



CBR Newsletter

A Newsletter of
Center for Bioethics and Research





Welcome

The Center for Bioethics and Research (CBR) is the leading organization in provision of training in research ethics in Nigeria. CBR has trained a critical mass of professionals within and outside the health care sector including scientists, policy makers, physicians and journalists who contribute to review of research protocols, advocacy and promotion of research ethics in order to ensure the conduct of ethical research in Nigeria. In this edition of the CBR Newsletter describes the research ethics capacity and development activities of CBR – It is full of news about the achievements of CBR in the last 12 months. We wish you a happy reading.

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CBR receives new EDCTP Grant to support research ethics development in Nigeria

CBR led a Consortium that included the Council on Health Research for Development (COHRED), National Health Research Ethics Committee (NHREC) and National Agency for Food and Drug Administration and Control (NAFDAC) to compete for a European & Developing Countries Clinical Trials Partnership (EDCTP) Ethics and Regulatory Capacities Funding Opportunity. The proposal titled "Deepening Research Ethics in Nigeria (DREIN)" was successful and we are very excited about this opportunity to continue to build the health research regulatory infrastructure in Nigeria.

The grant will support M.Sc. Bioethics training for one member of staff of NHREC and of NAFDAC, Blended Diploma

in Research Ethics for biomedical researchers and members of ethics committees, implementation of electronic ethics review software, RHInno a unique, cloud-based research ethics management system, at more ethics committees in Nigeria, and joint mentoring and oversight visits to ethics committees in Nigeria by NAFDAC and NHREC. The 2 year grant nicely complements our ongoing United States Fogarty International Center (FIC) bioethics training program - Entrenching Training and Capacity in Research Ethics in Nigeria (ENTRENCH) Program.

We are excited about this grant and the NHREC staff has already been admitted into the M.Sc. Bioethics training program and the first EDCTP supported Blended Diploma program is planned for March 2018.

M.Sc Bioethics Trainees

Seven students were admitted for the 2017/2018 session into the masters degree program on scholarships provided by the Fogarty International Center of the U. S. National Institutes of Health (FIC/NIH) and the European Developing Countries Clinical Trials Partnership (EDCTP).



1. Dr. Mrs. Victoria Ijeoma Ezeome is a Consultant in Obstetrics and Gynaecology at the University of Nigeria Teaching Hospital. Her research interest is 'Current Practices of Informed Consent in Artificial Reproductive Technologies (ART) in Nigeria'.

M.Sc Bioethics Trainees contd.



2. Dr. Olusola Aluko-Arowolo is a Senior Lecturer in the Sociology Department of Olabisi Onabanjo University Ago Iwoye, Ogun State. His research interest is 'Client-Physician Relationship and Ante-natal Seeking Behaviour in Hospitals and Traditional Birth Attendants' Home'.



3. Dr. Saheed Akinmayowa Lawal is a lecturer in the Sociology Department of Olabisi Onabanjo University Ago Iwoye, Ogun State. His research interest is 'Ethical Challenges and Advancing

Genomics Research in a Multicultural Society (Nigeria)'.



4. Dr. John Seyi Akinloye is a dentist at Dalhatu Araf Specialist Hospital, Lafia, Nasarawa State. His research interest is 'Should priority be given to patients with low socioeconomic status'.



5. Dr. Emeka Ibeh Nnanna is a dentist at Saint Gerard's Hospital, Kakuri Kaduna State. His research is on 'Mandatory vaccination in Nigeria'.



6. Mr Isaac Akinkunmi Adedeji is an assistant lecturer in the Sociology Department of Olabisi Onabanjo, University Ago Iwoye, Ogun State. His research interest is 'The Social Contexts of Quarantine administration for Re-emerging and new infectious diseases: in West Africa'.



7. Mr Ado Danladi is the Desk Officer at the National Health Research Ethics Committee (NHREC), Federal Ministry of Health, Abuja. His research interest is 'Broad consent in research conducted on vulnerable population'.

2017 NIH/FIC supported Blended Diploma in Research Ethics

The Center for Bioethics and Research (CBR) implemented the 2017 diet of its United States' National Institutes of Health/Fogarty International Center funded Blended Diploma in Research Ethics from 7th of October to 10th of December 2017. The course is aimed at building the capacity of trainees to review research projects by providing them with advanced training in research ethics and protection of human participants in clinical trials. The program was designed mainly for members of ethics committees and ethics committee administrators who are unable to take long periods away from their primary assignments to attend advanced training programs like our M.Sc. Bioethics degree course at the University of Ibadan. The contents of the flagship research ethics courses



Picture shows Prof. Temidayo Ogundiran (W.A.B Academic Director) during a meeting with faculty members to discuss the implementation of the Online blended Diploma course and the M.Sc Bioethics program. First row from right is Dr. J. Akintayo, Dr. (Mrs.) I. Ajayi, Prof. A. Ajuwon and Dr. O. Adejumo. Second row from the right is Dr. E. Eyelade, Prof. C. Agulanna and Prof. A. Malomo.

of the M.Sc. degree formed the basis for the Diploma course contents.

The Blended Diploma course consist of online and in-person modules. Most of the course materials were delivered through the online modules which is based on Moodle® courseware while the retreats provide opportunity for trainees to interact directly with faculty, review concepts that they found challenging during the online component of the course, participate in mock ethics review meetings and complete course evaluations.

Trainees were drawn from

diverse professions including Doctors, Nurses, Lecturers and Ethics Committee Administrators. Trainees were provided with internet access and course materials to aid their learning. Each week, during the training period, students were required to log on to the online diploma courseware to access reading materials for specific program modules, participate in online chat sessions with faculty members and take a quiz to test their knowledge and understanding of the module.

My Experience as an Online Diploma Student by Dr Adetokunbo Olawuyi.

I came across call for application to the program on social media (Facebook), then I followed the link and noticed there were no fees, the program was completely free; it looked too good to be true. Nevertheless, I applied and was admitted.

The program commenced first week of October, though I initially had challenges logging on to the course website, I had timely assistance from the site administrator. The course reference textbook, "Institutional Review Board: Management and Function, authored by Elizabeth A. Bankert and Robert J. Amdur" was delivered to my workplace in the first week of the course. This book is what you can call the Holy Bible of Research Ethics and Ethics Committee

function. The program also paid for me to have Internet access for the duration of the course so that I could have access to the online lectures. There were online lectures for each week of the course with additional reading materials available on the site. I also had to take the quiz after each lecture. The lectures were explanatory, clear and concise, while the quiz tested not just my level of understanding of the materials but also how the concepts in Bioethics can make a difference in how research is done on human subjects, not only in the institution where I presently work but in the world at large. At the end of each week, there was an opportunity of rubbing minds with fellow students and course instructors in the online chat room. Grey areas encountered in the lectures and course materials were resolved.

Major principles of research bioethics based on the Belmont



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report are Respect for persons,



Blended Online Diploma Students 2017

Beneficence and Justice. I learnt from this course how important these three principles are in the conduct of research on human subjects.



My Experience as an Online Diploma... contd.

In addition, I learnt that research should generate new information for the good of the society, there must be voluntary consent of human subjects participating in the research, the experiment must be carried out in a way to avoid all unnecessary physical and mental suffering and injury, the degree of risk to be taken by research participants should never exceed that determined by the scientific importance of the problem to be solved, the human subject should be at liberty to quit the study at any

time without fear, the investigators must be ready and willing to stop the study at any stage if there is any serious or unexpected adverse event to any of the research participants, and if continuation of the study may likely result in injury, disability, or death to the research subjects.

There were 2 weekend retreats where students and course instructors eventually met in person, we had a review of all lectures and mock ethics committee sessions. The retreat also featured eye-opening lectures such as "Big data, Small data, My data, Whose data?"

Ethics of data sharing in poor countries delivered by Dr. (Mrs.) Akintola, and 'Vulnerability, Paternalism and Feminism: Engaging Women in Research in Nigeria' delivered by Prof. (Mrs.) Ebunoluwa Olufemi Oduwole. This course is the best thing that has happened to me this year and yet I did not have to pay for it. I hope to conduct research adhering to the principles of Bioethics, to contribute my quota to ensuring research protocols in my institution do not violate the principles of Bioethics and to propagate the gospel of Bioethics as much as possible.

Onsite Institutional Ethics Committees and Health Researchers' training

The following onsite trainings were conducted by the Center for Bioethics and Research from January 2017 to date.

Institution	Date	Attendance	Participants	Training type
National Health Research Ethics Committee Members (NHREC) and Federal Ministry of Health Staff, Abuja, Nigeria.	March 4 - 5	41	New Members of NHREC.	Basic Modern Research Ethics.
Lily Specialist Training Hospital, Warri. Delta State, Nigeria.	May 9 - 11	15	Members of Health Research Ethics Committee.	Basic Modern Research Ethics.
Lagos State University Teaching Hospital, Lagos, Nigeria .	October 18 - 19	19	Members of Health Research Ethics Committee.	Basic Modern Research Ethics.
APIN Public Health Initiative, Abuja, Nigeria .	November 7 - 8	7	Members of Health Research Ethics Committee.	Modern Research Ethics.
College of Health Science, Bayero University, Kano, Nigeria.	December 5 - 6	33	Members of Health Research Ethics Committee.	Modern Research Ethics.

Onsite Institutional Ethics... contd.

These trainings are part of the requirements by the National Health Research Ethics Committee (NHREC), for

members of an Institutional Review Board and the registration of a newly inaugurated Ethics Committee or Institutional Review Board.

The trainings are designed to teach participants the functions of an IRB, methods of validating

informed consent, and other areas of Bioethics regulations and laws in Nigeria. They are complemented by the CITI online training which all attendees also have to complete.



At the Center, Dr Adebayo Adejumo, CBR Faculty member speaking at the APIN training workshop in Abuja for newly selected ethics committee members of APIN public health initiative.



Participants at the APIN Public Health Initiative training in Abuja



CBR facilitators and participants at the end of an ethics training workshop for selected ethics committee members of APIN Public Health initiative at APIN Office Abuja. fourth from the left, Dr Adebayo Adejumo and fifth from the right is Prof. Christopher Agulanna – CBR Facilitator

Appointments and Achievements.

Promotions

·Dr. Mrs. Bola Lanre–Abass was promoted to Professor of Philosophy by the University of Ibadan.

·Dr. Mrs. Yinka Eyelade was

promoted to Reader (Associate Professor) in Anesthesia by the University of Ibadan.

Achievements

Dr. Ms. Omodu Chittu Princewill- An M.Sc. Bioethics graduate of the University of Ibadan sponsored by CBR

earned a Ph.D. in Bioethics at the Institute for Biomedical Ethics (IBMB), University of Basel. She completed her program in three years, making her the second person and the first Nigerian to complete the program in record time from the Institute.



Dr. Ms. Omodu Chitu on her graduation day.





Convocation Ceremony



At the recent convocation ceremony of the University of Ibadan which took place from the 14th to 16th of November 2017, six CBR-sponsored students graduated with MSc. Bioethics degree. They all performed excellently well enough to be able to proceed to PhD without doing an MPhil. They all expressed gratitude to the Center for Bioethics and Research (CBR) and Fogarty International

Online Collaborative Institution Training Initiative

As part of our partnership with the University of Florida Miami's CITI program, we provided 1,953 online CITI

Center (FIC) of the United States' National Institutes of Health for the opportunity to be a part of the program. They are:

i. Mrs. Sandra Olukemi Ogwu–Richard.

Title of dissertation: Attitude of Participants in a Diabetes Mellitus Research to Faecal Microbiome Research.

ii. Dr. Mrs. Omokehinde Olubunmi Fakorede.

Title of dissertation: Perspectives of Researchers in Nigeria on Data and Samples Sharing.

iii. Ms. Olubukola Adefemi.

trainings in Informed Consent, Responsible Conduct of Research and a specialized module on the Nigerian National Code for Health Research Ethics from 1st of January to 30th of November 2017.

Title of dissertation: The role of Peer Pressure in Research Misconduct.

iv. Dr. (Mrs.) Modupe Ladipo.

Title of dissertation: Informed consent in Paediatrics Research.

v. Dr. Samuel Odeh.

Title of dissertation: Incentives for participation in research in Nigeria.

vi. Mr. Gbadamosi Raymond Ojo.

Title of dissertation: Expectation, Experience and Evaluation of Participation in a genomics research project in Africa.



Bioethics Seminar

The Center for Bioethics and Research (CBR) resumed its monthly seminars. The first seminar for 2017 was held in June, 2017 in the tutorial room of the Department of Surgery, College of Medicine, U.C.H, Ibadan. In attendance were some faculty members of CBR, medical students and individuals from various departments within the College of Medicine. Dr. Eyelade was the Moderator, and she gave a brief welcome address to declare the seminar open, afterwards she introduced the first speaker of the day as Prof. S. A Jegede.

Prof. S. A Jegede, spoke on the topic 'Advance Directive in End of Life Decision Making among the Yoruba of South-Western Nigeria'.

During his lecture he explained that "Advance Directive" is a process of giving or providing direction on what to do when individuals are not conscious to

make informed decision about their will, or how to go about their treatment within the social and cultural context of the Yoruba.

Prof. Jegede explained that Western and African perspectives differ. He said ethnomethodology assumes that social order is illusory. He listed the following to support his theory.

- Ethnomethodology believes that social life merely appears to be orderly but in reality, it is chaotic.
- Social order is constructed in the minds of social actors: "If men define situations as real, they are real in their consequences" (W.I. Thomas 1929)
- Individuals bring order to, or make sense of their social world through psychology.
- Once the pattern has been established, it is used as a framework for interpreting new facts, which arise within the situation.

He added that value contributes to the decision that individuals make about issues that concern their lives.

Prof Jegede also explained the Yoruba concept of death as socially constructed – Iku – end of existence. It has both physical and social significance.

The fears and attitude people have toward death are not instinctive, but rather learned from educational and cultural vehicles such as words – Iku ko gboogun (death does not respond to treatment and recovery), arts, and beliefs.

Death can be serial – in which case several people seemingly die one after another of physically unrelated causes – Iku awoku.

Death is spritual – "ewure jelejele, aguntan jemojemo, alangba t'o nrin kiri lara ogiri" symbolizing spirit.

Certain animals are associated with news of impending death e.g. owl, dog, etc.



Bioethics Seminar

Death is seen as both personal and collective.

He added that post-death conceptions typically involve the integrity and continuity of one's personal self. The ultimate goal is often an undifferentiated and impersonal oneness with the universe expressed in ancestor worship – Oku olomo kii sun (The dead who left children behind do not sleep or slumber because they watch over their living children).

Death is a transition process of joining the ancestors – “ma j’okun, ma j’ekolo, ohun ti won ba ti nje l’orun ni ki o maa ba won je” (meaning: eat neither millipede nor worm – as in do not tarry in the grave but move rapidly to the heavens and start partaking in the menu in heaven). This is also obvious in burial rituals before and after death. Burial rituals take place after death but can be a

consideration before someone dies. It is one of the reasons why some people prefer to die at home than in the hospital because the hospital protocols before releasing the corpse may hinder the ritual process.

Prof Jegede explained that the process of Death can take place in any circumstance at any place or time. He said that in Yoruba culture, where and how death takes place is very important. Death at an old age is cherished and mostly preferred to be at home. Early death is abhorred, and prolonged care is encouraged. Peaceful death is most cherished and not one accompanied by pain and agony – “f’owo rori ku”.

He also talked about several key factors in end of life decision making and how they affect different individuals, some of them are:

- Talking about and planning

for death – Age specific: Age of patient influences end of life decision. While it is cultural to talk about end of life issue in a case when the patient is aged, it is a taboo to do so when the patient is a young person. For the aged, advanced plan and directive is acceptable not if the patient is a young person.

- Informing persons that they are dying – Age and nature of disease specific: Similarly, telling patients that they will die is much easier with aged persons than a young person. Most times aged persons do prepare their ‘home’ in advance of what may happen (written or unwritten).

- The role of individual, family members, and physicians: People play different roles in the end of life decision making process. This depends on relationship and gender. For instance, a family head may play significant role in such decisions.



Bioethics Seminar

Sometimes that significant role would be played by the first born or son or daughter, depending on the age and gender of patient. Sometimes, the family relies on the advice of the physicians.

- Duration of illness and Social Aspect of disease: End of life decisions may be difficult in some stigmatised diseases because many patients may not want people to know the nature of their ailment. As a result, they hide it from others and prefer to die silently. Example is cancer, some of which may have a hereditary component and patients may not want to reveal that they have it because their children may be stigmatized and this may affect things like getting married, etc.

Disease burden – role responsibilities: Economic burden of some diseases like cancer can be enormous and therefore may influence end of

life decisions as well as the perspectives of the patient's relatives. Yoruba believe that "iku ya ju esin" meaning "death is better than shame".

Quality and quantity of available care: The quality and quantity of care including access to appropriate treatment may affect end of life decisions. Many people prefer to die at home especially if they need overseas treatment that they cannot afford. The cost and distance associated with prolonged care may be a challenge for family members.

Following Prof Jegede's presentation, the second speaker, Dr Akintayo of the Faculty of Law spoke about the legal implications of 'End of life Decision Making. He spoke briefly that many scholars have discussed the stages of death, dying, and grief. The stages in the process of dying are mostly determined by the cultural meanings attached to the

cause of death. The legal aspect there is the advance directive (written or unwritten) and enforceable legally in line with the laws of Nigeria and customarily by tradition.

After the presentations, Professor Soyannwo of Anaesthesia Department, College of medicine, University College Hospital, Ibadan commented that it would be good to conduct research projects on 'Culturally Appropriate Palliative Care' and 'Stoic Endurance of Pain while expecting death'.

The Bioethics seminar continues to hold on the 4th Wednesday of every month with scholars from diverse fields making presentations on different topics in relation to ethics.



BeOnline Journal – Accepting Manuscripts for Review and Publication

BeOnline, the Bioethics Online journal of the Center for Bioethics and Research is an open-access online journal that provides a platform for individuals to contribute to the global discourse on bioethics by adding the voice of Africans and research in Africa to the discussions about clinical and research ethics, primarily in Africa and in the world at large.

The Bioethics Online (BeOnline®) journal has published its 3rd edition at <http://www.bioethicscenter.net/journal/index.php/journal1/issue/view/BEOnline-Journal-Vol3/showToc>.

The papers can also be found on PubMed:

1: Jegede A. S., Adegoke O. O. Advance Directive in End of Life Decision-Making among

the Yoruba of South-Western Nigeria. BEOnline. 2016 Nov; 3(3): 41 - 67. doi: 10.20541/beonline.2016.0008.

Epub 2016 Nov 22. PubMed PMID: 28344984; PubMed Central PMCID: PMC5363404.

2: Ewuoso C. A. Systematic Review of the Management of Incidental Findings in Genomic Research. BEOnline.

2016;3(1):1-21. doi: 10.20541/beonline.2016.0006.

Epub 2016 Nov 22. PubMed PMID: 28361093; PubMed Central PMCID: PMC5370178.

3: Ebunoluwa O. O., Kareem F. A. Ethics of trial drug use: to give or not to give? BEOnline. 2016;3(2):22-40. Epub 2016 Nov 22. PubMed PMID: 28367458; PubMed Central PMCID: PMC5371348.

4: Fayemi A. K., Macaulay-Adeyelu O. C. Decolonizing Bioethics in Africa. BEOnline. 2016;3(4):68-90. doi: 10.20541/beonline.2016.0009.

Epub 2016 Nov 22. PubMed PMID: 28344985; PubMed Central PMCID: PMC5364804.

We invite you to submit your work to our panel of experienced reviewers and published in the BeOnline journal. Rapid review and decision is guaranteed. We also provide text editing support to improve the quality of your papers. Let the world hear your view about research ethics.

For more information on how to submit a manuscript for review, please visit us @ <http://www.bioethicscenter.net/journal/> or send an email to admin@bioethicscenter.net



Happy New Year



Center for Bioethics and Research



CLOSING REMARKS

Thank you for taking your time to read this 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@bioethicscenter.net**

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