



West African Bioethics

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United States' National Institute of Health

WAB-Newsletter

● VOLUME 5, ISSUE 1

● NOVEMBER 2010

A Newsletter of West African Bioethics Training Programme

A program for teaching, service and research
in modern international research ethics

SPECIAL

**Engaging Research Participants in
Effective Communication for Informed Decision
Making by Prof. A.S. Jegede** ⑧

**WAB Trainee Experience
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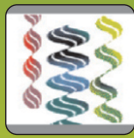


From The Director

What a trip! That is the best way I can describe the past 5 years. In our multifaceted approach to developing research ethics primarily in Nigeria and in the rest of West Africa, we have often wondered whether our goals were not altogether too ambitious! The trick to accomplishing what we have done to date is to find a group of rather excellent collaborators and put in place the infrastructure that empowers them to deliver. Then get out of their way! This is not original, a lot of successful administrators have shown that the best way to accomplish one's goals is to surround one's-self with excellent resource persons. So the praise and recognition for the work that has been accomplished by WAB over the past few years rightly belongs to our faculty members and staff who have succeeded beyond all expectations.

Nigerian academic culture frowns upon "blowing one's trumpet". This attitude is so deeply ingrained that even in academic writing, passive voice is pervasive and grade scores tend to be conservative. Students will readily agree with the latter! I believe that these attitudes have served the society well in past but they need to change. Folks need to own what they have accomplished. As a friend of mine once observed, "if you do not blow your trumpet, who will?" or to put it colloquially, "if you've done it; it ain't boasting!" So our faculty members working within the structure of the University of Ibadan have accomplished great things and I doff my hat to them.

In the last academic year, we adopted a new strategy of working with students on their projects. This method required more hands-on collaborative interaction between student and supervisor that engages with ongoing research projects so that the student's project is immediately relevant to ongoing scientific research projects. We were able to demonstrate that with this method, students can accomplish high quality research project within a reasonable period of time and complete their degree. The 2 students who were enrolled in the 2010 M.Sc. course pioneered this system – Mr. Michael Igbe (Public perspectives on biobanking in Nigeria) and Mr. Lawrence Fagbemi (Knowledge, attitude and practices of Nigerians towards genomics tests for Complex Diseases) – and they presented their research at the African Society of Human Genetics meeting in Cape Town, March 2011 with support from an Administrative supplement to our grant from the United States' Fogarty International Center (Grant Number 3R25TW007091-06S2) and the results were very well received with a lot of stimulating discussions. We hope that with this approach, we can finally lay the ghost of delayed completion of thesis projects to rest.



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From The Director

contd.

Finally, we are pleased that the West African Bioethics Training Program has been funded again by the United States National Institutes of Health's Fogarty International Center. This opens an opportunity for the next phase of development of research ethics in Nigeria and West Africa. There will be consolidation of the work done to date and new developments including increased focus of Research Misconduct and Research Integrity. More on that later.

WAB trainees for 2009/2010 M.Sc. Bioethics Program

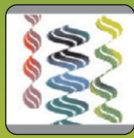
WAB gave full sponsorship to 2 students to train in Masters of Bioethics at the Department of Surgery University of Ibadan in the 2010 - 2011 academic year. The 2 students resumed on 1st February 2010 for their first semester and ended their first session in September 2010. They received full sponsorship from WAB for their training from generous funding by the United States National Institutes of Health/Fogarty International Center. Both students were drawn from the Nigerian Federal Ministry of Health in Abuja and they are:

- 1. Mr. Fagbemirolawrence Oluwasesan - Principal Pharmacist Food and Drug Service Department Federal Ministry of Health, Abuja.**
- 2. Mr Igbe Michael Adikpe – Senior Scientific Officer Department of Public Health Federal Ministry of Health Abuja.**

The students' sponsorship covered - tuition, laptop, books, accommodation and stipend. Upon completion of their course work the students proceeded to their project work and completed it and made presentations at a conference in South Africa.)



from left Mr. Fagbemirolawrence,
Mr. Igbe Michael



2009 WAB trainee's Experience

Name of Student Here

One Year Journey with West African Bioethics Programme. Background

I am one of the two students admitted for M.Sc. Bioethics programme in year 2009/2010 session. Lectures started on 1st February 2010 in a totally strange but interesting way. That was the smallest class I have ever been and more interestingly the first time to receive lecture in a lecturer's office. The programme ran in modules and each module lasted 3 weeks.

Mode of lecture delivery was through slides using interactive method most times. A typical day used to start with lectures between 9.00am - mid-day, after which there would be time for break, discussions and assignment. Some very few lectures however, held in the evenings. Each day usually have more than enough assignment to do before day break. Doing assignment was easy because the WABP provided a comfortable accommodation with electricity back-up. In addition, internet modem was made available and all required texts were provided.

The Most Valuable Textbook

The most valuable textbook to me during the programme was Principles of Biomedical Ethics by Beauchamp and Childress.

Most Favourite Lecture

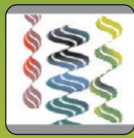
Qualitative Research Methods

Most Organized Lecture

Introduction to Philosophy for Bioethics.

Favourite Lecturers

All



2009 WAB trainee's Experience

Contd.

Accommodation

The accommodation was in Ashi, a serene part of Ibadan. It is a serviced apartment with all facilities necessary for valuable learning.

Usual Transportation Route

Taxi from Ologede busstop (close to the hostel) to Ojuurin and from Ojuurin to either University College Hospital (UCH) or University of Ibadan (UI) for lectures.

Challenge(s)

Difficulty in working on project after returning to my job.

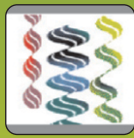
Weakness

Too compacted programme with little or no time for leisure/social interactions.

Recommendations

1. The duration of the programme should be extended to create about one month break between semesters and more time for each module.
2. Students should be encouraged to stay back and finish their projects before leaving Ibadan.
3. Time for seminars should be more regular.
4. Specifically reflect in the time table when students are expected to watch the ethics committee review sittings.





Focus on Faculty Member

Mrs. Oluwatoyin Akintola was awarded the African fellowship for Bioethics and Human rights for 2010/2011 session by the Georgetown University Center for Clinical Bioethics. We wish her success in all her endeavors.

WAB M.Sc. Bioethics Graduates

WAB M.Sc. Bioethics Graduates

Three M.Sc. Bioethics trainee completed their course work and project and received the award of Masters of Science in Bioethics from the University of Ibadan. in 2009/10 session.

These are the first set of graduates of the program since inception. The graduates are:

(1) Dr (Mrs.) Olayinka Eyelade is a Lecturer in Anaesthesia, University of Ibadan and Consultant Anesthetist at the University College Hospital Ibadan.

She joined the program in 2007/2008 session and finished in 2009/10 session. She did her research on Audit of Protocol submissions to the University of Ibadan/University College Hospital health Research ethics Committee (2002-2007).

(2) Dr Omokhoa Adeleye is a Lecturer in Public Health, University of Benin and Consultant Public Health Physician at the University of Benin Teaching Hospital. He joined the program in 2007/2008 session and graduated in 2009/2010 session. He did his research on Conduct of Ethical research: perceptions, barriers and motivators in health research institutions in Edo and Delta states of Nigeria

(3) Mr. Kodjo Kudadze is a Togolese who joined the program in 2008/2009 session and graduated in



From left to right is Dr. Adeleye, Dr. (Mrs.) Eyelade and Mr Kodjo



From WAB Faculty

Engaging Research Participants in Effective Communication for Informed Decision Making by Prof. A.S. Jegede

Introduction

Effective implementation of western-oriented bioethics principles in non-western cultures is a subject of debated. Morally, ethics demands that researchers do their work fulfilling Hippocrates' oath of 'do no harm' in which he said "I will use my treatment to help the sick according to my ability and judgment, but never with a view to injury and wrong-doing" [1]. Ever since the days of Hippocrates efforts have been to improve relationship with research participants. While the western perspective of individual autonomy has become dominant in the field scholars are now reappraising the applicability of its principles in the Africa setting for the following reasons:

- 1) The rapid growth of the discipline in Africa in recent years as attested to by the emergence of a number of new bioethics training centers across the continent justify the need to reappraise the bioethics principles if it will serve the need of the people.
- 2) Health research is gaining ground in developing countries including Africa for a) pressure is being mounted to redirect attention from using western countries as sites for drug trials [2] and b) second, there is emphasis on affordable, accessible and available health technology to improve population health in resource constrained countries
- 3) Participants' participation in research as autonomous individual in Africa needs critical consideration. This paper discusses informed consent as a major concern for research participation.

Need for informed consent

Scholars have argued that self "construals" are considered to influence, and in many cases determine, the very nature of individual experience [4

– 9]. In their work, Markus and Kitayama defined two construals as an independent view and an interdependent view [6]. This paper adopts the former to examine the role of informed consent in the new born screening.



Engaging Research Participants in Effective Communication for Informed Decision Making by Prof. A.S. Jegede **Contd.**

Introduction

Effective implementation of western-oriented bioethics principles in non-western cultures is a subject of debate. Morally, ethics demands that researchers do their work with sincere love according to Hippocrates' oath of 'do no harm'. To achieve this autonomous decision making has been identified as a key ingredient. While the western perspective of individual autonomy has become dominant in the field of bioethics scholars are now reappraising the applicability of its principles in the Africa setting due to the following reasons: 1) The rapid growth of the discipline in Africa in recent years as attested to by the emergence of a number of new bioethics training centers across the continent justify the need to reappraise the bioethics principles if it will serve the need of the people. 2) Health research is gaining ground in developing countries including Africa for a) pressure is being mounted to redirect attention from using western countries as sites for drug trials and b) there is emphasis on affordable, accessible and available health technology to improve population health in resource constrained countries. As a result, participants' participation in research as autonomous individual in Africa needs critical consideration due to process required for obtaining informed consent. Hence, this paper discusses informed consent as a major concern for research participation in Africa.



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1. McCormick RA, Notes on moral theology: the abortion dossier. *Theol Stud.* 1974 Jun; 35(2):312-59.
 2. Daar AS and Singer PA, Pharmacogenetics and geographical ancestry: implications for drug development and global health, *Perspectives* vol. 6, March 2005: 241-246.
 3. Daar AS, Thorsteinsdottir H, Martins DK, Smith AC, Nast S and Singer PA, Top ten biotechnologies for improving health in developing countries, *Nature Genetics* vol. 32, October 2002: 229 – 232.



Engaging Research Participants in Effective Communication for Informed Decision Making by Prof. A.S. Jegede

Contd.

Need for informed consent

Autonomy is synonymous with discussion of 'independent decision making'. In their work, Markus and Kitayama discussed autonomy using the concept of self "construals" which they believe to have influence, and in many cases determine, the very nature of individual experience. In their work, Markus and Kitayama identified two construals as (a) an independent view, and (b) an interdependent view. This paper adopts the former to examine the role of informed consent in health research.

It has been argued that a person with an independent view identifies oneself as an autonomous individual who holds personal set of values and a unique perspective.

4. Markus HR & Kitayam S, Culture and the self: implication for cognition, emotion, and motivation. *Psychological Review*, 1991; 98: 224 – 253.
5. Geertz C, On the nature of anthropological understanding. *American Scientist*, 1975; 63: 47 – 53.
6. Holland RW, Roeder UR, van Baaren RB, Brandt AC, and Hannover B, Don't stand so close to me: the effects to self-construal in interpersonal closeness. *Psychological Science*, 2004; 15,4: 237 – 242.
7. Markus HR & Kitayam S, Culture and the self: implication for cognition, emotion, and motivation. *Psychological Review*, 1991; 98: 224 – 253.
8. Sampson EE, The debate on individualism: indigenous psychologies of the individual and their role in personal and societal functioning. *American Psychologist*, 1998; 43: 15 – 22.
9. Van Baaren RB, Maddux WW, Chartrand TL de Bouter C & van Knippenberg A, It takes two to mimic: behavioural consequences of self-construals, *Journal of Personality and Social Psychology*, 2003; 84,5: 2093 -1102.
10. Triandis HC, The self and social behaviour in differing cultural contexts, *Psychological Review*, 1998; 96: 506 – 520.
11. Markus HR & Kitayam S, Culture and the self: implication for cognition, emotion, and motivation. *Psychological Review*, 1991; 98: 224 – 253.
12. Markus HR & Kitayam S, Culture and the self: implication for cognition, emotion, and motivation. *Psychological Review*, 1991; 98: 224 – 253.
13. Akabayashi A, Informed consent revised: Japan and the U.S., *The American Journal of Bioethics*, 2006; 6,1: 9 – 14.



Engaging Research Participants in Effective Communication for Informed Decision Making by Prof. A.S. Jegede

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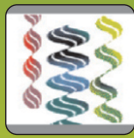
According to Markus and Kitayama, "the view of the self derives from a belief in the wholeness and uniqueness of each person's configuration of internal attributes The essential aspect of this view involves a conception of the self as an autonomous independent person". This suggests that individuals who hold independent view will feel more comfortable making decision about participation in research because it gives meaning to participants' right to self-determination, profound impact on the nature of researcher/participant relationship. It also enhances effective communication. In addition, it gives participants' assurance of quality of care without which there may be negligence or substandard care that may lead to litigation. However, this role may be far from being achieved if information is not well communicated.

Information and informed consent

Information is an important aspect of informed consent. If adequate information is not provided informed consent obtained from research participants becomes questionable. Generally, provision of information may not necessarily lead to adequate knowledge of a research objective, its risks and benefits as well as the rights of and costs to the participants. It may remain at the level of awareness. In their study titled, "Culture and the self: implication for cognition, emotion, and motivation", Markus and Kitayama reported that although the women participants were aware of newborn screening they desired more information in order to acquire more comprehensive knowledge of the test. This shows that research participants may participate in a study without adequate knowledge of it. Sreenivasan pointed out that a solid appreciation or what he calls a "grasp" of what the research participants are getting involved in should be sufficient, as long as the other necessary protections are in place.

Informed consent without adequate information about study procedure is meaningless. The relevance of informed consent as the measure of participants' understanding of the procedure and commitment is subject of debate. For instance, Loue,

14. Markus HR & Kitayam S, *Culture and the self: implication for cognition, emotion, and motivation. Psychological Review*, 1991; 98: 224–253.



Engaging Research Participants in Effective Communication for Informed Decision Making by Prof. A.S. Jegede

Contd.

Okello & Kawana in a study in Uganda found that researchers have difficulty in applying the widely recommended bioethics principles due to socioeconomic inequalities between researchers and participants resulting in participants' feeling of coercion. Anthropologists and other scholars have identified gaps in obtaining meaningful informed consent. They found that there was lack of commitment to the studies even though participants signed informed consent. This suggests that there is a scarcity of information between researcher and the participants in the study. This is because information received by participants may not be enough to generate comprehension of information that can help them make informed decision which can motivate them to participate in research. This may lead to little commitment to research despite the fact that they signed informed consent form as legally required.

The Way Forward

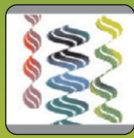
To fill the gap between information dissemination and signing of informed consent the following must be taken into consideration.

First, some form of communication aimed at establishing a shared framework of understanding about the social enterprise of research is needed. There is need for a way to mark the transition from prospective research participants, to participant with a process that communicates the fundamental ideas. To communicate effectively with people there must be constant dialogue ongoing and this must be culture specific justifying the recognition of individual participant peculiarities.

15. Luo S, Okello D & Kawama M, Research bioethics in the Uganda context. *Journal of Law, Medicine and Ethics*, 1996, 24: 47 – 53

16. Sreenivasan G, Informed consent and the therapeutic misconception: clarifying the challenge. *J Clin Ethics*. 2005 Winter;16(4):369-71; PMID: 16447525 [PubMed].

17. Marshall PA, The relevance of culture for informed consent in US funded international health research consultation. Report for the President's National Bioethics Advisory Commission Volume 11 Ethical and Policy Issues in international research: Clinical trials in developing countries. *US National Bioethics Advisory Commission*, 2001 (cf.)



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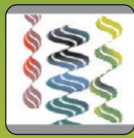
Second, participants must be targeted recognizing the heterogeneity of human society. According to Neves "it is in that (informed consent) encounter that consent can be achieved through dialogue or silence, through gesture or glance, or through some cultural ritual, that each person is recognized in his/her unique originality, and not considered homogeneously and undifferentiated among the others." This is because "consent"...is necessary and effective in maintaining the human character of relationships among individuals in extreme situations of deep vulnerability, to guarantee the ethical nature of those relationships. As indicated in different ethical codes; researchers seeking to conduct medical tests on humans must explain the purpose of the tests, the methods to be used, and the risks involved and must obtain their subjects' voluntary consent.

Finally, informed consent requires some form of engagement between investigators and the potential participants. The participants must be engaged in constant deliberation about the subject matter for them to process the decision making resources properly.

18. Neves MP. Cultural context and consent: an anthropological view. Medicine, Health Care and Philosophy 2004.

19. Nuremberg Code of 1947 and the World Medical Association's Declaration of Helsinki as amended 2002

20. Also, part of the endnotes to Section 2 of the Tri-Council Policy Statement indicates that "*free and informed consent lies at the heart of ethical research involving human subjects. It encourages a process that begins with the initial contact and carries through to the end of the involvement of research subjects in the project. As used in this policy, the process of free and informed consent refers to the dialogue, information sharing and general process through which prospective subjects chooses to participate in research involving them.*"



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CLOSING REMARKS

Thank you for taking your time to read the issue of the newsletter, Your comments about the current issue, and ideas for the next issue are what will keep the West African Bioethics Newsletter an interesting and lively newsletter!!

Please send contributions and suggestions to admin@westafricanbioethics.net

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