Chapter 16
Scientific Response to Deadly Novel Epidemics: The Role of Health Research Ethics

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16.1 Introduction: Ethical Considerations During an Epidemic

Bioethics is an important inter-disciplinary and rapidly emerging field. The concept of biomedical ethics emanates from the process of doing right and good action in the biological and medical setting (Veatch 1999). In general, ethics has been defined as the moral principles governing or influencing conduct. *Ethics* is the science of criteria, norms, and values for human action and conduct (Beauchamp and Childress 2001). It is engaged in reflection and analysis of morals concerning whether an act is good or bad and how it influences our basic quest for meaning, our search for humanity, and our attempt to create a humane society (Engelhardt 2011). Its intention is to safeguard human dignity and to promote justice, equality, truth, and trust. On the other hand, *Medical ethics* is not only about the moral behaviour of clinicians, but about ethics and health care (Andorno 2009; Jacobson 2007). It can be described as a reflection on moral actions within the framework of health care. Its objective is to promote health, to care, to heal, to alleviate pain, and to prevent suffering (Jacobson 2007).

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Major international guidelines for the conduct of medical research identify three universal principles which should guide the conduct of research. These include the principles of autonomy, beneficence/maleficence and justice (Department of Health, Education, and Welfare and National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 2014). Historically, these principles were developed following a series of inhumane medical research with the goal of safeguarding the rights and dignity of research participants.

In 1947, the Nuremberg Code was created as a result of the unethical experiments carried out during World War II at Nazi war camps by German physicians. Consequently, these physicians were tried and charged at the Nuremberg Military Tribunal. Ten codes were developed during the trial that set forth the ethical principles that guide the conduct of research involving humans (Code 1949). The Universal Declaration of Human Rights (December 10th 1948) was also adopted and proclaimed by the United Nations after the atrocities of World War II and it further reiterated the human factor involved in medical experiments (Howard-Jones 1986; Macrae 2007).

The Declaration of Helsinki was developed in 1964 by the World Medical Association (WMA) which put a lot of focus on the protection of the rights of human subjects. Subsequently, WMA developed the Declaration of Helsinki that involves ethical principles aimed at guiding physicians and other participants in medical research involving human subjects (Declaration 2013; World Medical Association 2008). The Declaration of Helsinki emphasises the duty of the physician to promote and safeguard the health of the people. In 1979, The Belmont Report was developed by the National Commission for Protection of Human Subjects of Biomedical and Behavioural Research which identified the three main ethical principles which have come to be known as the universal ethical principles and include (Department of Health, Education, and Welfare and National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 2014):

1. **Respect for Persons**: This principle acknowledges the dignity and freedom of every person. It requires obtaining informed consent from research subjects (or their legally authorised representatives)
2. **Beneficence**: This principle requires that researchers maximise benefits and minimise harms (non-maleficence) associated with research. Research-related risks must be reasonable in light of the expected benefits.
3. **Justice**: This principle requires equitable selection and recruitment and fair treatment of research subjects.

Worthy of note is that, although the development of the principles was well intended, their application in different contexts has been the subject of debate for several decades. Understandably, these debates have been well-intentioned, given the diversity of communities and circumstances where these principles are applied, including where there are huge power imbalances between researchers and research participants as well as deficiencies in health systems, huge health burden, economic disparities which expose communities involved in research to unique and varied forms of vulnerability that require more rigorous protection than provided for by the mainstream ethical framework.

Indeed, most of the ethical issues related to research in public health emergency situations are the same as those already addressed in general ethics guidelines governing biomedical research. Problems are however likely to arise with regards to perceptions of risks, benefits and trust which must be taken into account in the ethics review process; a heightened need for attention to organizational values like accountability and transparency; and the fact that, there may not be sufficient time for standard ethics review processes which in many countries can sometimes take months (Morrison et al. 2009). It is essential that clinical trials conducted during an emergency observe all the necessary ethical review processes. Importantly, oversight and regulatory authorities must be particularly keen to ensure research participants are not put under unreasonable risks and are adequately respected and protected. If there is any step that should be exempted or avoided, such a decision should rest on the appropriate regulatory authority or Research Ethics Committee (REC) instead of the individual researcher/Principal Investigator. On the other hand, regulatory authorities and RECs should come up with ways that will ensure a fast but good quality review is conducted before approval is granted.

Finally, there is a critical need to ensure REC members are adequately trained and that nations and regions have adequate capacity to conduct thorough ethics review. Existing gaps may be complimented through the use of novel methods of ethics review such as online review platform (www.rhinno.net), outsourcing of reviewers from external experts who have the knowledge, experience and expertise to carry out the required review and able to appreciate the urgency of the review. Importantly, Researchers, public health agencies and other stakeholders should work together to develop short courses, degree programmes and other training modalities aimed at building skills and capacity of local researchers and regulatory authorities to ensure optimum protection of research participants. For Africa where epidemics have the greatest impact, it is important to ensure that funding agencies direct appropriate support towards capacity building to ensure a timely and robust review is conducted during an epidemic.

16.2   Challenges with Mainstream Bioethics Frameworks

There is no doubt that mainstream ethical frameworks rely heavily on a western epistemology. For example, although aimed at protecting individuals involved in research, the principle of autonomy puts a lot of emphasis on an individual's ability to make a free and informed choice; and places the individual as an independent and autonomous agent. As such, it assumes that once the individual has been given all the necessary information, is deemed to be of sound mind and competent capacity to comprehend the information given; and makes an independent choice free of any influencing factors, then that individual's decision is deemed final. In her book *Moral Prejudices: Essays on ethics*: Harvard University Press; Baier (1995) notes that this approach assumes equalization of power. Unfortunately, it fails to take into account situations where some individuals may lack full autonomy because of

certain positions, roles prescribed to them by the community or certain conditions that may make them feel powerless and unable to exercise their full autonomy. In such circumstances, applying the principle of autonomy in its strict form may not augur well with the tradition and expectation of such a community or make the particular individual any better, in exercising their autonomy. Furthermore, if bioethics is concerned with the moral principles associated with doing what is right or good, then it is important to appreciate that what is good or right depends on the context and what the people believe is right or good in that context. For example, it is acceptable all over the world that respecting people is generally a good thing. However, the way one community shows respect may differ greatly with how another community shows respect. This is true for many actions and behaviour in life, which may be acceptable in one community but remain unacceptable or even an abomination in another community.

According to the internet encyclopedia of philosophy, the traditional but deficient view concerning ethical reasoning and decision making in applied ethics is that one simply "applies" a particular ethical theory such as utilitarianism or deontology in a given context in order to solve the moral problem in question (Bacon et al. 2008). This top-down approach of ethical reasoning and decision making adheres to the idea that ethics is quite similar to geometry, in that it presupposes a solid foundation from which principles and general rules can be inferred and then applied to concrete cases independent of the details of the particular case. The locus of certitude, that is, the place of the greatest certainty for principle ethics---approaches using one master principle---concerns its foundation; the reasonableness of the ethical decision is passed on from the foundation itself.

What Needs to Be Done?
The above examples demonstrate how difficult it is to have universal bioethical principles. This calls for the need to develop an indigenous African framework that will take into account some of the context-specific issues related to conducting research in Africa. A few attempts have been made to develop or advocate for the development of more culturally sensitive guidelines, including Yoruba, indigenous groups in New Zealand, Canada and Australia and the Aboriginal communities.

This chapter presents a framework for ethical conduct of research in indigenous African contexts. We believe that this framework will be used to guide all researchers and research ethics committee on the best practices in conducting research in Africa.

Why Is It Necessary to Have an Africa Indigenous Framework for Bioethics?
According to Onuoha (2007), a bioethics framework is supposed to be a system that informs all bioethical practices and choices. In addition, it should guide ethical evaluations of the actions, decisions and policies of individuals, groups and organisations and must provide the ground for the articulation of duties, obligations, and expectations of those involved in making bioethical decisions (Onuoha 2007). Despite the existence of what is claimed to be universal bioethical rules and principles, these principles do not resonate with the holistic view held by African cultures (Chukwuneke et al. 2014; Onuoha 2007). For example, the way Africans

perceive the concept of health and illness, death and the dying and personhood as a whole differs significantly with the western construction of the same. As such, biomedical ethical principles developed in the west have been known to be highly individualistic, with a strong leaning towards the western culture but failed to incorporate the pluralistic and communal nature that defines the majority of the Africa culture and epistemology. During an epidemic or any calamity for that matter, most African communities tend to be more cohesive and come together to offer moral support and demonstrate their togetherness and brotherhood. Such behaviour, while offering moral support might promote the spread of highly infectious diseases. Without this understanding, any principles applied in this context that might be seen to negate the prevalent African spirit might be construed to lack respect for the cultural values of the community and be divisive. Understanding this behaviour can lead to developing effective ways through which the community can be well engaged, feel respected and be more responsive to any proposed intervention during an epidemic.

The need to develop an indigenous African bioethics guideline is also informed by the process from which the universal principles were developed. In addition to the principles being individualistic and western-culture oriented, the process followed to develop these principles talks nothing about how Africa as a region or continent was involved. For example, major international guidelines on ethical conduct of research link the genesis of biomedical ethical principles to the infamous atrocities conducted in the early 1900 and during the First World War, including the Tuskegee and the Nazi experiments. Accordingly, during the trial of the Germany Nazi physicians, some 10 codes were identified as key in the conduct of research involving humans. These codes were later modified and developed to what came to be known as the universal ethical principles. Importantly, throughout the process, the contribution of African philosophers and experts in developing these codes is completely missing. In fact, the codes were developed during an era when Africa was still perceived as the "dark" continent, with absolutely nothing to offer in the process. Thus, the process assumes Africa as merely a recipient rather than an active and equal partner in developing the guidelines. This presumes Africans as a whole are at a disadvantage and unable to participate in the process. It is no wonder therefore that the codes do not take into account the African culture, value and epistemology.

There is no doubt that the African continent makes a significant contribution to the medical research field. Recent decades have seen a massive increase in the number of studies and clinical trials being conducted in Africa. With the majority of these studies being transnational studies that are funded by the West but implemented in Africa, it makes sense that the claimed universal ethical principles, which guide the conduct of such a large volume of research in the region take into account the unique cultural and world view of the African continent. Unfortunately, there is a huge gap regarding the extent to which the current ethical guidelines take this into account. The discussion presented in this chapter provides insights on how this gap can be filled. There is no doubt that the international ethical guidelines have been extremely important in shaping the conduct of research in the world. In fact, the

whole world can take pride in conducting more ethically sound research as a result of the existing ethical guidelines. However, given the dynamics of research, it is high time that an indigenous African bioethics framework was developed that can take into account important dimensions that influence bioethical practices in the African context, including but not limited to ethnicity, culture and language; all of which differ significantly from the West. Importantly, such a framework must be sensitive of and respect the pluralistic and communal nature of the Africa culture and be based on Africa's own ethnological, cultural, and philosophical underpinnings.

To do this effectively, it is important that such guidelines appreciate the diversity of African cultures. African bioethics guidelines should be premised on the understanding that Africa operates under a context of unique cultural, economic and researcher-participants power dynamic where the majority of transnational clinical studies take place.

16.3   Guideline/Framework for Conducting Research in Africa

Important principles to be considered when conducting research in Africa, especially during an emergency epidemic include;

16.3.1   Respect for the Community Hierarchies and Leadership

The Mijikenda community, which is a collection of nine tribes; and one of the biggest tribal groupings in Kenya have a saying that goes "*sikiro karikira kitswa*", which literally means, an ear can never grow longer past the head. This saying is often used to send a strong message regarding family and community hierarchies that are not written anywhere yet every member of a family or a community is expected to adhere to. Many a time, this saying is used to warm people when they try to override the decision of older people in the family or community. In such cases, it doesn't matter how old you are; when someone above your age tells you something, their decision is final. This saying applies in most African communities. For example, most people in Africa believe that when an adult gives the final decision and a young person overrides that decision, something bad will happen to the young person, including that decision backfiring or a bad incidence happening against them. Thus, in this community, the final decision maker in any serious matter regarding the family or any member of the family is usually the most senior member of the family.

Although this example relates specifically to the Mijikenda community, most African societies have a very deep respect for familial or communal hierarchies. In most African settings, elders are believed to possess immense wisdom which allows

them to critically consider all corners of the world before making their decision. In addition, because of their age, elderly family members have a lot of general life experiences-with a rich knowledge base which they are expected to utilize to facilitate decision making. This is why elderly men and women are often consulted to tackle complex issues in the community. It is also for this reason that young people are required to defer decision making to the elderly members of their families, even when the person is an adult and able to decide on their own.

This is an important principle to be observed when conducting research in Africa. Observing this norm will ensure families involved in research remain harmonious after research comes to an end. This is also a show of respect for the values withheld by families or communities involved in research. Although the universal ethical principles advocate for individual autonomy, it is important to apply this principle within the acceptable African norms and values. For example, when implementing research in a given community, it would be important for the researcher to first obtain permission from the highest traditional ruler of the region before approaching the individuals for individual consent. Additionally, where for example, the head of a household refuses to allow members of their household to participate in a given study, it should be the duty of the research team to find out why the old man refused and come up with ways through which the expectations of such people can be included in the research planning and their concerns addressed. Perhaps one may argue that this process is too tedious and practically complex to implement. Of course, this is likely to be the case when there is a lot of focus on getting studies implemented as oppose to putting emphasis on the actual process of implementing such projects. It is especially important to realize that studies that follow procedures that are acceptable in the community, such as the one described above, are more likely to be seen as respectful to the community hence better able to win the community trust and receive overwhelming support from community leaders and members. This may ultimately make recruitment of research participants easy, reduce mistrust and promote uptake of research outputs after the study. Similar approaches have recently been advocated for by proponents of community engagement and community-based research approaches.

It is also important to understand that a human being in the African context is not merely an individual who is autonomous, independent and mentally competent and able to make an independent decision. In fact, a human being is considered to be of sound and stable mental state; competent; and a reliable adult if such a person is able to articulate the societal hierarchies and defer issues such as critical decision making to the social entities bestowed with the moral and legitimate authority to make such decisions. For this reason, a person who ignores the existing channels of decision making is considered to be disrespectful and undermine the decision-making authorities. This construction of personhood is embedded in all aspects of life, including upbringing of children, ownership of property, ill and good health just to mention but a few. For example, although the key responsibility of child upbringing rests on the parents, when a child misbehaves, anyone in the community has a right to reprimand or punish the child without obtaining permission from the biological parents. This holistic and pluralistic construction of the person has impor-

tant implications on decision making. People who have very close ties to a village, for example, might feel much respected and develop trust in the research team if they knew the village elder was already informed and gave permission for everyone to give consent. Understanding these contractions and perceptions can help researchers to appreciate the entire cobweb of interconnectivity among people in the community and provide space to discuss alternative decision-making mechanisms which the community deems most appropriate and acceptable, which is paramount especially in delicate and sensitive matters affecting the community.

We would, therefore, like to advocate for a more inclusive approach to community entry, consultation and informed consent seeking in which, hierarchies for community leadership and entry are identified and followed in order to enhance respect for the structures which the community reserved respect for, before seeking individual consent. In addition, where discordance arises between the prescribed community hierarchies and the target individuals, research teams should solve such differences amicably and only involve the target individuals when doing so is likely to promote harmony between the parties involved. This is a much wider and a more inclusive construction of the principle of respect, acceptable in many parts of the African continent.

16.3.2   Health and Illness

Most communities in Africa believe that health and illness are both associated with God's will. For example, across East and West Africa, a number of communities believe that one lives a healthy life because God/Allah has allowed them to be healthy and they become ill when God/Allah wishes them to be so. Accordingly, God/Allah operates in a spiritual manner, hence, although no one can see God, he is present everywhere. In certain parts of Africa, they believe God exists in the form of spirits that take different shapes, including fellow human beings, birds, plants, and other living things. These spirits operate in two main distinct categories, namely, evil spirits and angels/good spirits. Evil spirits are responsible for causing ill health while good spirits (sometimes called Angels) are responsible for good things, including health. Thus, when one gets sick or experiences a bad incidence in life, it means they have committed some bad acts that made God angry or someone prayed to God that they get sick or experience such a bad incidence. It is for this reason that some communities believe that no medicine-traditional or biomedical-has healing powers unless God grants such powers. In fact, most people believe that doctors and all traditional healers are merely a conduit through which God sends his healing to individuals who have ill health. It is therefore common for people to say "*mulungu nde andekuhoza*" meaning God is the one who will heal you, soon after a treatment has been administered to a sick person, even when they are not believers per se. This implies that regardless of how good your treatment is, actual healing comes from God.

The belief that good health and ill health all come from God also implies that people who cause ill health and those who treat, all must pray to God for such action to happen including witchcraft. It is all a matter of who has the strongest faith. Importantly, there is a strong connection between ill health and evil spirits or evil power. Thus, when one becomes sick, its either they have some evil spirits or some witchdoctor exerted some evil power in them. For this reason, most people believe an effective treatment should involve negotiating with the bad spirits to leave the sick person's body or extorting them by force through some medicine. Of course, underlying this whole process are either direct or indirect prayers to God.

This belief system on the origin of health and illness has a strong influence on the health-seeking behaviour of the indigenous community. It is for this reason, for example, the Mijikenda community from Kenya, in East Africa; rather take their children suffering from cerebral malaria to the traditional healer as opposed to the hospital. To them, cerebral malaria is caused by a bad spirit that gets into the child through a flying bird called *yuni*. When *yuni* flies over a child, the bad spirit enters the child and the child starts convulsing. During convulsions, if the child is given an injection, the injection aggravates the spirit and the spirit then kills the child. They are therefore better off taking the child to a traditional healer who will negotiate with and peacefully take the spirit out of the child before giving the child an oral concoction.

Although not exactly related, similar views related to the existence of bad and good spirits are also held by those following Christianity and Islamic values. Although Christians rarely consult traditional healers, almost all religions in many African settings believe in extorting evil spirits as part of the healing process. Interestingly, quite a number of communities believe in the healing powers of traditional medicine men.

The above epistemology may sound primitive but is important to understand and consider in developing ethical principles that respect indigenous African cultural values. In so doing, it is important that such principles take into account how such indigenous knowledge and values can be incorporated into any framework developed. For example, the knowledge possessed by traditional healers and what they practice in treating people during an epidemic should be considered and incorporated into any public health education and future interventions that may be developed towards the treatment of the prevailing condition/disease. Acknowledging the original source of this knowledge in a publication is a good way of showing respect to the indigenous community and sharing the benefits of the research output; while pursuing alternative methods of managing the disease. In addition, understanding the link between health and illness; good and evil spirits and the power of the will of God towards good and poor health may enhance how discussion and messages aimed at restoring an individual's psychological and full health could be formulated.

Indigenous African bioethics guidelines, therefore, should underscore the need for researchers to take time to understand from the community perspective how they conceptualize health and illness and consider these constructs into any interventions they develop. Importantly, as primitive as these concepts may sound, it is important

that anyone conducting clinical research in the affected community acknowledges the existence of the indigenous knowledge and credit it in publication if they utilize such information in any way in the process of their research. It is also important to understand that, before the introduction of biomedicine in the community, the community had respect for life and followed an indigenous health system that took care of all their health needs. Rubbishing this system as primitive only serves to ridicule the community that has been part of these practices since time immemorial. Using a dialogic approach that allows both traditional and biomedical worldviews to prevail is likely to nature a more harmonious co-existence of both views. This way, an environment filled with mutual respect and understanding is likely to prevail. It may also be important to understand why so many indigenous people trust traditional medicine men. Trust is an important component of value ethics that must be natured between researchers and the community at all times, and more so during an epidemic. Understanding what constitutes trust and what attributes the community considers essential in nurturing trust is essential in ensuring researchers who work in the community use the same attributes to develop appropriate levels of trust with the community members.

16.3.3   Gender

There is a notion that most African settings undermine the status of women. This is a notion that is often misinformed. Many African men are brought up in a belief system where men are expected to provide for and protect women. As such, there is a tendency for men to undertake the most challenging roles in the society and leave the light or less challenging roles to the women. Because of the need to protect women, women's roles have often been overshadowed by the men's prominence in undertaking their roles. Over time, most African women have been brought up in families where the role of women is defined as the 'nurturer'. On the other hand, most parts of Africa believe that a respectful woman is one who listens to and is less aggressive compared to their male counterparts. Part of this submissiveness involves the ability to consult with spouses and senior members of the family before making decisions, understandably because most families in the old days lived in extended families and making certain decisions that had serious implications on the family would be too heavy a responsibility for any one person to undertake, especially given that women often joined their matrimonial families. The requirement for women to consult their spouses and avoid making unilateral decisions is also related to the issue of familial hierarchies discussed above. Unfortunately, recent debates around this issue have been reduced it to a gender and women exploitation issue, a view that is often misguided and misinformed.

   One issue that Africans have guarded selflessly is the importance of their family ties. Most African settings believe in the need to promote, protect and respect the family unit. Importantly, the woman is considered as a critical element of the family. Within the Giriama community, in Kenya for example, there is a saying that goes

"*mudzi ujengwa ni muche*" meaning, a home is built by a woman. This implies that the woman is the key pillar of a family. Contrary to the popular western belief about African women as being submissive and oppressed, there is a very huge responsibility the society places on women, which entails ensuring the family is always well kneaded together and at peace. This responsibility is often unspoken but no doubt the most important role in a family. In fact, many people believe that a happy family and disciplined children usually reflect the behaviour and family management skills of the woman in the family. So important is the responsibility of a woman towards maintaining the family ties that the Giriama have a saying that implies that if a woman decides, she can break an entire family (not just her home) in a day. One important way that is believed to keep the family, especially amongst the rural communities in Kenya is the need to continuously consult among family members. Understandably, this promotes collective responsibility, mutual respect and harmony in families and avoids unnecessary disagreements and tensions. Unfortunately, the inability for women to make outright decisions in order to consult their spouses or significant family members has often been blown out of proportion and reduced to feminine talk.

As stated previously, mainstream bioethics guidelines were developed with the western cultural context in mind. As such, there is an assumption that every potential research participant would be an independent autonomous agent who would be able to make free and informed unilateral decision. Obviously, this does not apply in certain settings in Africa. There is, therefore, a need for researchers to create a dialogic space between spouses and family members and facilitate them to reach consensus regarding their participation.

Within extended families with married couples; many decisions concerning the wife are made in conjunction with the wife. However, advice and final words may be from the husband. On this basis, rather than regarding family consultations as a manifestation of the women oppression and indecisiveness, this should be encouraged, respected and natured as an important African family value. Where necessary, information about studies should be given to both spouses, where the researcher's role becomes to facilitate and allow the couple to make informed choices.

Excluding husbands from influencing the decision making of their wife, for example, only serves to create doubts, anxiety and unnecessary tensions during participation. These types of tensions should be avoided as much as possible by ensuring researchers proactively create space for consultation and collective decision making among significant family members and spouses, even if the target participant is an independent woman.

16.3.4   Power Differences

Much of the discussion around power differences between researchers and research participants, especially during epidemics, relates to congested and constrained health systems which often lack adequate supplies to meet the health needs of the

population. As such, people involved in research may find themselves in a situation where the research product constitutes the only health care accessible to them. Such situations make the already vulnerable populations; by virtue of being poor, even more vulnerable. In addition, researchers may be seen to belong to certain elite social classes. This may make research participants feel powerless and unable to refuse whatever is asked of them, not forgetting that participants may not even have the mental capacity to comprehend the information being given to them, due to the conditions they are going through at the time. This scenario was well presented in the case of Mama Kadzo in the previous chapter. But a less obvious aspect related to power differences relates to communication and complexities of communication tools used. It is an undisputed fact that all participants need to be given all the necessary information before making an informed decision. However, understanding such information requires having a great level of competence, and sometimes specific speciality in a given area of study. Although not always obvious, the use of technical language and medical jargon often renders research participants totally helpless as they struggle to understand the different concepts presented. This is a common mistake made by many clinical-research personnel!

While GCP guidelines and the principle of respect for persons emphasize the need for a truly-informed consent, little is said about how to achieve this principle. It is important to appreciate that most people in Africa may have low literacy level. As such, they are linguistically challenged in comprehending complex terminologies which are usually used in clinical research protocols. On the other hand, it is important to understand that low literacy level does not denote stupidity or foolishness. In exactly the same way that foreigners struggle to understand the local language, so do local people struggle to understand complex medical terminologies. It is therefore important to ensure indigenous language is used to communicate key concepts in the research. To facilitate this process, research teams must utilize available resources such as local idioms, terms and analogies to ensure the messages being communicated are understood and that potential participants are able to relate to these messages. For example, instead of using technical terms to explain research (a term that is often misunderstood) community members could be asked to explain how they discovered a local plant is useful in treating a certain illness. Their explanation could then be used to facilitate explanations about medical research. Through this process, the community would be better able to understand the research being conducted and be able to contribute toward it in a more meaningful way.

Another important aspect related to power imbalance is lack of resources on the part of the community involved in research. This may mean that, while the research team's priority may be to find a cure for a certain epidemic, the community may have a different priority altogether. It is important that researchers planning to conduct research in Africa do so in consultation with the community. In addition, such consultation should endeavour to empower the community and improve their general wellbeing through support from the research team. This may be achieved by ensuring the target community is involved in the planning and implementation of the research as well as in disseminating the research finding. Using employees drawn from the community involved in the research may ensure there is more trust

in the research being conducted. On the other hand, employing such cadre of staff impact positively towards the living standards of the community involved. Carrying out community consultation should not be done as a public relations activity but as an integral part of the research project. This way, views and ideas gathered through the process of consultation can be used to directly inform the study team on the best ways to improve the conduct of the research. Additionally, projects identified by the process of consultation that had not been previously thought of as part of the research project may be added to cater for the community needs and expectations. This way, the community will be able to feel respected as equal partners in planning and executing the research as opposed to being treated as recipients of the research.

16.4   Conclusion

This chapter has argued for the need to have an inclusive and Afro-centric approach in the application of the universal ethical principles. In addition, the chapter has presented some limitations associated with the existing guidelines and proposed several ways through which the principles can be made more sensitive and responsive to the indigenous African culture and moral principles that promote the value system and aspirations of all Africans within and without the continent. In doing so, this chapter tried to use as many local examples as possible, including how the various principles can be applied on the ground. Although the proposed framework may not address all challenges; given the wide-ranging diversity within and without African national boundaries; this chapter provides insights on how researchers can conduct clinical research in Africa that takes into account the true African context where the research will be conducted. The authors stress that public participation in the crafting of such a framework and guidelines will be important in creating popular acceptance of the difficult choices that must be made during an epidemic.

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