot of false publishing. That's going to create a major problem such as misuse of your data. I wouldn't support that it should be mandatory for researchers to share their data.

A female anatomist said:

> If data sharing is made mandatory, then I would like to ask- "Why would I spend my money to do a research and be mandated to share my data? Because it is still your brain child. My research is my child. If parents are not allowed to share my children, why should I?

And a pediatrician stated:

> I don't think it should be made mandatory because it's my research. I think I should have some level of control. If you make it mandatory, that means you are forcing me to do something, and I don't believe in it. So that is why I don't believe it should be mandatory.

Respondents were of the opinion that samples or data with any form of identifier or without express permission of the research subjects to share should not be shared. In addition, samples that are obtained in the course of new drug discovery, highly contagious samples that can be tools of bioterrorism; samples whose biosafety had been compromised or samples obtained in the context of national medical disasters should not be shared.

4.3 Potential Benefits, Harms and Challenges of sharing Samples and Data

The potential benefits of sharing samples and data highlighted by respondents were numerous. This include increase in the number of publications/research output from Nigerian institutions; increased knowledge; greater possibility of publishing in high-impact journals; networking; better exposure of researchers to international standards; better analyses of research findings; career progression; sponsorship to conferences; capacity building; future collaboration; having larger/robust study samples; higher study power, promotion of openness in research; new discovery; and higher probability of obtaining grants for future researches.

The potential harms of sharing samples and data among researchers highlighted were dishonesty; fraud; the other partner publishing without the knowledge of the sharer (primary researcher); plagiarism; exclusion from authorship; being given a disagreeable authorship position; data theft; data alteration; breach of confidentiality/trust; non-acknowledgement; data misuse; exploitation; discrimination against research community; data fabrication; data cloning and loss of data ownership. For samples, potential harms suggested were inappropriate use of samples; inappropriate disposal of samples and transfer of diseases across countries.

Potential challenges Nigerian researchers may encounter despite the existence of regulations governing samples and data sharing highlighted were poor power supply; logistic problems; financial constraints in preparing samples or data for sharing; weak legal system; weak monitoring system to ensure partners comply with agreed terms; weak implementation of the sharing protocol; poor adherence to sharing protocol; dishonesty of claiming not to have data; researchers unwillingness to part with their samples or data; poor samples/data storage; poor data decoding; disparity of software use among sharing parties; multiple software use in Nigeria; self-funding of research and confusion as regards who bears the financial burden of sharing.

4.4 Adequate compensation for sharing Samples and Data

There were various opinions as regards what respondents considered adequate compensation for sharing their samples or data with other researchers. This ranged from authorship in the publications (2nd authorship position more favoured); refund of the cost of conducting the research; capacity development; training; provision/donation of research equipment; money; holiday trip abroad and reciprocal sharing. However, four of the respondents insisted that acknowledgement alone suffices and there was no need for their colleague to compensate them in any way. A male professor of medicine said:

> I don’t think I can be compensated for all I have gone through.

while a male research fellow said:

> Compensations, I don't think we need that. These are things that project us… that seems we are too local in Africa. If you believe in knowledge, that knowledge must increase.

However, all the respondents were of the opinion that collaborators in samples or data sharing should not be treated differently as "research is research everywhere" i.e research is universal. The respondents do not also have different expectations from sharing with researchers based in developed countries like the US, UK or developing countries like China or Nigeria.

4.5 Perceived ownership of shared Samples/Data

Respondents were divided as regards who they think owns samples or data shared with their fellow researchers. As regards samples; some believed the research subjects still owns the shared samples after sharing while others believed that the primary researcher who collected the samples own it. Another set of respondents believe that once sample is shared, the recipient now owns the shared samples. With regards to shared data, the interviewees were of the opinion that the primary researcher only; secondary researcher only or both jointly own the data.

4.6 Suggestions on the development and components of Samples/Data sharing policy

Respondents are of the views that some processes should be implemented before samples/data sharing takes place. These are:

vii. Full involvement of institutional ethics committees and the National Health Research Ethics Committee, both of which must give approval before the sharing can take place.

viii. A protocol addressing important issues must be issued by both stakeholders' IRB and filled by the stakeholders. Such issues should include personal details of stakeholders; mode and evidence of invitation to share; purpose of sharing; demonstration of willingness to share; agreement to share; acknowledgement by recipient; description of potential uses, duration and venue of use of what is being shared. Other important aspects that should be addressed in the policy are the means of sharing; destination of the material shared; cost of the sharing and expected contributions of stakeholders. In addition, most respondents stressed that primary researcher should also submit a copy of the informed consent form filled by research participants which shows agreement with sample sharing.

ix. Existence of a national sample bank or database to which all researchers must submit their research data or samples before sharing.

x. Formal notification of the institutions of both stakeholders involved in the sharing.

xi. Ensuring a written agreement exists between stakeholders intending to share. This document must provide these information as well: names, designation and caliber of intending stakeholders; restrictions on the use of samples/data (e.g. non-access to third party); attestation to the terms stipulated while also highlighting the legal and non-legal implications of non-adherence. In fact, to further guarantee that stakeholders comply to the agreed terms, one of the respondents suggested traditional oath-taking:

> …..the partners could also take oath together both in the law and out of law. The Yoruba has another way of substantiating the oath with a vow (*won mule*) as part of the agreement.

xii. Full involvement of the legal system in the development of a national policy guiding sharing of research samples or data.

xiii. Most researchers were of the opinion that guideline addressing samples and data sharing should be written under different sections of the policy as they are entirely different things. Respondents generally believed that samples could be easily manipulated and even to a greater extent than data and so many found it easier to share their samples. A male research fellow who believes that samples are more sensitive and he exclaimed:

> My sample is my life I can be traced with it. My data is just ordinary figure, I can disown it, I can't disown my samples. You use DNA to trace me and you get me, it's my life. It's different from... If I tell you my age is 30 and you get to ask my wife and my wife says I'm 47. I will say I'm not the one that told you. This is my age. I can't deny my samples if you've taken my blood, it's me. If you are taking any other thing from me….If you take my hair, it's me, you can trace me to it.

- The policy should also highlight the fact that intending stakeholders should have a roundtable discussion on pertinent issues such as authorship; formula for sharing the cost of sharing; what happens in cases of loss or liability; penalties to defaulting partners; potential benefits to the research community and definition of ownership of the samples or data shared.

CHAPTER FIVE
DISCUSSION

5.1 Perception on sharing Samples/Data

The view of respondents as regards the importance of samples/data sharing is in line with what other researchers in developed countries have noted (Asslaber and Zatloukal, 2007; Kuntz, 2013; Hate et al., 2015). This highlights the fact that the recent efforts of creating awareness on research ethics in Nigeria (Ogunrin et al., 2013) is recording some success. Just as the respondents noted, ensuring anonymity (such as removing identifiers) before "sharing" is in tandem with international best practices. However, studies have shown that that this in itself cannot guarantee 100% privacy of the research participants (Marzluff et al., 2013). Scientists are now considering data encryption and differential privacy as better measures (Erlich and Narayanan, 2014). However, some experts are of a different opinion as they believed that some links with the research participant should still be maintained for the purpose of contacting in the event of a new discovery that may ultimately benefit them (O'Brien, 2009). Either way, both views are relevant but confidentiality of information should not be compromised in any way.

Though some of the respondents insisted that they had the right to share or not to share their samples/data, some experts are of the view that the interest of the public good might supersede in some situations (Vayena and Gasser, 2016). Contrary to the views of some respondents, some scientists believe that data obtained in national emergencies needs to be shared and even quickly in order to get prompt answers/scientific solutions in such situations (Vallance et al., 2016). This, is also the World Health Organisation's stance on the issue (Boulton et al., 2012). A relevant example is the case of the recent outbreak of Lassa Fever in Nigeria in which samples and data had to be shared for the purpose of developing vaccines (Folayan et al., 2015)..

It was not surprising that the respondents in this study were not willing to share their research samples or data with other researchers outside their research group as similar views were also noted by professionals at a US cancer biobank (Pereira, 2013) as well as attendees of a WHO-led stakeholders meeting in Geneva. The major fear of the latter researchers was the possibility of their data being published behind them and even without recognition (Vallance et al., 2016).

5.2 Potential Benefits, Harms and Challenges of sharing Samples and Data

As highlighted in most literatures, the respondents in this study also pointed out similar benefits of sharing samples or data in research: critical roles in treatment discovery (Asslaber and Zatloukal, 2007), study of rare diseases (Mascalzoni et al., 2015); enhancement of the power of such studies (Kosseim et al., 2014) as well as increased research publications (Pienta et al., 2010). In other words, the concept of sharing samples/data in research has numerous advantages to the individual participants, research community, primary researcher, secondary researcher as well as the research community in general.

The major fears expressed by the respondents in this study were not at variance with those of other researchers outside Nigeria (Vayena and Gasser, 2016). These potential harms centers around trust (publishing without the knowledge of primary researcher; samples/data theft) and research misconduct (breach of confidentiality/privacy; social discrimination; plagiarism; falsification and fabrication of samples/data) which have been identified as pandemic problems among researchers (Whitbeck, 1995; Okonta and Rossouw, 2014).

The impediments to successful sharing posed by the obstacles of logistics, intellectual and financial origin feared by these respondents have also been documented in existing literature (Mascalzoni et al., 2015). This can be explained by the meagre resources available for conducting research in developing nations (Okpe, 2013).

5.3 Adequate compensation for sharing Samples and Data

The International Committee of Medical Journal Editors have highlighted the need to give adequate credit to sample/data generators (Taichman et al., 2016).

In a survey of 1564 academic researchers in Germany (Fecher et al., 2015), it was found out that about four-fifths of the respondents noted data citation and about one-thirds, co-authorship as being adequate compensation for sharing their samples or data with other researchers. Same observation was noted in a study conducted among researchers in developing and developed nations (Zhang et al., 2010). However, most respondents in this study favoured co-authorship as satisfying in exchange for sharing their research samples/data. The research output from Nigeria has been described as low (Okpe, 2013; Usang et al., 2007) and these researchers may perceive co-authorship in exchange for sharing as an avenue to increase the number of their publications (Pienta et al, 2010) which is necessary for their career progression. Also, similar to the comparative study, only a small number of the respondents view financial support as a means of compensating for their time and efforts. A larger percentage having dissenting opinion may be explained by individual moral/religious beliefs (Kim and Stanton, 2015).

5.4 Perceived ownership of shared Samples/Data

The Council on Health Research for development in its third guidance note highlighted the need for stakeholders in sharing to discuss the issue of ownership of the material shared (Council on Health Research for Development). However, this subject had been a controversial one in the field of samples/data sharing in research (Alta Charo, 2006).

Despite the consultation led by WHO in 2015 in which it drove home the point that sample shared belongs ultimately to the research participants from whom it was collected (Modjarrad et al., 2016), some of the respondents in this study still adopted contrary views. These researchers may have been of the opinion that they are in total control of the research they are conducting because they have forgotten that the samples are obtained from humans who are also autonomous agents (NIH Office of Extramural Research, 2016). This attitude may not be unconnected with the paternalistic view of researchers that is still quite prevalent in developing worlds like Nigeria (Adeleye and Adebamowo, 2012; Okonta and Rossouw, 2014).

5.5 Suggestions on the development and components of Samples/Data sharing policy

Though most respondents in this study were in favour of legal input in the development of a samples/data sharing policy, studies have also noted that understanding the material or data transfer agreements drawn by these experts even in developed countries may be challenging (Mascalzoni et al., 2015).

Total description of the samples and data to be shared as well as ensuring optimal biosafety precautions as noted by respondents in this study is in line with international best practices (WHO, 2006).

The various suggestions on the components of the policy are identical with what exists in some guidelines in developed societies. For instance, the Colorado Clinical and Translational Sciences Institute and Rocky Mountain Prevention Translation Center (Jarquin, 2012) highlight the documentation/formalization of agreement and regular meetings among stakeholders in the sharing process. In addition, the document from the Information and Privacy Commissioner in Ontario, Canada (Wright, 1995) emphasizes that the issues of ownership, storage, access of the samples/data shared must be clearly specified in the document.

Various authors have emphasized the full involvement of the institutional review boards of stakeholders' institutions in the sharing process (Goldenberg et al., 2015; Lemke et al., 2012). Same views were held by the respondents in this study and this may stem from the concern to ensure optimal ethical standards in the whole sharing process which is one of the key roles of the review boards (Cornell University Office of Research Integrity and Assurance, 2014).

5.6 Limitations of the study

The limitations of this work are:

i. Only biomedical researchers were interviewed. There are other researchers various fields in a university.

ii. Private-owned institutions were not included in the study sites. There are biomedical and non-biomedical researchers in these private-owned institutions too.

iii. This study was limited to the south-western part of Nigeria only. There are various academic institutions in the other geo-political zones in the country.

However, these shortcomings do not undermine the validity of the findings of this work, which has provided useful insights on the perspectives of Nigerian researchers as regards the sharing of samples and data.

CHAPTER SIX

CONCLUSION AND RECOMMENDATIONS

6.1 CONCLUSION

Researchers from some government-owned universities in South-Western Nigeria have varied views as regards the concept of samples and data sharing ranging from legal, illegal, ethical to unethical. Respondents also advocated that samples and data obtained in the context of national medical disaster, of compromised biosafety/biosecurity or with potential risk of bioterrorism should not be shared. Increase in publications, increased knowledge, networking, career progression was the benefits while dishonesty, fraud, plagiarism and theft were the potential harms of sharing identified. However, possible challenges that may impede full acceptance of the concept among researchers in Nigeria were logistics problems, financial constraints, weak legal system as well as weak monitoring system. Suggestions on satisfactory compensation for sharing ranged from monetary rewards to acknowledgement, second authorship and capacity development. Submission of samples/data to a national sample bank/database before sharing, full involvement of stakeholders' institutional review boards, legal input and development of a national policy on samples/data sharing were opinions on enhancing the successful inculcation of the concept among Nigeria's academia.

6.2 Recommendations

I recommend that:

i. The Institutional review boards and the National Health Research Ethics Committee should continue to educate researchers in Nigeria on the concept of samples and data sharing.

ii. The National Health Research Ethics Committee should also initiate efforts to collaborate with relevant sister agencies towards the creation of a national sample bank and database in Nigeria. These agencies may include the National Institute of Medical Research as well as the National Agency for Food Drug Administration and Control.

iii. The National Health Research Committee should also ensure adequate representativeness of all biomedical research disciplines as well as legal experts when saddled with the responsibility of developing a national guideline on sharing samples and data.

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APPENDICES

KEY INFORMANT INTERVIEW GUIDE

(For researchers who HAVE shared samples or data in the past)

1. Participant's identification tag: P….
2. Interview site:
3. Date:
4. Interview starts:
5. Age:
6. Gender:
7. Position:
8. Highest academic qualification attained and year:
9. Total number of years in research career:
10. Total number of papers published in verifiable international peer reviewed journals since career began till date:
11. Have you ever been involved in multi institutional collaborative research projects with other researchers in Nigeria? Yes No
12. Have you ever been involved in international collaborative research projects with other researchers outside Nigeria? Yes No
13. Have you ever shared samples with another researcher within Nigeria? Yes No
14. Have you ever shared samples with international researcher(s)? Yes No
15. Have you ever shared data with another researcher within Nigeria? Yes No
16. Have you ever shared data with international researcher(s)? Yes No
17. Have you ever received formal training in research ethics? Yes No
18. If yes, what training did you receive

    a. CITI online b. TRREE c. Onsite training d. others, ………… please specify

    When did you receive training in research ethics? …… years ago
19. Do you think you have adequate knowledge about the ethical, legal and social implications of samples sharing? Yes No

If yes, please mention what you know

……………………………………………………………………………………

AND how you came to know about it

……………………………………………………………………………………

20. Do you think you have adequate knowledge about the ethical, legal and social implications of data sharing? Yes No

    If yes, please mention what you know

    ……………………………………………………………………………………

    AND how you came to know about it

    ………………………………………………………………………………………

    …

21. Who do you think should educate Nigerian researchers about sample and data sharing?

    ……………………………………………………………………………………

    And why?

    ....

Questions

A. Samples/ Data Sharing

1. What are your views about sharing your research samples/data with another researcher?

   Prompts: Right? Wrong? Ethical? Unethical? Compulsory? Optional?

2. Can you please describe the events that led to sharing your research samples/data with another researcher?

   Prompts: Invitation to share? Willingness to share? Agreement? It was a condition for participating in the research by the collaborators? By the funders? Government?

3. Can you please describe the various researchers and organizations you shared research samples/data with?

   Prompts: Domiciled in Nigeria? America? Britain? South Africa? China?

4. Can you please elaborate on the actual process of sharing your research samples/data with another researcher?

   Prompts: Procedure? Shared part or all? Exact feelings when sharing? Regrets?

5. Can you describe your experience after sharing your research samples/data with another researcher?

   Prompts: Acknowledgement? Appreciation? Were you satisfied with the arrangements made with regard samples/data sharing in your experience? Compensation?
6. How do you feel about an "agreement" on samples/data sharing?

   Prompts: Best time? Initiated by who? Parties? Content? Enforced by who? Terms? Penalty for researcher in Nigeria, from another developing country, UK, US, SA, China who defaults from the agreement? Ownership? Compensation?
7. What mechanisms can be put in place to ensure that samples/data user use the samples/data **only for the exact purpose** for which it was shared?
8. What can you say about Nigeria's policy on samples/data sharing?

   Prompts: Awareness? Content? Areas an ideal and comprehensive national policy on samples/data sharing should address? Difference in terms of policy based on who the recipient is and where domiciled- in Nigeria, another developing country? UK, US, SA, China?
9. Can you tell me more about the gains of sharing your research samples/data with another researcher?

   Prompts: To yourself; institution; research participants; research community; Nigeria?
10. Did you have any regret for sharing your research samples/data with another researcher?

    Prompts: To yourself; institution; *research participants; research community; Nigeria?*
11. If you have another chance at sharing your samples/data, would you consider sharing again?

    Yes No

    AND why?

    ....
12. If it becomes mandatory to share samples/data with other researchers, what challenges do you think this will pose to the researchers in Nigeria?
13. Please tell me your views on whether there should be restrictions on the samples/data that can be shared and your reasons?

    Prompts: What restrictions? *Justification? Prerequisites to be met before sharing?*

14. Is there any other additional information you want to give me concerning samples/data sharing among researchers?

B. Sharing samples and Sharing data

1. Do you think that sharing samples is different from sharing data with other researchers? *Prompts: Reasons? In what ways?*
2. Biological samples are finite and difficult to reproduce while data can be easily reproduced. Knowing this, would you still be willing to share your samples with another researcher at another time? Does this information influence your decision to share samples?
3. When you share samples, it is gone and you cannot have those samples back. Knowing this, would you still be willing to share your samples with another researcher at another time? Does this information influence your decision to share samples?
4. Assuming you share your research samples in a future research project, who do you think owns the samples that you have shared?
5. When you share your research data, you still have a copy of the data in your custody. Does this information influence your decision to share data?
6. Assuming you share your research data in a future research project, who do you think owns the data you have shared?
7. Because of the points mentioned above, should policies on samples and data sharing be developed entirely separately OR as a single document in which what binds samples sharing also applies to data sharing?

We have come to the end of this interview. Thank you for participating.

Interview ends at ……………

KEY INFORMANT INTERVIEW GUIDE

(For researchers who HAVE NOT shared samples or data in the past)

1. Participant’s identification tag: P….
2. Interview site:
3. Date:
4. Interview starts:
5. Age:
6. Gender:
7. Position:
8. Highest academic qualification attained and year:
9. Total number of years in research career:
10. Total number of papers published in verifiable international peer reviewed journals since career began till date:
11. Have you ever been involved in multi institutional collaborative research projects with other researchers in Nigeria? Yes No
12. Have you ever been involved in international collaborative research projects with other researchers outside Nigeria? Yes No
13. Have you ever shared samples with another researcher within Nigeria? Yes No
14. Have you ever shared samples with international researcher(s)? Yes No
15. Have you ever shared data with another researcher within Nigeria? Yes No
16. Have you ever shared data with international researcher(s)? Yes No
17. Have you ever received formal training in research ethics? Yes No
18. If yes, what training did you receive

    a. CITI online b. TRREE c. Onsite training d. others, …………please specify

    When did you receive training in research ethics? …… years ago
19. Do you think you have adequate knowledge about the ethical, legal and social implications of samples sharing? Yes No

    If yes, please mention what you know

    ……………………………………………………………………………………

    AND how you came to know about it

    ……………………………………………………………………………………

20. Do you think you have adequate knowledge about the ethical, legal and social implications of data sharing? Yes No

    If yes, please mention what you know

    ……………………………………………………………………………………

    AND how you came to know about it

    ………………………………………………………………………………………

    …

21. Who do you think should educate Nigerian researchers about samples and data sharing?

    ……………………………………………………………………………………

    And why?

    ....

Questions

A. Samples/Data Sharing

1. What are your views about sharing your research samples/data with another researcher?

   Prompts: Right? Wrong? Ethical? Unethical? Compulsory? Optional?

2. If sharing samples/data is made mandatory in the research community, describe the process you think it should entail

   Prompts: Invitation? Willingness? Acknowledgement? Agreement? Compensation? Ownership? Sharing part or all?

3. Can you please describe the various researchers and organizations you would not mind to share your research samples/data with and why?

   Prompts: Locations of the researchers-Nigeria, Another developing country, US, UK, SA, China? Kinds of the organizations?

4. What are your opinions on what the recipient of the samples/data should do immediately after receiving shared samples/data?

   Prompts: Acknowledgement? Appreciation? Compensation?

5. As a researcher what would you regard as being "adequate" compensation for sharing your samples/data with another researcher? Factors you may consider in arriving at this decision?

   Prompts: Money-One time payment or yearly? Duration, if yearly? Authorship? Sponsored travelling to have a discussion with the researcher with whom samples will be shared or the representative?

6. How do you feel about an “agreement” on samples/data sharing?

   Prompts: Best time? Initiated by who? Parties? Content? Enforced by who? Terms? Penalty for researcher in Nigeria, from another developing country, UK, US, SA, China who defaults from the agreement? Ownership? Compensation?
7. What mechanisms can be put in place to ensure that samples/data user use the samples/data **only for the exact purpose** for which it was shared?
8. What can you say about Nigeria’s policy on samples/data sharing?

   Prompts: Awareness? Content? Areas an ideal and comprehensive national policy on samples/data sharing should address? Difference in terms of policy based on who the recipient is and where domiciled- in Nigeria, another developing country? UK, US, SA, China?
9. What would you regard as potential gains of sharing your research samples/data with another researcher?

   Prompts: To yourself; institution; research participants; research community; Nigeria?

   To recipient; recipient’s institution; other researchers in recipient’s community; recipient’s country
10. What will you describe as potential harms of sharing your research samples/data with another researcher?

    Prompts: Harms to yourself; your institution; your research participants; your research community; other local researchers; Nigeria?

    Harms to recipient; recipient’s institution; other researchers in recipient’s community; recipient’s country
11. If it becomes mandatory to share samples/data with other researchers, what challenges do you think this will pose to the researchers in Nigeria?
12. Please tell me your views on whether there should be restrictions on the samples/data that can be shared and your reasons?

    Prompts: What restrictions? *Justification? Prerequisites to be met before sharing?*
13. Is there any other additional information you want to give me on samples/data sharing among researchers?

B. Sharing samples and Sharing data

1. Do you think that sharing samples is different from sharing data with other researchers? *Prompts: Reasons? In what ways?*
2. Biological samples are finite and difficult to reproduce while data can be easily reproduced. Knowing this, would you still be willing to share your samples with another researcher at another time? Does this information influence your decision to share samples?
3. When you share samples, it is gone and you cannot have those samples back. Knowing this, would you still be willing to share your samples with another researcher at another time? Does this information influence your decision to share samples?
4. Assuming you share your research samples in a future research project, who do you think owns the samples that you have shared?
5. When you share your research data, you still have a copy of the data in your custody. Does this information influence your decision to share data?
6. Assuming you share your research data in a future research project, who do you think owns the data you have shared?
7. Because of the points mentioned above, should policies on samples and data sharing be developed entirely separately OR as a single document in which what binds samples sharing also applies to data sharing?

We have come to the end of this interview. Thank you for participating.

Interview ends at ……………

INFORMED CONSENT FORM

IRB Research approval number: ####

This approval will elapse on: dd/mm/yyyy

Title of the research: Perspectives of researchers in Nigeria on samples and data sharing

Name(s) and affiliation(s) of researcher(s) of applicant(s):

This study is being conducted by Dr Omokehinde Olubunmi Fakorede of the Department of Surgery, University of Ibadan.

Sponsor(s) of research:

West African Bioethics Training Programme

Purpose(s) of research:

As part of the requirements for the award of the masters' degree in Bioethics at the University of Ibadan, I will be conducting key informant interviews to ascertain the perspectives of researchers in Nigeria on samples and data sharing.The purpose of this research is to assess the perspectives of researchers in Nigeria on samples and data sharing.

Procedure of the research, what shall be required of each participant and approximate total number of participants that would be involved in the research:

A total of 46 participants will be recruited into the study. Each participant will be interviewed with questions that bother on their views about samples and data sharing among researchers. The interviews will be conducted at the participant's office.

Expected duration of research and of participant(s)' involvement:

Each participant would be interviewed once and the duration of an interview would not exceed an hour

Costs to the participants, if any, of joining the research:

I will be taking some of your time out of your busy schedule to participate in this interview **Benefit(s):**

Participating in this research is an opportunity for you to represent many researchers in Nigeria by providing an objective assessment of their perspectives on the subject matter. Findings from this research will also aid in the development of policies and regulations that may help protect the Nigerian researcher in situations that mandate him to share research samples or data.

Confidentiality:

All information collected in this study will be kept only in the custody of the researcher and no name will be recorded. This cannot be linked to you in anyway and your name or any identifier will not be used in any publication or reports from this study. As part of my responsibility to conduct this research properly, officials from West African Bioethics

Training Programme and National Health Research Ethics Committee may have access to these records.

Voluntariness:

Your participation in this research is entirely voluntary.

Alternatives to participation:

If you choose not to participate, this will not affect your person, job or career in any way.

Due inducement(s):

As a token to appreciate your participation; I will be giving you two blue ink pens but you will not be paid any fees for participating in this research.

Consequences of participants' decision to withdraw from research and procedure for orderly termination of participation:

You can also choose to withdraw from the research at anytime. Please note that some of the information that has been obtained about you before you chose to withdraw may have been modified or used in reports and publications. These cannot be removed anymore. However, the researcher promise to make effort in good faith to comply with your wishes as much as is practicable.

What happens to research participants and communities when the research is over:

The researcher will inform you of the outcome of the research by giving you the details of the article when the result of the research is published.

Any apparent or potential conflict of interest: None.

Statement of person obtaining informed consent:

I have fully explained this research to ____________________________________ and have given sufficient information, including about risks and benefits, to make an informed decision.

DATE: _____________________ SIGNATURE: ____________________________

NAME: ____

Statement of person giving consent:

I have read the description of the research and have had it translated into language I understand. I have also discussed with the researcher to my satisfaction. I understand that my participation is voluntary. I know enough about the purpose, methods, risks and benefits of the research study to judge that I want to take part in it. I understand that I may freely stop being part of this study at any time. I have received a copy of this consent form and additional information sheet to keep for myself.

DATE: ___________________ SIGNATURE: _________________________________
NAME: ____
WITNESS' SIGNATURE (if applicable): ___________________________
WITNESS' NAME (if applicable): ______________________________________

Detailed contact information including contact address, telephone, fax, e-mail and any other contact information of researcher(s), institutional HREC and head of the institution:

This research has been approved by the Ethics Committee of the University of Ibadan and the Chairman of this Committee can be contacted at Biode Building, Room 210, 2nd Floor, Institute for Advanced Medical Research and Training, College of Medicine, University of Ibadan, E-mail: **uiuchirc@yahoo.com** and **uiuchec@gmail.com**

In addition, if you have any question about your participation in this research, you can contact the principal investigator, Name: FAKOREDE Omokehinde Olubunmi
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PLEASE KEEP A COPY OF THE SIGNED INFORMED CONSENT.