Nurturing the Development of Bioethics in Kenya
Editorial

On behalf of the Bioethics Society of Kenya, I would like to welcome you to the first issue of our society’s newsletter— the BSK NEWS. Through this newsletter, you will receive the latest bioethics news and issues from Kenya and around the world.

The Bioethics Society of Kenya was founded in 2012 when a group of scholars gathered at the Kenya Medical Research Institute (KEMRI) under the leadership of Professor Elizabeth Ann Bukusi and Dr Simon Langat. The society was officially registered in 2014. The vision of the BSK is to be a vibrant platform for multidisciplinary debate on bioethical issues and its mission is to support the development of ethics and the creation and diffusion of knowledge in medicine and the life sciences.

This inaugural issue consists of five articles by the officials of the BSK. The first article by Karori Mbũgua focuses on the concept of bioethics and its origins. His second article highlights some key individuals who have made significant contribution to the bioethical discourse in Africa. It also highlights the activities and events that have helped to institutionalize and promote the growth of bioethics in the continent. Elizabeth Bukusi's paper focuses on the teaching of medical ethics in Kenya’s two premier medical schools, namely, the University of Nairobi and Moi University. The article by Simon Langat is a historical survey of the development of research ethics in Kenya. Adiel Magana’s paper discusses the challenges faced by institutional research ethics committees (IERCs) when reviewing biological and social sciences research proposals, and the article by Lucy Maina focuses on the ethical issues that arise when conducting research involving older people. Also included in this issue are the profiles of the BSK officials.

I hope you will find this newsletter interesting and useful and look forward to receiving your contributions and valuable feedback for continuous improvement. I would also like to invite you to visit our website www.bioethicskenya.org where you will find more information about our society’s activities, including the forthcoming inaugural conference to be held from 16th to 17th December 2015.

With warm wishes for a joyous season and a very happy new year.

Karori Mbugua
Editor
Until 1997, it was wrongly believed that the first person to coin the term ‘bioethics’ was the American oncol-
gist Van Rensselaer Potter, who used the term in 1970
to denote an ethic that incorporates not just humans
but the entire biosphere. Today, however, we know that
the first person to use the term was the German theolo-
gian Fritz Jahr. In a 1927 article entitled “Bio-Ethik: Eine
Umschau fiber die ethischen Beziehungen des Men-
schen zu Tier und Pflanz” (in English “Bio-Ethics: a review
of the ethical relationships of humans to animals and
plants”), Jahr called for the acceptance of moral obliga-
tions not only to humans, but also to animals and plants.

The word “bioethics” comes from two Greek roots, “bio”
and “ethikos”, which means life and character (or cus-
tom), respectively. But what exactly is ethics? It is a field
of study, which together with metaphysics, epistemolo-
gy and logic constitutes philosophy. Ethics is the study of
what is morally right or wrong in human conduct. It seeks
to provide us with a guide for moral living. Bioethics may
therefore be defined as the branch of applied ethics that
deals with the ethical issues arising from the biologi-
cal and medical sciences and technology. It is important
to emphasize that unlike the traditional medical ethics,
bioethics goes beyond the doctor-patient relationship.

Although bioethics is a somewhat recent area of study,
some scholars have traced its roots back to 400 BC when
the famous Hippocratic Oath was formulated. However,
other scholars have traced its origins further back to 1754
BC when King Hammurabi of Babylon created the famous
Hammurabi code, which sought to regulate medicine and
to protect patients’ rights. Bioethics as we know it today
emerged in the late 1960’s in response to advances in bio-
medical knowledge and technology, which raised a host
of new ethical, legal and political questions. Among these
technologies, include mechanical ventilation, renal dial-
ysis, in-vitro fertilization and organ transplantation. The
atrocities committed by the Nazi doctors during the Sec-
ond World War, as well as the notorious Tuskegee syphilis
study conducted by the U.S. Public Health Service between
1932 and 1972 gave impetus to the growth of bioethics.

The publication in 1979 of Tom Beauchamp and James
Childress’s book entitled Principles of Biomedical Ethics
also played a critical role in the development and gradu-
al institutionalization of bioethics as a respected field
of study. The two authors proposed four principles (also
known as the “Georgetown mantra”), namely, autonomy,
beneficence, non-malfeasance and justice, which are con-
sidered by many as the standard theoretical framework
from which to analyze ethical situations in medicine today.

Bioethics was given a shot in the arm when the United Na-
tions General assembly published the Universal
This document sought to deal with ethical issues raised
by revolutionary advances in both biology and medicine.

Bioethics is, without doubt, one of the most rapidly de-
veloping fields of study. Although it originated in North
America, it has become global and evolved into an inter-
derdisciplinary field with its own methods, standards, litera-
ture and professionals. Numerous bioethics centers, so-
cieties, and journals have been established and research
ethics committees now exist in most countries. Develop-
ments in biomedical knowledge and technology will al-
ways raise new ethical questions. For this reason, bioeth-
ics is likely to continue to flourish for a long time to come.
Bioethics in Africa:

Personalities, Centers, Journals, Newsletters,
Programs, Societies and Conferences.

By Karori Mbugua
University Of Nairobi

Bioethics as a field of study in Africa is less than 30 years old. However, within this short period, a number of bioethicists have emerged, bioethics journals, societies and centers have been established, and bioethics conferences and meetings have been held. This short piece highlights some key bioethicists who have made significant contribution to bioethical discourse in Africa through publications in scholarly journals. It also highlights the activities and events that have helped institutionalize and promote the growth of bioethics in Africa.

Individuals who have Contributed to Bioethics Discourse in Africa
Godfrey Tangwa and Clemetus Andoh (Cameroon); David Benatar, Solomon Benatar, Kevin Behrens, and Thaddeus Metz (South Africa); F. M Murove (Zimbabwe); Sana Loue and David Okello (Uganda); Temidayo Ogundiran, Segun Gbadegesin, Ademola Fayemi and Samuel Jegede (Nigeria); Stuart Rennie, Bavon Mupenda and Sébastien Mulombe (Democratic Republic of Congo); Jacqueline Azetsop (Chad); Sirkku K. Hellsten (Tanzania). Of course this list is not exhaustive.

Bioethics Centers
Malawi: Center for Bioethics in Eastern and Western Africa –CEBESA; South Africa: The Steve Biko Center for Bioethics (University of Witwatersrand); Bioethics Center (University of Cape Town); Center for Medical Ethics and Law (University of Stellenbosch); Nigeria: The Center for Bioethics (University of Ibadan); Kenya: The UNESCO Regional Bioethics Centre (Egerton University).

Journals and Newsletters

Bioethics Programs
International Research Ethics Network for Southern Africa (IRENSA); West African Bioethics Training Program; Fogarty African Bioethics Training Program (FATP), training occurs both at Johns Hopkins University and at partner African institutions; Indiana University-Moi University Academic Research Ethics Partnership (IU-AREP); Middle East Research Ethics Training Initiative (MERETI), trainees in this program have come from Egypt and the Sudan and other Middle –Eastern countries.

UNESCO Bioethics Chairs
Kenya (Egerton University), Sudan (Khartoum University), and Côte d’Ivoire (University of Bouake)

National Bioethics Committees
With the support of UNESCO, national bioethics committees have already been established in the following countries: Chad, Côte d’Ivoire, Kenya, Uganda, Gabon, Guinea, Ghana, Togo, the Democratic Republic of Congo, and Malawi. The following countries are in the process of establishing national bioethics committees with the help of UNESCO: Cape Verde, Comoros, Namibia, Nigeria, Tanzania and Uganda.

Bioethics Conferences and Meetings
First Regional Conference of National Bioethics Committees (Cairo-Egypt, 2007); Pan-African Bioethics Initiative (PABIN) 3rd Conference (Addis Ababa, Ethiopia, 2003); The First Days of Bioethics for West and Central Africa (Dakar, Senegal, 2005); The 14th session of UNESCO’s International Bioethics Committee (IBC) (Nairobi, 2007); International Conference on Bioethics (Egerton University, Kenya, 2008).

Bioethics Societies and Initiatives
Cameroon Bioethics Society (CBS); Bioethics Society of Kenya (BSK); Pan-African Bioethics Initiative (PABIN); Cameroon Bioethics Initiative (CAMBIN); EthiopianBioethics Initiative(ETBIN).
Medical or clinical ethics is a set of moral principles, beliefs and values that guide decision making and choices concerning medical care. Although ethics does not determine what is right or wrong, it provides a framework for making decisions in healthcare. Medical ethics ultimately empowers doctors to provide the best possible care and treatment that benefit, respects and safeguards the wellbeing of a patient.

This article examines the importance of medical ethics in medical schools, inspects the status quo and recommends strategies to ensure the training curriculum equips doctors with adequate knowledge and ability to apply ethical values and principles in their daily interaction with patients. Recently, we have witnessed two cases of gross misconduct in the Kenyan medical sector. In one case, a ‘doctor’ (later found out to be an unlicensed nurse) was highlighted by a local TV station. The ‘doctor’ had been practicing medicine illegally for over 5 years unnoticed; the media further allegedly caught him on camera sexually abusing a sedated female patient. In another more recent incident in Nairobi, an accident victim died after spending more than 18 hours in an ambulance being shuttled back and forth between healthcare facilities and medical personnel before accessing critical care. This avoidable loss of life should never have happened in a city with the highest concentration of hospitals in the country. Media reports indicate that the patient was turned away by three private hospitals allegedly because the patient’s family could not raise the required financial deposit to allow for admission into the ICU for care. Such incidents are evidence of glaring weaknesses in our health system, specifically, an indication of a concern over an inadequate medical regulatory system and a possible absence of assured right to the highest attainable standard of health, which includes the right to health care services, including reproductive health care to every Kenyan citizen as enshrined in Chapter 4, Article 43 (1) a of the Kenyan Constitution (2010). These two incidents call for reflection on what guides decision making for and in our healthcare system. Has ethics been thrown out of the window, was it ever a part of our health care culture?

By Elizabeth Anne Bukusi and Timothy Kipkosgei
Kenya Medical Research Institute (KEMRI)
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In a nutshell, it is not adequate to teach medical students on diseases etiology, diagnosis and treatment without teaching the ethical analysis skills that empower them to deal with inevitable ethical dilemmas in medical world.

Every licensed and practicing doctor in Kenya must have taken the famous Hippocratic Oath upon being conferred with a degree in medicine. Some of the fundamental tenets of this oath are the vows to put the patients’ life first, respect, and preserve human life. It is therefore important to impart the very people in charge of preservation of human life with the ethical principles desired to guide their decision-making and the process used to reach those decisions. Instilling a culture of ethics through effective teaching of medical ethics is one important way of improving the quality of patient treatment and care, which in turn should enhance health outcomes. If student doctors are equipped with the necessary skills of decision making in regards to patient care, then it is likely that the dignity of patients will be protected and cases of medical negligence in our healthcare system will be reduced if not eliminated. It is not enough to teach medical students disease etiology, diagnosis and treatment without teaching them ethical analysis skills that would enable them deal with ethical dilemmas in medical world. I was privileged to attend medical school in 80s; I also practiced medicine in 90s before focusing much of my energy into medical research for the last two decades. Throughout my career journey in the medical field, I can attest the significant role that knowledge on medical ethics plays when making decisions regarding the lives of patients. The awareness of the importance of ethics informed my decision to investigate what is taught, how it is taught and what ought to be taught in medical schools in Kenya. This study was done to fulfill the requirement for the award of a Master in Bioethics degree. The study was done at both the University of Nairobi and Moi University—the two oldest medical schools in Kenya during 2013.

In the course of my research on teaching of medical ethics, I found out that both the University of Nairobi (UON) and Moi University (MU) teach medical ethics. Moi University teaches ethics as an independent topic in first year and final year while UON has a different approach where ethics is taught within other core units such as behavioral sciences, law and ethics and forensic medicine. Ethics is not taught throughout the years of undergraduate medical school in both universities. However, at both universities postgraduate students are taught some elements of research ethics since they are required to do independent research as part of their postgraduate training. The teaching of ethics in Kenyan medical schools embraces a more theoretic approach than practical approach, particularly at the UON, while at the MU; it includes modules or case studies in clinical setting which are closer to real life settings. Sadly, in both institutions, ethics is not examined independently but within other core units and probably counts for less than 5% of the total marks given the wide scope of the medical field.

In terms of capacity, both universities are short of staff with training in clinical/medical ethics, most teachers of ethics are doctors who do not have any advance training in bioethics. Others lecturers have training in allied social sciences and humanities like anthropology and philosophy. The students and lecturers alike indicated that not enough time is put into the teaching of medical ethics. They cited a lack of dedication/commitment to teach ethics and that those who are assigned the topics do not always do due diligence and teach. Moreover, the curriculum does not explicitly detail the course objectives, deliverables and necessary references for teaching medical ethics to students. Most lecturers are consultant doctors, who dedicate some portion of their time in private practice. This leads to unavailability of lecturers, depriving the students of crucial mentorship opportunity during their learning and formative years in the medical field. However, remuneration of the lecturers was also cited as a challenging reality—as after all the years of training, the lecturers also need to provide for their families and make ends meet. Additionally, Students cited the lack of role models in how to practice medicine ethically as a big challenge.

The Kenya Medical Practitioners and Dentist Board (KMPDB)—the regulator of the medical profession in Ken-

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Drawing from the findings from the two universities, it is evident that the current state of teaching medical ethics is not adequate to prepare the students for medical practice in this age of information overload and litigation at the slightest error. Most lecturers and students also concurred that the current medical ethics training curriculum is below par—requires universities to teach 3 units of Medical Ethics, Professional Conduct and Medico-Legal Issues Course during medical clerkship/rotation. This course is meant to equip the students with the knowledge on ethical and medico-legal issues of the practice of medicine. However, KMDPB does not explicitly prescribe the teaching methods, minimum time allocations and when these courses should be taught. The type of instructional methods, teaching and learning approaches is therefore left to the discretion of the universities. The universities consequently design the teaching ethics according to the available resources and capacity to teach the subject. This tactic leads to diverse standards of teaching and training across the medical schools and across universities in Kenya.

Drawing from the findings from the two universities, it is evident that the current state of teaching medical ethics is not adequate to prepare the students for medical practice in this age of information overload and litigation at the slightest error. Most lecturers and students also concurred that the current medical ethics-training curriculum is below par. Some culpability is directed to the regulator not providing more guidance and monitoring training to ensure compliance. The regulators are however quick to follow up and act on complaints regarding medical practice and litigation follows. The universities were also cited as accountable for neglecting courses in ethics in favor of the core medicine courses— or not weaving ethical attitudes in every aspect of teaching the core subjects in medicine. The examining of medical ethics within other core units is a major contributor to students not taking the subject seriously; instead, students choose to read and put more effort towards passing the core units, which they view as more important towards their successful completion of medical school training. The high numbers of medical students under training may also add to these challenges, as the training numbers have expanded without a similar expansion of facilities or a simultaneous increase in teaching staff.

The successful teaching of medical ethics in Kenyan medical schools will require candid reconsideration. The existing approach of teaching medical ethics demands overhaul, the most appropriate plan will be to develop and implement a hybrid system of training that incorporates sufficient theoretical and practical approach in teaching medical ethics. Highly ranked universities in North America and Europe take a different approach from Kenya in teaching medical ethics. In these institutions, ethics teaching is centered on clinically oriented situations, case-based scenarios and continuously reinforced across the students’ years at medical school. Such models may need to be examined for possible modification and adoption for the Kenyan system. The teaching of medical ethics with other core units is an ideal approach, for example teaching issues of do not resuscitate (DNR), or the ethical dilemmas of euthanasia are best addressed when teaching neuroanatomy, neurophysiology and brain death. Such an approach is crucial in enabling students appreciate the important role of ethics in decision making especially in scenarios of ethical dilemmas in clinical setting. This will hence reinforce the significance of ethics thought out the training years.

The timing of the teaching was also cited as a concern. Ethics should be taught continuously from the first year to the final year. The Kenyan approach of teaching medical ethics within a few units in the 1st and 2nd years and then in the final year of medical school should be modified by integrating ethics in other rotation courses. Such an approach takes advantage of student’s practical engagement with patients in the wards in presence of their teachers; it also eliminates the flaws associated with prescribing a short 3 to 10 unit course to cover all the major ethical and legal issues encountered in all major specialties. In addition, the integration of ethics gives a good opportunity for Clinicians to participate actively in the teaching effort both as instructors and as role models for the students. Such in-
Interactions encourage discussions and mentorship to students as they are able to witness and ask clarification on the process of decision making during the rotation.

The improvement of quality of teaching of clinical ethics will also require a concerted effort of the universities to build staff capacity to teach ethics, allocation of more time, and change in evaluation methods for medical ethics courses. Universities need to identify and train lecturers dedicated to teaching medical ethics to advance ethics courses such as master or PhD in ethics; this will equip universities with qualified trainers vital for wholesome quality teaching. Finally, students feel that the examination of ethics within other core units diminishes its importance; it is therefore prudent for universities to consider how best to evaluate medical ethics independently. This may encourage the students to put more effort towards understanding ethics and also allow the universities to effectively evaluate quality of training in medical ethics.

Doctors who lack proper grounding in medical ethics are more likely to put the lives and dignity of their patients at risk through negligence and other possible cases of misconduct. Deficiency in medical ethics knowledge also puts the profession at risk of disrepute; moreover, it leaves the medical practitioners vulnerable to litigation because they lack information on various ethical and legal issues in the medical field. It is therefore the opportune time now for all stakeholders to consider the best mechanism necessary to develop and implement a training curriculum that is responsive to ethical and moral needs of the medical profession. This may make the teaching effective and improve patient outcome, which is line with the doctors’ vow to prioritize, safeguard and preserve life.

REFERENCES
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A Quarter Century of Research Ethics in Kenya

By S. K Langat, National Commission for Science, Technology and Innovation (NACOSTI)

During the early 1980’s it became necessary to create a framework for reviewing research ethics in Kenya. Research is an important function of any thriving health sector in any country. The discussions of how to develop ethics took place at the National Council for Science and Technology (NCST), the predecessor of the National Commission for Science, Technology and Innovation (NACOSTI). This followed the Council for International Organizations of Medical Sciences (CIOMS) guidelines developed in 1992 in Geneva. Records available in NACOSTI indicate that the CIOMS document was one of the main reference material used to develop the first guidelines. The country had a new medical research institute-KEMRI, and an expanding medical school at the University of Nairobi. The NCST had created a research endowment fund and the research scene was set to get more vibrant. With the rising numbers of clinical trials and other medical research projects, it became clear to the NCST that it was important to have an ethics review committee to ensure that ethical issues were appropriately. This led to the establishment of the Health Sciences Specialist Committee, chaired at the time by the Director of Medical Services and among its members were eminent scientists. The committee later could not handle all the new proposals as they increased making it necessary to expand the regulatory mechanism. KEMRI was requested to establish its own committee. This brought the number of committees that could review research proposals to three. The medical school had established a committee earlier as student proposals needed to be reviewed. The role of the committee at the NCST changed as research activities in the country grew. It took on regulatory duties focusing more and more on policy and advice.

In 1985, a new university was opened. Moi University had a medical school and could not be served adequately by ethics committees in Nairobi. The university created another ethics committee under supervision from the Health Sciences Specialist Committee of the NCST. During the late eighties, the HIV pandemic was starting to be felt, several foreign NGOs came to the country to start research projects among various communities in the country. This highlighted a new need; to have regional ethics review committees that understood local cultures better. Some Provinces did have ethics committees operating under the offices of Provincial Medical Officers. As the number of research institutions grew, the demand for review increased. New committees were created at the newly established universities. It also became apparent that it would not be pragmatic to have one committee handling policy and reviewing ethics. National research priorities, responses to changing national requirements and reviewing research ethics should not be handled together. Thus the move to establish a dedicated national committee that would exclusively deal with development of guidelines, accreditation, arbitration and other policy matters in ethics review. The committee known as the National Bioethics Committee (NBC) was formed in 2009. Still within the NCST, the committee was given the mandate to spearhead the development of ethics and coordinate ethics review. Its functions would include developing guidelines, promoting ethical conduct advising the Government in ethical issues arising from technology development and arbitrating in cases where institutional ethics committees are not able to resolve.

As development in ethics review progressed, the legal environment also changed. The Science and Technology Act Cap 250, of 1979 was repealed and in its place the Science, Technology and Innovation Act number 28 of 2013 was enacted. It re-established the NCST as the National Commission for Science, Technology and Innovation (NA-
COSTI). The new law clarifies regulatory issues, making it mandatory to adhere to quality standards and report regularly to the Cabinet Secretary. Institutions and researchers have to ensure ethical conduct and quality is maintained at all times. NACOSTI issues a license to individual principal investigators for each research project. Institutions must be registered to engage in research activities and periodically monitored and accredited appropriately. This will enable the country to benefit from new knowledge and pursue a well developed strategy that ensures research focuses on local priorities. The Act also creates a National Research Fund (NRF) to facilitate funding of research that is beneficial to the country. Under an independent board of trustees the NRF will raise an equivalent to 2 percent of Kenya’s GDP for supporting research. A National Innovation Agency is the third institution created by the new law. Its mandate is to promote research and ensure public support for research and development.
Challenges IERCs face in Reviewing Research Proposals in the Biological and Social Sciences

By Adiel Magana
Chuka University

In the past five years, the Kenya National Commission for Science Technology and Innovation (NACOSTI) has facilitated establishment and accreditation of slightly over twenty Ethic Review Committees in various universities and research institutions in the country. These committees popularly known as Institutional Ethics Review Committees (IERCs) are mandated with the task of evaluating research proposals to ensure physical, emotional and social safety, and well-being of the research participants.

One of the most common impediment faced by IERCs particularly those that review proposals in Biological and Social Sciences is lack of basic infrastructure and secretarial services to support their work. Essential facilities like office space, furniture, stationery and equipment such as computers and scanners are hardly availed to the IERC members. Most of these committees rely on secretarial services from their respective sections and departments to hold meetings, write minutes and to do other clerical work. There is a common fallacy held by some institutions’ executives that these committees play a peripheral role in research therefore their activities can be accommodated in the existing institutional structures. Although this arrangement seems to work, efficiency of such committees is likely to be compromised and confidentiality of their work cannot be ascertained.

The host institutions hardly give any budgetary allocation of funds to support their IERCs and members of such committees have to work with little or no funds. Any attempt by IERCs to levy a fee on research proposals is usually received with skepticism by the host institutions management boards. Lack of recognition and support for IERCs is likely to demotivate the members making them less committed to their work. Another area of concern is the shortage of suitably qualified persons in membership of IERCs. It is recognized that some officials of IERCs lack requisite skills and experience to review research proposals effectively. In addition to academic qualifications, one requires research experience and training in ethics review to be an efficient reviewer. Inadequate training of members in this regard will no doubt have a negative impact on the quality of ethical review.

It is also evident that some researchers have little or no training in research methodology and ethics. It is not uncommon for reviewers to be presented with research proposals with topics that bear no relationship with the study objectives, methodology and the budget. Studies of this nature do not seem to add any value to existing body of knowledge. Such proposals have no intrinsic value as they tend to serve narrow interests of satisfying the sponsors or fulfilling requirements for academic awards. Participating community and the general public do not stand a chance of gaining anything for their effort in the research.

There are many cases where a community is requested to participate in research without proper information about their rights, obligation and privileges. There are cases where informed consent is not given. To fulfill the requirement of seeking informed consent some researchers merely state that consent of participant will be sought, however, little or no attempt is made in this regard. There are cases where participants are required to reveal their confidential information. Where questionnaires are used as tools of collecting data you may find names of participants, their age, sex, marital status, among other things being displayed thereby denying participants their confidentiality.

Whether participants will be assigned to control or experiment groups and potential risk, discomfort or adverse effects once research has started is not clarified to the participants, neither are they informed of their right to seek legal redress where need arises. Hardly is there any information in the research proposals on data sharing among the stakeholders. Where minors are engaged in research, consent is sometimes sought from their teachers, institutional administrators and guardians. They are usually not
informed of their right to participate or withdrawal from research. Cases of unintentional breach of confidentiality have been reported in circumstances where interviews have been held in staff rooms or offices that are not soundproofed where private information leaks to other parties.

Monitoring and evaluation of research work once a study has commenced is rarely undertaken by IERCs. All research involving human participants involves a certain level of risk and it is therefore important for research to be monitored as this will ensure early detection of adverse events that may arise during the study. The role IERC is to determine the degree of risk to participants and ascertain if a study can continue even after an adverse event has occurred.

Finally, there are cases of researchers who conduct research in the community without seeking ethical approval from either the local IERC or NACOSTI. This is an issue of great concern, as it is likely to contribute to human rights abuses. The relevant authorities should device ways and methods of dealing with the vice. Despite these challenges, most IERCs are doing a commendable job but they need be supported so that they can carry out their tasks effectively.

Bioethics Society of Kenya

MISSION

Supporting the development of ethics in the life sciences and diffusion of knowledge for equity and progress in health care

Be a member now- Open for all to Join

The Bioethics Society of Kenya is a self-governing organization whose main objective is to foster the development of bioethics in Kenya. The BSK is a not-for-profit, non-political, non-discriminatory, multidisciplinary organization. The society seeks to promote ethics in research, medicine and health care. Membership in the BSK is open to all Kenyans or persons residing in Kenya who shares the objectives of the BSK. Our mission is to support the development of ethics in the life sciences and diffusion of knowledge for equity and progress in health care.

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NB- 20% discount on registration and annual retention fee will be granted for IRBs that register as a group

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The definition of older persons varies by region and is largely an attribute of both cultural and social variables. Chronologically, older persons are those individuals who have attained the age of 60 years (UNFPA, 2015). Though different countries differ on the actual age by which they designate old age as starting, the range is between 55-65 years of age in most countries. Ageing is also a multifaceted construct; it can be physical, psychological, social and even medical (Morgan, L. & Kunkel, S. 2015). Generally, old age defines a period in the life of an individual when retirement from active working life occurs but also a period when an individual is viewed as entering a final phase of life often characterized by deteriorating health and physical capabilities and therefore greater dependency and a shift in demands and resources. Currently, global statistics estimate that 12.3% of the populations are older people. Demographers project that by the year 2050, this statistic will nearly double and that for the first time in history, there will be more people aged 60 years and above than children under 15 years (Help Age International, 2015). This demographic transition stimulated by improvement in health and nutrition, will demand a more robust policy and programming framework for dealing with the enlarged population of individuals.

Research with older persons has been rising and is expected to increase for a number of reasons. Some of the key factors accounting for this trend is the increased rights awareness among older people, the demand to include stakeholders in policy making, the need for wider participation in development planning and the increasing empowerment of groups previously regarded as minorities (Walker and Engelsrud, 2008). This increased inclusion of older people as participants rather than subjects and as sources of information in research presents a number of controversies.

While there is no valid reason why older people should be excluded from participating in research, there are still a number of counter-arguments anchored on the ‘fitness model’ that views old age as akin to disability and other impairments. Other arguments for non-inclusion centre on the lived experiences of a majority of older persons such as vulnerability, poverty, confinement (older persons are likely to be living under care), abuse and neglect, loneliness, and health status. Medically, older people are more likely to suffer degenerative ailments and impaired cognitive capacity. Among the most common of such conditions may include severe conditions such as Dementia, Alzheimer’s, Parkinson’s disease and deliriousness.

Hence, the ethical imperative that confronts researchers aiming to conduct research among older persons is the issue of striking a balance between the principle of beneficence and that of causing ‘no harm’ creating a cauldron of sorts. These concerns thus require researchers to be more conscious of this factor in their design, conduct, interpretation and application of research. At the same time, researchers may often find themselves further constrained by the inability to really assess the capacities of older persons at the point of research and run the risk of either underplaying or over-playing the meaning of their contributions to research. In addition, a number of other ethical considerations arise when researching with older people.

a) Vulnerability aspect

Research with humans always entails a choice regard-
ing the relative weight of importance of the research against the welfare, right and dignity of the subject. Most social research aims at discovering personal attributes and behaviors that shape a particular reality and intrusion into individual privacy would be expected. Research often requires one to re-collect past events and experiences. For older persons, this might be a time of nostalgia or it may conjure up locked emotions and unpleasant experiences leading to trauma. In some cases, the pain of being reminded of such experiences may linger for a while especially if such older persons are living alone or have no strong social networks. While researching with older persons, it is not unfortunately not always possible to determine if an investigation will cause harm due to their lived experiences, which may latently cause nostalgia, regret and even trauma.

**b) Health matters aspect**

Research among older population often centers on health, welfare, care and intergenerational relationships. The high incidence of illness among older persons also contributes to their vulnerability. For older persons, health status may slowly deteriorate and without immediate diagnosis, there is no telling at the onset, just how healthy or well an older person may be. Though old age is not in itself a disease, experiences of symptoms and diseases greatly impair their abilities to hear and respond appropriately. A researcher may be constrained to critically review the health status and may proceed with the activity oblivious of such impaired capacity. For older persons, such conditions as being hard of hearing, faulty vision, frailty and difficult in movement may translate the research process into a strenuous and sometimes damaging encounter. In addition, research with older persons may entail establishing health capacities or may take the form of drug trials or investigating unknown health conditions. Thought somewhat necessary, such research may present discomfort, confusion and even cause unintended harm. Further, when the researcher intends to find out more about their impaired conditions, older respondents may feel a sense of intrusion and the reminder of a painful or discomforting condition may increase their sense of not feeling well. Hence, the principle of beneficence becomes a paramount consideration.

**c) Consent aspect**

Older persons may be constrained with regard to the ability to personally evaluate an investigation as either harmful or not. They are also likely to volunteer and consent to research without a clear understanding of what it entails due to factors such as low literacy levels, need to be heard by somebody or to alleviate loneliness. Though the intent of a research may be declared, it may not be firmly understood due to reduced cognitive capacity. Hence, the consent undertaking may have to be discussed with caregivers of the older persons.

**d) Interpretation of research findings**

One of the key challenges affecting interpretation of research conducted with older persons is ageism, a term used to refer to a discriminatory attitude towards older persons borne out of a belief that old people are inferior or do not have much to offer to society. Researchers who portray ageism (even without knowing it) might misinterpret the views of older persons or ask leading questions informed by their belief. At times, insensitivity in the questioning as well as the attitude that older persons may not know much about the subject under investigation may creep in. During a research session, older persons may take too much time elaborating a point and a hurried researcher may object or show impatience thereby offending the respondent. Other unethical practices with this population border on over-generalization of older population views due to pre-conceived beliefs, use of wrong or ageist terminologies ridden with negative meanings. For instance, there are terms used to refer to older persons such as ‘aged person’ or ‘the elderly’ that may carry negative connotations.

Though there are sufficient grounds to believe that research with older persons is necessary and should be conducted, there is need for researchers working with this population to adapt a more deeper evaluative element with relations to ethical research. Older persons may possess wealth of knowledge and experiences but inquiry into these experiences call for a profound and critical analysis of the principles of informed consent, beneficence, voluntarism, no harm, interpretation and use of findings bearing in mind the circumstances and realities of older people which vary from region to region.

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Meet the BSK Founders

Prof Elizabeth Ann Bukusi
MBChB, M.Med (ObGyn), MPH, PhD, PGD(Research Ethics), MBE(Bioethics), CIP (Certified IRB Professional).
Chairperson, BSK

Prof Elizabeth Bukusi is a Chief Research Officer and the Deputy Director Research and Training in Kenya Medical Research Institute (KEMRI). She is the Co-director of the RCTP-FACES program. Her main interests in research focus on sexually transmitted infections, reproductive health, and HIV prevention, care and treatment. Prof Bukusi is a champion in matters of bioethics in Kenya; she currently oversees research regulation at the KEMRI where she is the acting unit head of the newly formed KEMRI Scientific and Ethics Review Unit (SERU). Prof Bukusi is keen on the development of systems and structures for regulation of research in KEMRI and the whole country. In 2011, she was awarded grants by three institutions to streamline research regulation process and strengthen the KEMRI’s Ethical Review Committee (ERC). Working under a taskforce with fellow KEMRI staff, she headed the reorganization of KEMRI’s research regulation system, transforming it to one of the most effective in the country.

Prof Bukusi also advocates for capacity building in bioethics; she has created training linkages with Center for Biomedical Ethics and Culture (CBECC) in Pakistan, enabling Kenyans to be trained on short courses in bioethics and full bioethics degree programs in Pakistan. Additionally, she has been instrumental in facilitating online ethics training and certification courses such as CITI training and Certified IRB Professional (CIP) for researchers and ethics committee members in the country. Prof Bukusi is the chairperson of Bioethics Society of Kenya, together with other professionals; she endeavors to introduce, develop and promote Bioethics in the education, healthcare and medical research sectors in Kenya.

Dr Langat is a long time Kenyan public servant with over twenty five years’ experience in research administration. He served at the ministry of Science and Technology at the Department of Research Development and currently, the National Commission for Science, Technology and Innovation, (NACOSTI) where he is the head at the health sciences department. Dr Langat has dedicated most of his time on science policy making majoring on putting up structures for research regulation and ethics review in Kenya. He has been actively involved in the development of ethics review in Kenya for the last twelve years. He participated in the development of national policies for research ethics review, including drafting of guidelines, an accreditation process for institutional ethics review committees, and training programs for the National Bioethics Committee (NBC). In 2012, he, together with other professionals conceptualized and spearheaded the establishment of a Bioethics Society to promote Bioethics in Kenya. He serves as the vice chair of the Bioethics society.

Margaret Mbuthi holds a BA in Counseling Psychology and is currently pursuing an MA in Child Development at Day Star University. She is the Vice-Chairperson of the Aga Khan University (Kenya) Ethical Review Board. Ms Mbuthi has special interest in child development and is passionate about ensuring the wellbeing of children and families.
Dr. Lucy W. Maina is a Senior Lecturer in Sociology and the Director of the Institute of Peace and Security Studies at Kenyatta University. She has researched on a wide variety of areas in the social sciences including enterprise development, community livelihoods, quality of life, gerontology and retirement systems, public health and gender. Dr. Maina’s works appear in several Journals including: Girlhood Studies: an Interdisciplinary Journal, Global Public Health Journal, Journal of Ethnic and Cultural Diversity in Social Work, Women and Aging International and Journal of Agricultural and Environmental Ethics.

Prof. Karori Mbúgua is an Associate Professor of Philosophy in the Department of Philosophy and Religious Studies, University of Nairobi. He holds a BA and an MA in Philosophy from the same university, an MSc in Philosophy and History of Science from the London School of Economics, and a PhD in Philosophy of Science from the University of Cape Town. His areas of academic interest include Philosophy and History of Science, Bioethics, Environmental Ethics, African Philosophy and Philosophy of Religion. He has published a number of articles in the field of bioethics. Prof. Mbúgua is a member of the National Bioethics Committee (NBC).

Prof. Adiel Micheni Magana holds a doctor of Natural Sciences degree (PhD) from the University of Vienna, Austria. He is an Associate Professor of Ecology and Aquatic science and current dean of the Faculty of Science Engineering and Technology at Chuka University. He is the chairman of the Chuka University Ethics Review Committee, and a board member of the Bioethics Society of Kenya. Prof. Magana has been instrumental in establishing several academic and research collaborations, notable among these is “the Njoro River project – Tropical Ecology Initiative”, funded by the Austrian Academy of Science. His current research interest is in public health and veterinary aspects of wild and cultured fish, and climate change mitigation strategies in Kenya. He is a supervisor of a number of masters and doctoral students in his area of specialization.

Prof. David Ayuku is a Professor of Clinical Psychology of Moi University, College of Health Sciences, School of Medicine department of Behavioral Sciences he obtained a BSc in Psychology from Mid-America Christian University (Formerly Gulf-Coast Bible College Houston, Texas), MA in Clinical Psychology from Texas Southern University, and PhD in Clinical Psychology from the University of Maastricht. His recent research and publications have been driven by a keen interest in how children develop and adapt under difficult conditions, with a particular focus on street children. Other ongoing research Projects include: Orphaned and Separated Children’s Assessment Related to Their Health and Well-Being (OSCAR). In addition to his position as Co-Principal Investigator of the Indiana University-Moi University Academic Research Ethics Partnership (IU-Moi AREP), he has been instrumental in developing curricula for Bachelor of Science in Medical Psychology; and Master in International Health Research Ethics—a collaborative Programme between Moi University and Indiana University in the USA; both approved by Moi University Senate.

Rev. Joseph Kigen Katwa is a Church Minister with the African Inland Church (A.I.C). He is currently Chaplain Moi University College of Health Sciences. Rev. Kigen holds a Master of Arts degree in Community Pastoral Care HIV/AIDS and MSc in International Health Research Ethics from Moi University School of Medicine.

His major area of interest is holistic health, where a human being is cared for with dignity, health wise, spiritually and physically.