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Social Science Research Ethics in Africa

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Preface

Social science is the scientific study and research of human society at large, as well as the relationships and interactions among different groups and individuals in specific. Modern social science is a relatively new form of science which has its formal origins in the period following the enlightenment in the late seventeenth and eighteenth centuries (Heyck 2015). However, the importance of social roles and responsibilities predates the formal proclamation of this academic field. Regardless of the birthdate of formal social science, the fact exists that compared to other sciences, it is a relatively young field of study with unique attributes and challenges in a technologically advancing world. To some extent, the natural sciences, with more predictable variables, can be easily codified and controlled through various protocols and guidelines (i.e. good clinical practice guidelines, US Food and Drug Administration codes, research protocols). The same cannot be said for the social sciences, as one of the main focal areas is the study of human behaviour and relationships, which can easily be influenced by researcher bias and other contextual factors.

The primary purpose of science is to understand the world we live in and how it works; this is closely linked to the secondary aim, namely, to apply this knowledge (Heyck 2015). Assuming that knowledge will be applied, it will consequently influence the environment of living organisms. This in turn leads one to the question "what is good science" since the hypothesis can be posed that good science will lead to good outcomes for living organisms. As a potential outcome to this hypothesis, it could be postulated that good science needs to be built on the values of trust and integrity in as much that society at large needs to trust scientists to present the results of their research with integrity (Horn 2013). The scientific community has endeavoured to build this trust and conduct research with integrity by virtue of codifying specific behaviours and attitudes in the form of research ethics principles. General human rights atrocities and scientific misconduct of scientists during the Second World War (i.e. German Nazi doctors' research and Japanese researchers at Unit 731 in China (Tsuzuki 2000)) gave rise to formal codes of ethics. Certainly one

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of the most well-known initial guiding documents of research involving human subjects is the Nuremberg Code of 1947 (Bauman 1993). This code has consequently been followed by many other widely recognised codes, such as the 1948 Universal Declaration of Human Rights by the United Nations, the Declaration of Helsinki (first version in 1964) by the World Medical Association, the 1978 Belmont Report by the National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research in the United States in response to atrocities of the Tuskegee syphilis study and the code by the Council for International Organizations of Medical Sciences (CIOMS), to mention but a few (Callahan 1995).

On the African continent, research on human participants has largely been guided by the codes and guidelines developed by various Medical Research Councils which were established towards the middle of the previous century, in particular South Africa (1969), Egypt (1971), Zimbabwe (1974), Nigeria (1977), Tanzania (1979), Kenya (1979) and Uganda (1988) (ASRT n.d.; MRC/UVRI Uganda Research Unit n.d.; Ndebele et al. 2014; NIMR n.d.). Although the work done by all these national organisations over the last almost half a century is commendable, especially in the fields of HIV/AIDS and tuberculosis (TB), there is still a gap at large regarding the capacity, policies and guidelines governing social science research on the African continent (Mutenherwa and Wassenaar 2014). It is not difficult to appreciate the significant need to address the issue of social science and integrity in Africa when reflecting on the social questionability of various studies conducted in developed countries over the years. The most well-known of these studies include the following: Stanley Milgram's 1963 study on obedience to authority (Milgram 1974), Robert Humphreys' 1970 "Tea Room Trade" study looking at homosexual behaviour of men in the United States (Allen 1997), Philip Zimbardo's 1971 Stanford Prison Experiment (Carnahan and McFarland 2007), Dutch social psychologist Diederik Stapel's work on race and stereotyping (Bhattacharjee 2013) and the 2006 US Army's "Human Terrain System" programme where social scientists were used to assist the US Army in warfare matters (McFate and Laurence 2015).

To this effect, leading African scholars from different fields have combined their years of research and experience to give insight into research ethical issues faced by social scientists in Africa. The collective experiences from all the authors bring with it an innate understanding of the uniqueness of the African continent and also the challenges posed in the drive to establish the discipline of research ethics and integrity across the continent.

To give voice to the principle of doing and presenting research of high standards as well as great integrity, all the chapters underwent double-blind peer review, and feedback was sent to the author(s) for each chapter. After the comments were integrated into the chapters, they were resubmitted and reviewed again. Upon final submission of the manuscript, the publishing house had the whole manuscript

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peer-reviewed by a panel of external expert reviewers. We are therefore confident that the scholarly work presented here will inform the debate on research ethics in Africa in a positive and constructive manner.

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Chapter 1
Research Ethics Governance – An African Perspective

Marelize I. Schoeman

Abstract Governance structures in research are generally a retrospective response to unethical research practices. Similar to the international research landscape Africa has not been immune to human research abuses inclusive of unethical experimentation and clinical trials. An increase in research was noted in Africa this past decade in response to serious psychosocial and health-related challenges the continent faced. This increase in research has not necessarily brought about improvements in the governance and oversight of human research practices. In contrast, it increased the risk of exploitative research funded by resource-rich countries who conducted studies in Africa that would be difficult to conduct in countries with more established and strict research regulatory frameworks.

Even though the impact colonialism and the internationalisation of research had on ethics governance is recognised, African scholars is of the opinion that the debate about research ethics governance largely represents the opinions of scholars from Euro-western countries, with little contribution being made by African scholars. Against this background, the chapter presents an Afrocentric viewpoint of research ethics governance. In addition, Westernised and African research ethics practices and oversight structures were compared to identify challenges and guidelines. The research ethics governance landscape is to a large extent still an uncharted landscape creating the opportunity to develop a research ethics governance framework that acknowledges the unique humanistic morality and normative set of social rules and principles that guide the conduct of people in African societies. The chapter aims to make a significant contribution by stimulate critical discourse about the relevance of ethical principles and governance structures currently used in Africa.

Keywords Research ethics governance · Research ethics committees · Biomedical research · Social science research

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1.1 Introduction

Contemporary research ethics governance is based on a system of scientific peer review under the auspice of institutional Research Ethics Committees (RECs). The debate for and against the use of protocols to govern research ethics, more specific in social science research and behavioural studies, is ongoing and active.

Historically, a model of self-governance was followed where the ethicality of research was the responsibility of a researcher and based on the professional judgement of the researcher as an individual and as a member of a scientific community (Dingwall 2012; White 2007). Unethical biomedical experimentation and the exploitation of vulnerable groups resulted in the need for a more formal system of governance. Consequently, research ethics governance shifted to a system of institutional regulations which currently applies to most research projects. This approach is widely criticised, particularly by social science scholars who are of the opinion that ethical regulations in social sciences are based on a model used for biomedical research which is not applicable to social science research. Several authors are very vocal in their protest (Iphofen 2017; Dingwall 2012; White 2007). According to Israel and Hay (2006, p. 1)

> Social scientists are angry and frustrated, their work is constrained and distorted by restrains of ethical practice who do not necessarily understand social science research.

Traditionally institutional governance was associated with the conduct of government. Within the past 15 years the emphasis shifted to also acknowledge the role that governance structures play in the social development and the creation of good institutions (De Vries 2013). In South Africa, the King IV Report expands on this idea by defining Corporate Governance as “the exercise of ethical and effective leadership” to create an enabling environment for “ethical culture, good performance, ethical control and legitimacy” (IoDSA 2016, p. 20). The values underpinning ethical and effective leadership are integrity, competence, responsibility, accountability, fairness and transparency for the purpose of achieving strategic objectives and positive outcomes (IoDSA 2016). These values will be investigated in this book as they pertain to social research ethics in Africa. These normative values are entrenched in the characteristics of good governance, namely it follows the rule of law, it is participatory, consensus-oriented, accountable, transparent, responsive, effective and efficient, equitable and inclusive. It aims to minimise corruption and ensure that the voices of vulnerable members of society are heard in decision making. Lastly, it strives to recognise the needs of present and past societies (Sheng 2006). Good governance is thus supposed to be an interactive process in which both formal and informal role players are acknowledged. Within the context of research ethics governance this implies recognising the research institution and any other organisational contributors (such as funders), the researcher but also the research participants and, if applicable, the communities they come from.

In essence governance, including research ethics governance, equates to the development of a regulatory system whereby both managerial decisions and the

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processes by which such decisions are implemented strive to improve society at large. As a former chair and current member of a research ethics committee (REC), and a passionate researcher, the author questions if the current system used to govern research ethics is achieving this within a diverse African context.

The chapter aims to describe the research ethics governance landscape from an African perspective. The chapter commences with a historical overview of the development of research ethics governance internationally and nationally followed by a description of the research ethics governance structures and frameworks in Africa. The differences between the assumptions underpinning research ethics governance from a Westernised and African perspective is explored in the third section. The chapter concludes by identifying challenges and proposing guidelines for research ethics governance in Africa.

1.2 Historical Overview of the Development of Research Ethics Governance

There is a distinct difference in the development of research ethics governance in biomedical and social science research. Notwithstanding this, the review process for both biomedical and social science research is to a large extent grounded in similar research ethics principles and procedures. This is the cause of controversy and heated debate among scholars since there is a distinct difference between the knowledge generation methods and knowledge matrix as well as the risks and benefits associated with research projects in these two fields (Chaps. 4 and 6 describe risks and benefits in social science research in more detail). In addition to this debate a debate questioning the relevance of Euro-western ethical principles and governance are also taking place among African scholars (as eluded in Chap. 2). It would be greatly important to take note of these debates in order to understand the factors that shape research ethics governance in Africa.

1.3 Biomedical Research and Health Studies

Research ethics governance in biomedical research originated as a retrospective reaction to the abuse of human research participants in the Western world. Examples of biomedical research, that shaped ethical governance include the Tuskegee syphilis study (1932–1972) and Nazi experiments that resulted in the Nuremberg trails. The Nuremberg code was established in 1949 as a direct result of the trails against 23 German physicians who conducted unethical medical experiments during the Second World War (Dingwall 2012). The code consisted of ten standards for medical experimentation on humans as laid down by the Nuremberg war crimes tribunal. The code was the first international document which advocated for the principles of

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voluntary participation and informed consent in research. It also included the ethical principles – do no harm, the right to withdraw from a study and the benefits versus risk determination. In addition it specified that researchers should be appropriately qualified for a study. These principles are currently still used as guidelines by RECs to review the ethicality of research projects.

The Nuremberg trails also resulted in the promulgation of the Declaration of Helsinki (1964) and the development of the International Ethics Guidelines for Biomedical Research Involving Human Subjects (CIOMS Guidelines) in 1982 (Israel and Hay 2006). The Helsinki Declaration expanded on the Nuremberg code by including a regulatory framework for research ethics governance in addition to the ethical principles researchers must adhere to. The regulatory framework determined that a research protocol should be developed for each study and that the protocol should be reviewed, and approved, by an independent REC. Research protocols should contain information about the ethical considerations for a study and indicate the steps taken to ensure compliance with the principles outlined in the declaration. In addition, research protocols should also contain information regarding funding, sponsors, institutional affiliation, incentives for participants and/or any other potential conflicts of interest. In accordance with the Helsinki Declaration RECs have the right to monitor studies and researchers are obligated to provide information to the committee, especially in the case of serious adverse incidents (World Medical Association 2001).

The purpose of the CIOMS Guidelines, in turn, was to provide international ethical principles and procedures for biomedical and health-related research in low-resource settings (CIOMS 2002). Guideline 23 provides requirements for the establishing of RECs and for review protocols. Similar to the Helsinki Declaration guideline 23 also stipulates that all health-related research including humans must be submitted to a REC to access the study's ethical acceptability. Expanding on the Helsinki Declaration the CIOMS Guidelines determine that a study must obtain approval or clearance before the study commences. It also includes specific guidelines for the composition and functioning of RECs (CIOMS 2002).

Another seminal document in the ethics governance landscape was the Belmont Report (1979) which was developed by the United States' Commission for the Protection of Human Subjects of Biomedical and Behavioural Research (NCPHSBBR) (Israel and Hay 2006). The Belmont Report bridged the gap between biomedical and social science research by including broader principles for ethical conduct in research relevant in the context of both biomedical and behavioural science research. Israel and Hay (2006, p. 35) is of the opinion that the ethical principles – respect for people, beneficence and justice is "intended to help understand the ethical issues associated with research involving human subjects". These principles remain an influential yard stick against which the ethicality of human research is measured.

It is clear from this discussion that from its inception research ethics governance in biomedical and health research developed to be a highly regulated field. This is contradictory to the development of ethics governance in social science research.

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1.4 Social Science Research

The development of research ethics governance in social science research was less dramatic and not triggered by overt disdain from public and professional communities as noted in the cases of biomedical human rights violation. Unethical research practices in social science research were not recognised and labelled as human rights violations but rather viewed as a moral wrongs or evils. Hugaas (2010) warns against minimising unethical behaviour in social science research as mere normative judgements. In this regard Hugaas (2010, p. 257) defines a moral evil as “to intentionally inflict pain and suffering on another human being, against her will, and causing serious and foreseeable harm to her”. In essence, unethical practices in social science research can result in “severe and often irreparable infringement of personal integrity – physical, mentally or socially” which constitute the violation of the principle of human dignity. Two notorious social science studies, the Milgram’s study of obedience to authority and Laud Humprey’s covert observation of the sexual practices of homosexual men are examples of where unethical behaviour transcends the boundaries of being a moral wrong to become violations of participants’ human rights. It not only highlighted unethical practices in social science research but also emphasised the inaptness of biomedical ethics codes for the governance of ethics in social science research (Israel and Hay 2006).

Social science research initially functioned in a largely unregulated environment. Ironically, pressure to regulate social science research also originated due to the abovementioned unethical biomedical studies.

Since the 1960s the governance of research ethics in social science research gradually shifted from being the responsibility of the researcher to it becoming regulated by institutions. Institutional regulation generally consist out of individual research institutions developing their own policies and regulatory systems to govern research ethics. These policies serve to ensure compliance with legislation and international regulatory instruments (Wessels et al. 2015; White 2007).

Numerous authors (Dingwall 2012; Israel and Hay 2006; White 2007) are of the opinion that the governance of ethics in social sciences developed because of a need for institutional risk management rather than for the protection of research participants, as described in Chap. 6. The rationale for this argument lies in the difference between biomedical and social science research, more specifically the argument that biomedical research has a higher risk of harm to participants than most social science studies because experimentation may result in “physical damaging and irreversible consequences that are difficult to predict in advance” (Dingwall 2012, p. 12). In comparison social science research is viewed as having a lower risk because firstly, the data collected draws from information about participants’ personal knowledge and experiences. Secondly, social science studies are dependent on the willingness of participants to participate in a study. Resultantly, due to the perceived lower risk, social science studies do not warrant such a rigorous review process as used in biomedical research (Dingwall 2012).

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The Ethics Rupture Summit during which the New Brunswick Declaration (2012) was developed took place against the background of the debate questioning if a one size fits all approach for biomedical and social science ethical reviews are the best approach to follow. The aim of the summit was to explore innovative alternative regulatory approaches for the research ethics governance of social science research (Iphofen 2017). The innovative nature of the declaration is evident in its structure which includes a list of affirmations, beliefs and actions the signatories undertake to ensure ethical research practices. The declaration is grounded in mutual respect and advocates for the recognition of constructive relationships between all the role players involved in a research project. Researchers are held accountable to ensure that professional standards of competence, integrity and trust are upheld. In this regard the declaration also recognises discipline-specific ethical standards in the governance of research ethics.

The declaration follows a more organic approach by encouraging a variety of means for the regulation of ethical conduct. This approach acknowledges the diverse expectations of role players in the research process. It calls for a regulatory structure in which administrators have the same level of respect for the researchers as researchers have for research participants. By doing so, the declaration follows a communitarian and relational approach in research ethics governance aimed at promoting the reproduction of ethical communities of practice.

Lastly, the declaration views research ethics governance as a dynamic process that evolves in accordance with the research environment. It therefore calls for the recognition of exemplarity and innovative ethics review processes and mechanisms. Such governance processes and mechanisms develop from critical analysis and research in which researchers and scholarly communities work together to bring new experience, insight and expertise to research ethic governance (New Brunswick Declaration 2012). The acknowledgement of the role research communities should play in the governance of research ethics is specifically relevant in the African context as will be discussed below.

1.5 Research Ethics Governance in Africa

Similar to the international research landscape Africa has not been immune to human research abuses inclusive of unethical experimentation and clinical trials. This past decade an increase in research was noted in Africa as a response to serious psychosocial and health-related challenges the continent faced and continues to face. This increase in research activates has not necessarily brought about improvements in the governance and oversight of human research practices. African countries has large numbers of vulnerable groups who, due to socio-economic circumstances, have limited access to education and health services and who are prone to accepting authority without questioning the benefit of the research to indigenous people (Dube et al. 2013). This increases the risk of exploitative research funded by resource-rich countries conducting studies in Africa that would be

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difficult to conduct in countries with more established and strict research regulatory framework.

Governance of research ethics was influenced by Africa's history of colonialisation. As such, the Euro-western world played a significant role in the development of research ethics norms, standards and requirements in Africa. Current ethics governance systems are based on international guidelines for human participants and often follow either the US Institutional Review Board system or the World Health Organisation (WHO) guidelines for RECs (IJsselmuiden et al. 2012).

Research ethics governance systems in Africa often developed in order to comply with oversight requirements of international research partners who funded research. Such pressures and resulting influences of Westernised countries were not always welcomed. It is perceived that regulatory frameworks for research ethics governance in Africa is influenced by Western scholars with little input from those in Africa (Ndebele et al. 2014). Consequently, some research studies are not socio-culturally sensitive and fails to address national priorities or the needs of local communities. This gives rise to the perception of indigenous research communities that "researchers are like mosquitoes; they suck your blood and leave" (Dube et al. 2013, p. 13).

The first recorded health REC in Africa was established in 1966 by the University of the Witwatersrand in South Africa (Wessels et al. 2015). This was followed by similar initiatives in tertiary institutions and research organisations in African countries, such as Zimbabwe, Tanzania, Kenya, Zambia and Cameroon. According to the MARC Initiative, an interactive database of RECs in Africa, 171 RECs were recorded in African countries of which the majority is in Southern African countries followed by Eastern and Western African countries. Central Africa has the lowest number of recorded RECs (IJsselmuiden et al. 2012). Even though the majority of African countries have some form of ethics review system in place the ever-increasing interest in health-related research necessitates the need to strengthen research oversight even more so to ensure the protection of research participants, communities, institutions and countries in general (Ndebele et al. 2014). As will be discussed later on in this chapter, the disparity between Westernised and African worldviews is an ever present ongoing challenge that hampers the development of Afrocentric review standards for the governance of research ethics in Africa.

1.6 Research Ethics Governance Structures and Frameworks in Africa

As mentioned earlier in this chapter, research ethics governance in Africa is predominantly informed by international research ethics regulatory frameworks and principles, such as the Singapore Statement on Research Integrity, the Montreal Statement on Research Integrity in Cross-Boundary Research Collaborations, the UN Human Rights Charter, the Belmont Report and the CIOMS Guidelines. Nationally the African Charter and Protocol to the African Charter on Human and

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People's Rights of Women in Africa (African Commission on Human and Peoples' Rights (n.d.)) are important documents which advocate for individual informed consent in research. The affirmation of individual informed consent in research as a human right reiterates the accountability of African and international research institutions to ensure sound ethical governance in research. Afrocentric views on informed consent are discussed in more detail in Chap. 12 of this book.

Similar to international ethics review systems the review process in Africa also tend to follow a top-down approach where it is regulated by legislation or some form of national ethics governance framework. Since no uniform ethics governance structure exists in Africa, these frameworks include local models developed in different African countries, with institutional or regional reviews; centralised models, with reviews on national level or private reviews by research institutions. In some countries the research ethics review system used is still informed by legislation while in others it is still informal. Several countries has established national bodies to regulate health research, such as the National Institute for Medical Research (NIMR) in Tanzania, the Kenya Medical Research Institute (KEMRI) and the National Health Research Ethics Council (NHREC) in South Africa, as discussed in Chap. 9. These bodies are predominantly responsible for the regulation of health-related research (Ndebele et al. 2014).

Although great progress has been made in the field of research ethics governance progress in Africa, further development is hampered by social-economic challenges facing the majority of countries in Africa. The ineffective functioning of RECs due to inadequate standard operating procedures and insufficient training of committee members were also noted as challenges hampering the effective governance of research ethics in Africa (Ndebele et al. 2014; Kasule et al. 2016). According to Ndebele et al. (2014) these challenges are symptoms of an undeveloped research oversight system. It highlights the need for ongoing capacity building and resource development in Africa to ensure that vulnerable populations are protected from research-related abuse, as illustrated in Chap. 15. In addition, current regulatory systems, which is largely based on Westernised models, should be reviewed and adapted to become applicable for an African research and cultural environment.

1.7 Research Ethics Governance: Considering a Westernised and African Perspective

Contemporary research ethics principles, such as confidentiality and anonymity, informed consent and voluntary participation originated from the Nuremberg Code (1947), the Declaration of Helsinki (1964), the Belmont Report (1979) and the CIOMS Statement (1982). As mentioned, these guidelines were predominantly developed for biomedical research with the exception of the Belmont Report, which focusses on both biomedical and behavioural science research.

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The Belmont Report (1979) includes three basic ethical principles, namely respect for persons, beneficence and justice. The three principles articulated in the Belmont Report forms the basis of contemporary research ethics governance since it is regarded as a universal yardstick against which the ethicality of a research project is measured. The first principle, respect for people, speaks to voluntary participation in research. The dilemma RECs face in using this principle during reviews is to find a balance between protecting vulnerable participants while at the same time respecting their autonomy to voluntarily participate in a study. From the author's experience as a previous chair and current member of a REC, committee members tend to err on the side of caution and would rather not approve a study based on its perceived risk of harm than to acknowledge participants' right to make informed choices about participation.

It should be noted that cultural sensitivity is required from RECs when it comes to the principle of informed consent because the conceptualisation of informed consent within an African context differs significantly from a Euro-western one. Chilisa (2009), using Botswana as an example, explains that in Africa after an institutional REC approves a study the researcher has to consult with the chief of the village where the research will take place. The chief in turn will call the people of the village to council to deliberate about the study until consensus is reached. Only then will the researcher be allowed to conduct the study in the village. In addition to this process the researcher will also have to ask individual consent from key participants and group consent if data is collected from, for example, a father about his family (discussed in more detail in Chap. 12). This method of obtaining informed consent diametrically opposes the individualised system of signed informed consent that is central to the current ethics review process. It is questionable if such a level of cultural sensitivity is evident in current review processes in the light of the mentioned challenges African RECs experience (Chap. 9 provides a comparison of individual and collective consent).

The second principle, namely beneficence deals with the principle of doing no harm. In essence it focusses on maximising the benefits of the research for the individual participants as well as society while minimising the potential harm of the study. The dichotomous relationship between harm versus benefit is acknowledged in the Belmont Report (1979) by recognising that "(L)earning what will in fact benefit may require exposing persons to risk". The challenge RECs face is to decide when it is justifiable to approve a study, despite the anticipated risks of harm, based on its potential benefit, and when the benefits should be foregone because of the potential risks. This is not an easy task, as White (2007, p. 554) aptly states "… in the real world of scientific research, risk assessment by third parties on behalf of the research subject is notoriously imperfect because it must take into account these highly individualized and variable context".

The last principle, justice, refers to the benefits and burden (harm) in research and proposes that the benefits and burdens of research should be justly distributed. In the Belmont Report the fair distribution of burden and benefit is calculated by taking the following aspects into consideration, namely "(1) to each person an equal share, (2) to each person according to individual need, (3) to each person according

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to individual effort, (4) to each person according to societal contribution, and (5) to each person according to merit" (Belmont Report 1979).

An aspect that RECs should consider with regards to the justice principle within an African context is the debate about individual versus collective good. The example of treating childhood diseases or the development of interventions for children is mentioned as an example in the Belmont Report (1979). It questions if it is justifiable to conduct research involving children which has more than minimal risk, or any participant as a matter of fact, if the research has no direct benefit for the participant in the study but potentially could benefit other persons in the future. Such conundrums requires great maturity in decision making from RECs which it seems the majority of Africa's REC currently do not yet have (Ndebele et al. 2014).

An in-depth exploration of the Belmont Report (1979) highlights the ambiguities and complexities imbedded in the three principles. Traversing these complexities requires insight from experienced ethicists. Due to the socio-economic challenges in Africa research ethics governance is compromised which inevitably impact on the effective management of the ethics review process (Ndebele et al. 2014; Kasule et al. 2016).

The assumption of the existence of universal ethical principles, such as in the case with the Belmont principles and CIOMS Guidelines, in which the primacy of the individual is championed, is widely criticised by African scholars (Kasule et al. 2016; Mutenherwa and Wassenaar 2014; Ndebele et al. 2014). African scholars are of the opinion that the idea that Euro-western ethical principles transcends African traditional and cultural boundaries is flawed and that the blanket application of these principles are "inappropriate, unfair, imperialistic and insufficient to address ethical issues in Africa" (Mutenherwa and Wassenaar 2014, p. 118). The misgiving stems from the lack of congruence between an African worldview of research ethics and the proposed universal ethical principles.

Within the African worldview human research is carried out within the context of an existing community which is viewed as an autonomous entity. It is believed that when "a researcher assumes that the ethics guidelines of a hypothetical 'research community' can take precedence over those of a real community of people (real faces and bodies) situated in space and time, this surely constitutes a breach of ethics" (Weber-Pillwax 2004). In Africa, research is viewed as a knowledge-seeking process governed by ethical principles that acknowledge the relationship with others.

This humanistic viewpoint indicative of the African Ubuntu philosophy is central to research ethics and ethics governance in Africa (see also Chap. 12). Within Africa, humanity is not just an anthropological concept, it is a moral term that reflects the association between all people with shared aims and interests (Gyekye 2011). Within this relationship *ubuntu* represents rules of conduct and social ethics central to the collective consciousness of the people of Africa (Nafukho 2006). Chilisa (2009) described this collective relationship as a circular process involving repetitive back and forward movements. For indigenous African communities, circular, back and forth movements allow us (speaking as an indigenous researcher) to go back into the past and invoke metaphors for our culture that help us build ethics

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protocols that promote social justice and respect for postcolonial/indigenous communities (Chilisa 2009).

Authors such as Chilisa (2009) advocate for the acknowledgement of African research ethics congruent of the *ubuntu* philosophy. Onuoha (2007, p. 261) developed an Afrocentric ethical framework for biomedical research that is rooted in the African values of humanity, community and morality which is fundamental values of the *Igbo* worldview.[1] The humanity principle speaks to respect for others since all people have dignity. Dignity is thus not only an individual attribute but also a communal one since it highlights the interdependence of people on one another. "Without sharing in humanity … there can be no talk about human dignity" (Onuoha 2007, p. 262). Morality develops in a community and reflects the interests and values people desire and protect. As such, individual and communal dignity is protected within the context of human interaction. It is within this interaction that all people are viewed as moral agents who are held accountable for their own behaviour. According to Onuoha (2007) ethics are therefore fundamentally grounded in the views of human life and, as such, it should be the ultimate purpose of ethics to find the best way to protect human life.

Within the context of research ethics governance it should be noted that the regulation of research ethics from an African perspective is not viewed as being an institutional responsibility but a collective and participatory action. Hence, the needs and rights of people involved in the research as well as their cultural and social environment should be taken into consideration during the ethics review process. Ethical review processes should therefore be reflexive of the community and/or context where the research takes place. It should also reflect the values and beliefs of "those making the decisions and those affected by the decision" (Onuoha 2007, p. 264–265). Research ethics regulating systems should therefore acknowledge the importance of consensus, interconnectedness and community (Israel 2015).

It is clear from this discussion that the disjunction between Euro-western and African views on ethical principles and the governance thereof is one of the challenges that needs to be addressed in order to improve the research ethics governance in Africa. With this in mind Onuoha (2007) warns that it remains important to acknowledge other shared non-African values and cultures in the development of an Afrocentric ethics framework but to be weary of being overshadowed by them.

1.8 Challenges Facing Research Ethics Governance in Africa

Social-economic challenges and inadequate REC infrastructures and capacity were already identified in the chapter as factors that negatively influences the governance of research ethics in Africa. Another challenge identified was the lack of cultural sensitivity in the recognition of indigenous research ethics practices.

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[1] The Igbo worldview reflects the traditions and practices of the Igbo people that live in south-eastern Nigeria. The Igbo worldview is also humanistic in nature similar to *Ubuntu* philosophy.

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An additional global challenge that is also evident in Africa is mission drift. Mission drift refers to the process where effective processes are gradually and mindlessly expanded until it is no longer capable of performing its original function (White 2007). Within the context of research ethics governance mission drift is noted in the implementation of a one size fits all review processes for both biomedical and social science research.

An examples of mission drift is the expansion of the definition of health research in the South African National Health Act (Act 61 of 2003) to include any research relating to biological, clinical, psychological or social matters, hence, including social science and behavioural research. This implies that all research involving human participants must be reviewed and approved by a REC registered with the National Health Research Ethics Council. This has far-reaching implications for the governance of research ethics in South Africa. Section 73 of the Act determines that every institution that conducts health research must have access to a Health REC (HREC) that is registered with the National Health Research Ethics Council (NHREC). The registration of RECs with the NHREC is a timeous and administrative intensive process and the administration of the committees is labour intensive. The review process followed by HRECs is focussed on the governance of biomedical and not social science research.

The intention with the amendment of the Act was to improve research ethics governance and to ensure that "South Africa's people are fairly and respectfully treated by researchers and that all research conducted in the country stands up to ethical scrutiny" (Department of Health 2015, p. 9). In contrast, the amendment threatens social science research because of the increased administrative burden of the application process and increased administrative burden it places on both researchers and the HREC. It is foreseen that the increased number of ethics review applications will have a knock-on effect impacting on the effective and timeous reviews of biomedical applications as well.

Such over regulation was found to result in researchers choosing research topics that have a low or negligent risk in order to avoid REC scrutiny (White 2007). It inhibits innovation and instead of protecting research participants may well result in researchers not undertaking, or watering down methodology, of studies that is of a higher risk even though such studies can make a valuable contribution to better the life of many people. According to Dingwall (2012, p. 19) "research is a right, and in some contexts, a duty of academics, to go where others do not dare, and to bring back the results for the benefit of society". Israel and Hay (2006) concur, stating that the ethics review process generally used today was developed with little understanding or awareness of the difference between biomedical and social science research. As a result the current social sciences ethics review process is a combination of biomedical research and risk minimisation models which are rigid and not appropriate for social science research that is relational in nature.[2] This gives rise to the

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[2] Social science research is reliant on the relationship between the researcher and research participants. Hence, social scientists tend to find regulatory practices associated with informed consent, confidentiality, beneficence which are all relational aspects challenging resulting in an adversarial relationship between regulators and researchers (Iphofen 2017; Dingwall 2012; White 2007; Israel and Hay 2006).

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perception that research ethics governance is focused on institutional risk management and not the protection of research participants (see Chap. 6).

1.9 Proposed Guidelines for Research Ethics Governance in Africa

In essence research ethics governance in both biomedical and social science research is about the protection of human research subjects. Factors, such as mission drift, a zero risk and risk mitigation culture resulted in ethics reviews becoming a process that is "bureaucratic and arbitrary and aimed at addressing speculative harms" (Israel and Hay 2006, p. 137). The research ethics landscape in Africa is in many instances still uncharted creating the opportunity for the development of an innovative and suitable governance framework. The tentative guidelines included in this section come with a caveat, namely that it is by no means proposed to be a complete discussion but rather aimed at stimulating discourse and encouraging further research in this area.

It is recognised in this chapter that legislation and regulatory systems can provide valuable guidance to ensure the protection of human research participants and communities. It is recommended that legislation and regulatory systems should not be so rigid that it leaves no room for discretion. Regulations aimed at the governance of research ethics should be flexible enough, and regularly revised, to ensure that they adapt to the ever evolving research landscape in both biomedical and social science research. It is important that legislation and regulatory systems should be culturally sensitive and participatory in nature.

The current governance system where one regulatory system is used for both biomedical and social science research should be scrutinised. In contrast to biomedical research where seemingly effective governance systems are in place, social science research still lacks such a system. The biomedical review system that is currently used is not effective for use in social science research. With regards to social science research the question should not be to review or not to review, but rather how to do so effectively. The fact that there are risks of harm to participants in social science research is sufficient grounds to have a formal governance systems in place. As mentioned, social science research is to a large extent relational, thus it will require a review systems that is rooted in appropriate ethical principles which is not only sensitive to the ethos of the research discipline but also the role players, including the participants and communities, involved in a study. Specific attention should be given to the development of guidelines for the negotiation of informed consent, confidentiality and beneficence if data is collected from vulnerable populations and communities in Africa.

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Chapter 2
A Critical Discussion on the Relevance of Biosocial Science Research Ethics Codes and Principles for Social Science Researchers in Africa

Francis C. L. Rakotsoane and Angelo Nicolaides

Abstract The chapter will critically discuss some popular biomedical research ethics codes and principles in order to determine their relevance for social science researchers in Africa and to stress the importance of ethical consent. Research done on health in Africa reveals that African societies, especially those found in sub-Saharan Africa, face a double encumbrance of infectious and chronic diseases. As a result of this challenging health situation, there is currently a lot of research going on in Africa in an effort to address the situation. With the world's recognition of the significance of Africa's rich genetic diversity for biomedical research, more international research projects are being initiated. Some of these research initiatives raise unique ethical challenges that arise from the interaction between frontline science and traditional communities that have their own unique worldviews and research contexts.

There are cases where research ethics codes and principles appear to be inadequate to help in the face of the said challenges. This brings into question the relevance of such ethical frameworks for researchers in Africa. This apparent inadequacy of the international ethical frameworks to help researchers has prompted a desire to want to closely examine the relevance of these frameworks for the African context. Thus this chapter is intended to critically appraise some of the most commonly applied or used international research ethics codes and principles with the aim of determining their relevance for the sub-Saharan African context.

Keywords Social science research · Ethics codes · African traditional worldview · Traditional communities · Ethics frameworks · Unique worldview

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2.1 Introduction

Research conducted on health in Africa reveals that African societies, especially those located in sub-Saharan Africa, are faced with a health crisis. De-Graft Aikins, Unwin, Agyemang, Allotey, Campbell and Arhinful (2010, p. 1) describe this crisis as follows:

> Africa faces a double burden of infectious and chronic diseases. While infectious diseases still account for at least 69% of deaths on the continent, age specific mortality rates from chronic diseases as a whole are actually higher in sub Saharan Africa than in virtually all other regions of the world, in both men and women. Over the next ten years the continent is projected to experience the largest increase in death rates from cardiovascular disease, cancer, respiratory disease and diabetes. African health systems are weak and national investments in healthcare training and service delivery continue to prioritize infectious and parasitic diseases.

As a result of the challenging health situation depicted above, there is currently a lot of biomedical and biosocial research going on in Africa in an effort to address the situation. With the world's recognition of the significance of Africa's rich genetic diversity for biomedical research, more international research projects are being initiated in Africa. One such project is the Human Heredity and Health in Africa (H3Africa) Initiative which is meant to enable a modern research method to the study of genomics and environmental determinants of common diseases with the intention of improving the health of people in Africa (https://www.h3africa.org). The H3Africa objectives are:

- To grow the number of African researchers trained in genomics and to encourage collaborations among African researchers, as well as with scientists outside the Continent.
- To support the expansion of specific types of infrastructure such as bioinformatics facilities needed by researchers to be able to conduct genomics research, for genome analyses and bio-repositories that are used for sample procurement, storing and dissemination.
- To give support to genomics research that combines clinical and environmental analyses and to make important discoveries about the genetic roots of diseases.

The genomic research, as De Vries et al. (2015) have correctly observed, raises unique ethical challenges in Africa that arise from the relationship between frontline science and traditional communities that have their own unique worldviews and research contexts. This has to be understood against the background that central to H3Africa Initiative is the international distribution of data and selected bio-specimens to promote their utility across the globe and to expedite discovery of new knowledge that could impact prevention and management of disease effectively (Bongcam-Rudloff 2016). A number of important ethical considerations that do not appear to be adequately addressed by any of the existing international biomedical research ethics codes and principles are raised when it comes to the implementation part of the H3Africa projects. The inability of some of the said research ethics codes

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and principles to help in the face of the said challenges, as will be seen later in the chapter, brings into question their relevance for researchers in Africa. The Anglo-Saxon focus of some of the international ethical frameworks to help researchers in Africa has prompted the authors of this chapter to want to closely examine the relevance of these frameworks for an African context. Thus this chapter is intended to critically appraise some of the most commonly applied or used international research ethics codes and principles with the aim of determining their relevance for the sub-Saharan African context.

Cognisance needs to be taken that there are a myriad of internationally recognised ethical frameworks such as the 2000 WHO Operational Guidelines for Ethics Committees that Review Biomedical Research, the Ethics of Research related to health care in developing countries by the 2003 Nuffield Council on Bioethics, the 2005 UNESCO Universal Declaration on Bioethics and Human Rights and the 2007 UNAIDS/WHO Ethical Considerations in Biomedical HIV Prevention Trials, as mentioned in Chap. 1. It is not possible to discuss all these given the limited scope of this chapter. Consequently, the chapter will focus on the Declaration of Helsinki by the World Medical Association (2013), the Principlism as seminally contained in the Belmont Report and elaborately espoused by Beauchamp and Childress in their world celebrated book, Principles of Biomedical Ethics (Beauchamp and Childress 2013), and International Ethical Guidelines for Biomedical Research Involving Human Subjects by the Council for International Organisations of Medical Sciences (CIOMS 2016). Apart from the issue of the chapter's limited scope, the three ethical frameworks chosen for discussion in this chapter have been chosen because each of them came into being as a step further regarding the ethical issues that were to be considered in biomedical research while the rest of those not listed for discussion appear to be more or less borrowing their content from these three key documents.

The chapter will first look at what it calls an African worldview in order to establish the basis for some of the ethical challenges generally experienced with biosocial and biomedical research in Africa. A special reference will be made to the San Code to demonstrate what is meant by the uniqueness of an African worldview. After this will follow a section on the need for ethical frameworks for research in Africa. The next section will involve a critical discussion of each of the three main ethical frameworks identified above, considering each framework's relevance and the extent to which it promotes ethical research in an African context. This will be followed by the chapter's conclusion.

2.2 Unique African Worldview

Funk (2002) describes the word "worldview" as the set of beliefs about central aspects of reality that ground and inspire all one's perceiving, thinking, knowing and undertakings. Thus worldview includes one's beliefs about the nature and sources of understanding, about the definitive nature of reality, about the origins and nature of the universe, about the meaning and purpose of the universe and its

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inhabitants, about the existence and nature of God, about the nature and purpose of man and about the nature of value and the value of things. According to Funk, these general beliefs tend to shape not only how one sees the world, but also profoundly influence the particular beliefs that one comes to hold, the judgments and decisions one makes, and all that one thinks, says and does (Funk 2002).

Just as, at times, people speak of the Western way of life despite the diverse ways of thinking observed among people in the Western countries, there is an African way of life. That is, a unique worldview that is predominantly identified with Black Africans. While it is true that such a worldview may not necessarily be shared by all Africans, it is generally identified with the majority of Africans as their way of life in the same way that people in the West are generally identified with a certain way of doing and perceiving things as their common worldview. It is a way of life that many Africans, especially in Black African communities of sub-Saharan Africa, identify with as a worldview that informs their actions, beliefs and thoughts in general.

The claim that Africans have a shared worldview (Cumpsty 1991) has always been a contentious issue in scholarly debates. Consequently there are those who prefer many African worldviews. One thing that such people fail to comprehend, however, is the observation that each assemblage of persons living in a given region under more or less a similar environment, social stimuli, practises and lifestyle, are likely to cultivate or secure a distinctive character and personality of their own. It is these aspects which then differentiate it from people emanating from elsewhere with different philosophies or views of life. Underlying Africa's diversity of worldviews is a somewhat collective view of reality (Cumpsty 1991). That is, a worldview in its furthermost definitive sense. Into this essential view of reality (which can be found in many places but is all but ubiquitous in Africa) experience has written a great variety of detail (Rakotsoane 2010).

Acknowledging the existence of such a unique African worldview to his Western interlocutor in the book, titled, *A Humanist in Africa*, Kaunda once said:

> Possibly 'psychology' is not the appropriate word, but I do believe that there is a distinctively African way of looking at things, of problem-solving and indeed of thinking—we have our own logic—system which makes sense to us however confusing it might be to the Westerners. (Kaunda 1966, p. 28–29)

Drawing further distinction between Africans who share the worldview spoken of above and the Westerners, Kaunda went further to say:

> Africans, being a pre-scientific people, do not recognize any conceptual cleavage between the natural and the supernatural … they allow both rational and non-rational elements to make an impact on them, and any action they may take could be described more as a response of the total personality to the situation than the result of some mental exercise. I think too, that the African can hold contradictory ideas in fruitful tension within his mind without any sense of incongruity and he will act on the basis of the one which seems most appropriate to the particular situation. (Kaunda 1966, p. 29)

One of the unique features of the African traditional worldview is that it imprints a predominantly monistic view of reality in people's mind. This means that what is

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out there, is perceived as a distinct cohesive whole of interconnection in which different constituents ‘hang harmoniously together like threads of a spider’s web’. This is to say that causes and their effects are within the same system, not outside of it. For people who maintain this kind of worldview, an injury to one is considered an injury to all. To them, the community is held like a “spider’s web” of which no single thread can be caused to vibrate without shaking the whole network (Tempels 1969). This way of perceiving reality gives families and the community more power over what happens to their individual members because of the interconnectedness and symbiotic relationship that exist between and among all members in a family or community. What happens to one member is believed to have repercussions for other members of the family or community. For this reason, communal living is preferred to an individualistic way of living (Mbiti 1989). This way of life, at the end of the day, limits one’s autonomy when it comes to decision making. The family or community tends to demand its involvement in whatever concerns its members and their welfare (Mbiti 1989). In this context issues of morality are looked at holistically. From this, it follows that the gravity of a moral or ethical offence is judged by how much it succeeds or fails to promote harmonious living and the common good of the community affected.

Based on the general tenets of the African worldview, the following points as criteria for determining the relevance of any ethical framework for an African context, can be considered:

- The extent to which such an ethical framework promotes harmonious communal relations;
- The manner in which research participants are engaged with ethically in terms of their consenting to be involved in any research that is conducted;
- The extent to which it maximises the family’s/community’s/society’s common good; and
- The extent to which it allows for the family’s/community’s/society’s engagement in the decision-making process in matters that concern their members.

2.3 The San Code of Research Ethics

Scientists from many parts of the globe have studied the San people of Southern Africa for many years, such as Barnard (1992). The San people with their unique hunter-gatherer lifestyles, a range of click languages and ancient rock art works, are indeed a special people. Some San people were among the first from Africa to have their complete genomes sequenced (Chennels and Steenkamp 2018). Unfortunately some unscrupulous researchers have taken advantage of the San and exploited them for individual gain (Chennels and Steenkamp 2018). To exacerbate the already poor unethical behaviour, these researchers also failed to disseminate the results of the research back to benefit the San (Gonder et al. 2007).

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The consequence is that San today correctly desire a greater say in any research relating to them (Chennels and Steenkamp 2018). The San people are members of numerous Khoisan-speaking indigenous hunter-gatherer people who characterise the first nation of Southern Africa, whose territories span areas of Botswana, Namibia, Angola, Zambia, Zimbabwe, Lesotho and South Africa. On 2 March 2017 three groups, namely the Khomani, the !Xun and the Khwe delivered their own ground-breaking research-ethics code which is the first from any indigenous group on the African continent (Callaway 2017). Canada's First Nations and Inuit have drafted similar codes as have the Aboriginal Australians, in attempts to mitigate exploitation and misinformation (Callaway 2017). This is a very important initiative as researchers need to be guided by ethical principles and values which serve as parameters within which researchers should operate with people from indigenous cultures. This includes respect for cultural values, treating people with dignity and valuing and respecting their autonomy (Sleat 2017). It implies that all research participation be voluntary and conducted with integrity, trust, transparency, accountability, open-mindedness, reflexivity, democratic participation and a fair and just measure of social responsibility in a spirit of inclusivity and empathy (Sleat 2017). The development of the San Code of Research Ethics (South African San Institute 2017), has been in the pipeline for a few years and was initially partially funded by The Trust Project (Sleat 2017) which promotes rigorous ethical standards in global research initiatives. It began collaborating with the San after a disagreement over a 2010 genome paper (Daley 2017). The code requires that researchers agree to adhere to five underlying pillars within the value system of the San peoples: justice and fairness, care, process, honesty and respect (Bernardo 2017).

The code is not legally binding but nonetheless obliges scientists to submit proposals for their intended research objectives in San communities relating to their culture, genetic composition, or heritage, to a review board of community affiliates. It is likely that in the absence of such proposal submissions, permission will not be granted in terms of the rules of the San Code of Research Ethics. The code is ground-breaking and was crafted by a group of traditional leaders of the! Xun, Khwe and Khomani groups of San who represent around 8000 people in South Africa (Callaway 2017). Much harm was done by previous researchers according to Collin Louw, a member of the South African San Council (SASC), as it is commonly held that: “The presence of researchers caused conflict in our communities and opened a lot of old wounds” (Bernardo 2017, p. 1).

The code urges researchers to treat the San reverently and not to publish information that might be regarded to be abusive. The code also requests scientists to allow communities to read and make observations on any findings prior to publication. The reuse of data from any research conducted with the San is not automatically possible. If any other research institution seeks to use any data from prior studies, they will first need to obtain informed consent from the San Council. While the San communities understand the value of research, they also request researchers to fulfil their promises and offer something to the community in return for its collaboration. There were past unethical issues in proposals relating to the use of academic language beyond participant understanding, incorrect translation issues, the use of

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incentives such as cigarettes and a clear clash of value systems. The San require community leaders to be approached for their consent before any individual community member is approached to participate in research. The San also objected to the use of insulting language and terminology such as the term “Bushmen”, which is considered to be an insulting colonial-era appellation (Daley 2017).

Any financial benefits should be passed on to the community in which research is conducted. Benefits to the relevant community could also be in the shape of knowledge, job opportunities, educational support and suchlike. The San reside in South Africa, but also Botswana and Namibia, and this means that the code will hopefully and ultimately be used by San in each of those countries. San processes must be adhered to before any meaningful research is to be undertaken in their respective communities, with benefits accruing to all stakeholders in a spirit of ethical practice.

2.4 A Need for Ethical Frameworks for Biomedical Research Done in Africa in General

Biomedical research ethics codes and principles are critically important for African usage given that African people are often exploited, especially when it comes to the quality of informed consent (see discussion in Chap. 12). If the latter is of a good standard the risks to members of especially poor communities are minimised. Given global inequality in the socio-economic spheres, the benefits of research and what it entails for African communities in biomedical research relationships between themselves and the wealthy, are increasingly being challenged when it comes to the question of justice as an important driver in ethical research practice, as referred to in Chap. 13. On the continent of Africa, South Africa was somewhat of a pioneer in 1977 when the Medical Research Council of South Africa (MRCSA) published the Guidelines on Ethics for Medical Research and these guidelines are often used although they are in no sense considered to be obligatory (Israel and Hay 2006). African communities ought to be informed of the potential value of any research for each of the potential recipients of its findings. There should thus be good social value embedded in collective strategies which are targeting alleviating substantial health problems via research. Any research should thus add value to the community in which it is undertaken.

In African nations, the requisite monitoring structures and independent oversight procedures are in many cases inadequate. In such a scenario, codes of principles that are “imported” are necessary to help diminish risks and mitigate exploitation by unscrupulous researchers (Participants in the 2001 Conference on Ethical Aspects of Research in Developing Countries 2002). However, Noor (2009) holds that various poor countries in Africa have created systems by which research proposals can be ethically reviewed about a decade ago. There are however some researchers from developed nations who conduct research in Africa because their own countries have

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stringent regulations in place. The effect of this is that citizens of less developed nations often suffer the brunt of unethical practice (Richards-Kortum 2017).

The standards of research in Africa and developed nations are clearly at different levels when it comes to protecting human participants and mitigating abusive practices. It is often the case that research sponsors undertake studies in the developing nations that would not be acceptable in developed nations and such research is thus duplicitous (Macklin 2004). Developing nations are then viewed as “soft targets” because they are far cheaper to work in and there are very few, if any, regulatory controls (Richards-Kortum 2017). There are also the added dimensions of exploitation of the less educated masses and the lack of social value. In such situations, such ethical principles as beneficence, non-maleficence, autonomy and justice fly out of the window. According to Weijer (2000) there is a need for greater fairness in the selection of participants to be involved in research and justice in the distribution of the encumbrances and the benefits of research which is undertaken, where a favourable risk-benefit ratio should be in place for participants and where there are risks, the social value of these must be validated.

It is therefore important to develop mutually beneficial research ventures between researchers and backers in developed countries, the researchers, policy architects and the local communities in the developing countries, in order that abusive practices can be mitigated as far as possible. Only research which is likely to benefit the community in which it is conducted should be sanctioned (Participants in the 2001 Conference on Ethical Aspects of Research in Developing Countries 2002).

Having gone this far with the need for ethical frameworks for research in Africa in general, in the following sections, the chapter will be specifically focusing on each of the three research ethical frameworks (mentioned earlier) that are generally used in many African countries. These are the Declaration of Helsinki, the Belmont Report and CIOMS. Their relevance for African context will be, among other factors, judged by how much they meet the four criteria referred to earlier in the section that dealt with the African worldview.

2.5 The Declaration of Helsinki

During the World War II human beings were subjected to torturous ordeals by both Imperial Japan and Nazi Germany with the purpose of obtaining data that might prove useful in their war effort (Fischer 2006). These torturous ordeals resulted in War Crime Trials in which the Nuremberg Code was drafted as a set of standards for judging physicians and scientists who had conducted biomedical experiments on concentration camp prisoners. The code is today generally regarded as the first international standard to lay out the basic principles governing the ethical conduct of research that involves human participants with a profound impact on human experimentation. This code which became the prototype of many research ethical codes that followed afterwards, banned forced experiments in humans, setting the basis for the 1964 Declaration of Helsinki (WMA 2013).

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Thus the Helsinki Declaration came as an improvement on the Nuremberg Code whose vague language rendered it inadequate for addressing some of the issues in the newly emerging medical ethics (Carlson et al. 2004; Fischer 2006).

Developed by the World Medical Association (WMA) in 1964 and adopted as a binding report of ethical principles used for medical research, the Declaration of Helsinki

> … is the central document in the field of ethics in biomedical research and has greatly impacted upon the content and thus formulation of international, regional and national legislation and codes of conduct. The Declaration is thus a wide-ranging international statement of the ethics of research involving all human subjects including those with capacity and those without, as well as communities. It sets out clear and carefully crafted ethical guidelines for physicians and researchers who are engaged in both clinical and nonclinical biomedical research. (Nicolaides 2016, p. 16)

The document is of great relevance for the African continent where the vulnerability of the general populace is more than that of their counterparts in the Western countries due to the high levels of poverty, poor regulatory frameworks and comparatively low levels of education.

Factors such as the high levels of poverty, poor regulatory frameworks and low levels of education that have become so characteristic of many countries in Africa make people in these countries particularly vulnerable to being wronged or incurring additional harm. Thus by introducing research ethics committees, among other important issues, the Declaration of Helsinki has ensured that the vulnerability of the research participants in such countries is reduced. This is because such committees are mandated to, among other important functions, see to it that the researchers do not in any sense expose the participants in the research to any physical or psychological impairment.

Where research could be problematic in the sense that participants could feel physically uncomfortable, the Declaration requires that they should be alerted to this well before the research is conducted. What is essentially required is an honest brief description of the character of the study at hand. Those who give their willing consent to participate and are of an acceptable age and have mental capacity to do so, should be given a description of what it will mean for them to be involved and they should be informed that whatever participation they agree to can at any point in time be terminated at their will. If there are any risks or possible discomfort likely to result, participants must be aware of this. The participants should receive guarantees that whatever they may agree to participate in, their responses will not be disclosed and they will remain anonymous. Any data that is collected should be kept confidential. The right to privacy is non-negotiable and the subjects must be respected as unique human beings and treated appropriately. It is undoubtedly the duty of research to consider the possible effects of the research on participants before they begin with any study. The researchers must take the utmost care not to harm participants in either the physical or psychological sense (Goddard and Melville 2005).

One of the ongoing debates that arises from the Declaration of Helsinki in which African developing countries may have an interest is a dispute over when the use of

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placebo or no intervention for the control group is permissible (Marouf and Esplin 2015). The Declaration only states that new interventions should be tested against the best proven intervention (Principles 16–17 Risks, Burdens and Benefits). It is not clear whether this means the best intervention available worldwide or the best intervention available in countries where the intervention is being tested. Providing the best worldwide standard of care is not something that appears to be feasible in many developing countries and thus this situation may obstruct important research that could improve health conditions in these countries (Wendler et al. 2004). This lack of clarity can serve as a major stumbling block against the promotion of the common good, namely, the good health for all. From another standpoint, the unavailability of interventions in many developing countries often points to very limited local standards of care or no care at all, creating an unfortunate and unethical double standard in clinical trials involving the rich and the poor. Such a double standard can create animosity between the rich and the poor nations of the world and thus lead to undesirable disharmony (Wendler et al. 2004).

Although the *Declaration* has many positive points regarding the scientific standards that should govern scholarly research, it ignores the importance of the social value of each research by overemphasising the individual autonomy as opposed to collective autonomy that uniquely characterise people in sub-Saharan Africa. It is in sub-Saharan Africa where morality or what is good is first and foremost the concern of the whole community and where greater emphasis is placed on social rather than individual moral responsibilities. By remaining silent on the possible role of families or communities in research that involves the participation of their members, the Declaration has denied itself a very important partner for successful implementation of its basic tenets. It is still the case that in many countries of sub-Saharan Africa, the individual's exercise of autonomy is still largely limited by their families or communities. In this context, the individual may decide autonomously to either engage in something or not. If that individual's family is not made part of what is undertaken, the chances are that an individually and exclusively taken decision will be difficult to implement as the chances are that it will remain prone to being fought against by either the family as a whole or some members within the family, in one way or another.

In African societies management of the issues that are important is generally handled in a communal fashion. This is in line with the ethical practices of decision making by the combined body of members of a community within the African philosophical notion of Ubuntu (Tshikwatamba 2004). Ubuntu refers to the idea that people are divinely inspired to live according to the norms of the society and the culture in which they were raised and their morals must be based on the fact that they are human beings who are tasked to demonstrate divine presence when working with fellow human beings (Mulemfo 2000). Thus any guiding principles for ethical research should consider Ubuntu and make serious attempts to reduce any risk leading to the exploitation of indigenous populations when research is conducted (Angell 2000; Tangwa 2004).

Thus inclusion of the family or community in matters that require their members' participation is very critical if success is to be achieved in these African countries. Some scholars attribute the failure of the vaginal microbicides trials in

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Southern African countries to these trials researchers' failure to take this important aspect of the African life into consideration (Jewkes et al. 2005). It is said that the husbands of the trials participants, in particular, frustrated efforts of their wives to have the microbicides gel used during their sexual interaction with them (Moodley 2007) which is problematic if the research is to be useful.

2.6 The Belmont Report: Principlism and Its Relevance for Biosocial Research in Africa

In her article, titled "Ethics of International Research: What does Responsiveness Mean?" Christine Grady (2006, p. 235) articulately emphasises the risk of misuse of human participants, in the following words:

> International research is essential to understanding and ultimately controlling emerging and long-standing infectious diseases. Yet, such research, when sponsored by developed-world entities (both public and private) and conducted in the developing world, is beset with inherent and complex ethical issues. An overarching ethical concern is the possible exploitation of vulnerable individuals or populations through research. Avoiding exploitation, usually understood as an unfair distribution of benefits, may be more of a challenge in international than in domestic research because of background disparities in health, health resources, and power between developed and developing countries.

The above quotation expresses more or less the reality as seen and experienced by many people in Africa where vulnerable masses of people are said to be exposed to all sorts of exploitation because of the fragile situation into which disparities in education, health care and power between them and people in developed countries have placed them (Macklin 2004). There is some concern that research sponsors prefer conducting research in developing countries because in such countries they are at liberty to do things that would otherwise be considered unethical in developed countries due to lack of relevant policies, regulatory frameworks and well-developed ethical guidelines to guide research (Macklin 2004). According to people who express this concern, "… sponsors choose to do research in the developing world because it is less expensive, subject to fewer regulatory constraints, and provides access to large numbers of treatment-naïve patients, thus allowing investigators to get away with meeting lower standards" (Macklin 2004, p. 236).

Born out of the need to address experiences and observations that were similar to those expressed by Grady in the above quotation, the Belmont Report remains one of the few international research ethics codes whose suitability for African context cannot be overemphasised given the ethical principles it stands for, especially as expatiated espoused by Beauchamp and Childress (2013), and their relevance in minimising the possibility of exploitation and in maximising protection of the participants' rights and welfare in general. As the document that was developed and meant to provide adequate and increased protection to vulnerable groups of people who participate in research, the report provides the necessary ethical framework which, if followed well, can adequately protect the rights of the vulnerable populations in Africa.

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One of the principles advocated by the report is the principle of respect for autonomy (Belmont Report 1979). This principle requires that the decision-making capacities of research participants as autonomous persons should be respected by researchers. Through the principle the individuals are enabled to make informed and voluntary decisions or choices. This implies that the research participants participate freely in any research without any controlling influences that would mitigate against a free and voluntary act. If followed as required, this principle can protect vulnerable African populations from abuse by researchers. It is therefore a relevant principle for researchers in Africa. One major shortcoming with this principle, however, is its lack of clearly defined room for a collective exercise of autonomy as observed in communities where collectivism as opposed to individualism limits one's personal exercise of autonomy. In collectivism individuals see themselves primarily as parts of a whole, which may be a family, a tribe or one's community. In this way individuals' actions are mainly motivated by the norms and responsibilities imposed by the collective entity. One thing with collectivism as Gorodnichenko and Roland (2011, p. 1) correctly observe is that it "… makes collective action easier in the sense that individuals internalize group interests to a greater degree. However, it also encourages conformity and discourages individuals from standing out".

As it is, an overemphasised collectivism can serve as a breeding ground for abuse of individuals by their leaders or groups they belong to. It makes those in power dedicate all efforts to the promotion of the common good at the expense of the individual's rights – a position whose tenability remains questionable in today's democratic dispensation.

In certain African traditional communities, for instance, this kind of collectivism has led to the existence of certain stereotypes that have, for a long time, subjected individuals, especially women and other vulnerable groups in society, to oppression by both the society and certain individuals in positions of power. In some extreme cases some individual members of a community may be ritually murdered in the name of fulfilling the requirements for performance of certain rituals that are meant to benefit the community (Rakotsoane 2008). In such abusive cases the principle of respect for autonomy becomes handy because it promotes the decision-making process that is free of coercion or coaxing and thus limits exploitation of the vulnerable.

Another principle whose relevance for Africa's situation cannot be overemphasised is that of non-maleficence as presented by Beauchamp and Childress (2013). This requires researchers to not intentionally create a harm or injury to the research participants, either through acts of commission or omission and considers it negligent if researchers impose a careless or unreasonable risk of harm upon any research participants. This principle affirms the need for professional competence. It articulates a fundamental commitment on the part of researchers to protect their research participants. Closely related to this principle is the principle of beneficence which, according to the Belmont Report, requires the balancing of benefits of research against the risks and costs and demands that researchers should act in a way that benefits the research participant. Since their goal is to provide benefit that can be

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applied both to individuals and the society as a whole, the two principles are very relevant to African situations where people are generally vulnerable to abuse because of their socio-economic environmental factors already discussed in the previous sections.

The last principle contained in the Belmont Report is that of justice which requires researchers to distribute benefits, risks and costs fairly among all parties involved and that people in similar positions should be treated in a similar manner. The principle ensures that scarce resources are fairly distributed and people's rights as well as morally acceptable laws are respected. The relevance of a principle such as this in communities where poverty, illiteracy and non-availability of regulatory frames are the order of the day cannot be overemphasised. When fully observed, this principle makes it difficult for unscrupulous researchers from developed countries to exploit vulnerable research participants in developing countries by warranting that developing countries should determine for themselves, whether research that is undertaken in such countries is indeed considered to be acceptable and is likely to alleviate local community health problems.

As Marouf and Esplin (2015, p. 1) *have correctly observed:*

> Protecting human dignity and preventing exploitation are core concepts in both bioethics and human rights. In fact, the principles that guide biomedical research ethics were developed in response to specific incidents of exploitation, including the infamous Tuskegee Syphilis Study. Yet the rapid globalization of biomedical research in recent decades presents new challenges in preventing exploitation. Affluent countries and multinational corporations now commonly conduct clinical trials in developing countries, a practice known as 'off-shoring.' The advantages of this practice for the sponsors of the trials are clear: it significantly reduces the cost of trials, sometimes as much as 90%, helps avoid the increasingly bureaucratic regulatory environment in many wealthy countries, and renders legal accountability extremely unlikely. However, these same factors increase the risk that research subjects will be exploited, especially since nearly half of the clinical trials in developing trials escape review by an ethics committee.

Bioethics in any form or shape, is morally obliged to protect fundamental rights and prevent the exploitation of vulnerable populations and persons who should not be viewed a "soft targets" due to illnesses, socio-economic status, gender and or sexual orientation or sub-standard economic circumstances.

2.7 International Ethical Guidelines for Health-Related Research Involving Humans by CIOMS

Unlike the other ethical frameworks discussed so far, the Council for International Organisations of Medical Sciences (CIOMS) guidelines have been developed and revised with the challenges and problems of carrying out medical research in developing countries in particular.

CIOMS is an intercontinental non-governmental organisation established jointly by the WHO and UNESCO in 1949. Focusing on making the Declaration of Helsinki

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applicable in developing countries, the CIOMS Guidelines generally mirror the conditions and needs of biomedical research in developing countries and the implications for multinational or transnational research in which such countries might be partners. With its emphasis on what should ethically be obtained when dealing with the vulnerable populations in general and life situations in developing countries in particular, the CIOMS Guidelines distinguished themselves as ideal research ethics guidelines for developing countries of the world. This is what is implied in the following words as contained in the Guidelines:

> "CIOMS, in association with WHO, undertook its work on ethics in relation to biomedical research in the late 1970s. At that time, newly independent WHO Member States were setting up health-care systems. WHO was not then in a position to promote ethics as an aspect of health care or research. It was thus that CIOMS set out, in cooperation with WHO, to prepare guidelines "to indicate how the ethical principles that should guide the conduct of biomedical research involving human subjects, as set forth in the Declaration of Helsinki, could be effectively applied, particularly in developing countries, given their socioeconomic circumstances, laws and regulations, and executive and administrative arrangements". The World Medical Association had issued the original Declaration of Helsinki in 1964 and an amended version in 1975." (CIOMS 2002, p. 5)

The CIOMS guidelines have been revised with the same purpose of providing internationally vetted ethical principles as well as detailed commentary on ways in which such principles should be applied, especially when it comes to conducting research in low- and middle-income countries. The revision of the CIOMS' guidelines has made these guidelines even more relevant for an African context. The relevance of the guidelines is manifested in the challenges that have been addressed in them by ensuring that research carried out has a social and scientific value and it addresses important questions that lead to improved health, using sound research methods. By addressing this challenge, the CIOMS' guidelines have maximised the family's/community's/society's common good—an aspect which, as seen in the criteria given earlier in the chapter, appears to matter for determining of any ethical framework's relevance for Africa.

Research needs to be conducted according to guidelines such as the ethical principles set forth in the CIOMS guidelines above for it to lead to a world in which all people can enjoy optimal health and health care. As research practices change with time, new challenges come into being and guidelines need to be adapted. The changes made in the new CIOMS guidelines reflect an international effort to provide well-reasoned answers to such challenges (Van Delden and Van der Graaf 2017).

2.8 Conclusion

The relevance of the biosocial science research ethics codes and principles for social science researchers in Africa cannot be understated since concentrating on the ethics of the relationships between stakeholders in terms of human rights and upholding of human dignity is a moral imperative. Ethics, justice and fairness are critical elements in all biosocial science research activities.

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Aspects such as inter alia, community engagement events and the role and effective operation of ethics review boards require urgent attention. There is an incumbent moral obligation on researchers and their proxies to act ethically at all times when research is undertaken in Africa.

Research ethics capacity strengthening must be a priority for biosocial science research ethics in Africa and in this regard effective ethically driven codes and principles are required. In especially an African context, it is imperative to maintain a climate of trust in the practice and consequences of biosocial research which is ultimately concerned with the vibrant relationships between biology, human experience and behaviours. It encapsulates proficiency from areas including the medical, biological and social sciences. Its ultimate value resides in its ability to advance the positive influence of research on public and private policy and society in general. It is thus important to understand what ethical research involves and it is then incumbent upon researchers to be au fait with mandatory ethical principles and the policies which inform actions to be followed so as to safeguard research subjects against unethical practices and outcomes. Furthermore, such knowledge will likely avert negligent research being conducted. When one engages in biosocial research, there needs to be a system in place in which there is some guarantee of ethical coordination in place which must of necessity be upheld by researchers. Risk and harm to participants must be minimised, thus a researcher must be bound by specific responsibilities relating to ethical aspects, so as to uphold the trust of stakeholders such as colleagues, sponsors of research and the public in general (Iphofen 2011, p. 5). Researchers have a duty to familiarise themselves with what is expected of them in terms of their duties and responsibilities towards their research participants. They need to carefully consider aspects such as anonymity and confidentiality of participants, issues of informed consent and how to deal with vulnerable people or groups. Whatever they do, should be aimed at maximising benefits for individuals and also for society at large.

The San Code of Research Ethics is an important first research code for Africa. It speaks to the notion of honesty, but in a way which is not patronising but which considers prior informed consent to be essential. Justice and fairness in research as well as an adherence to processes that are set out are non-negotiable. Care should also be taken to align research to the needs of the local community and to improve the lives of people.

It is also unacceptable for research to disrupt the natural environment and those within it so that unsatisfactory research practices result in devastating outcomes. The findings of research must be honestly and reliably stated and there should be no fabrication or distortion of evidence, data, findings or conclusions.

Biosocial science is important, but this does not mean that there must be no respect for the privacy, autonomy, diversity, standards, morals and values as well as the dignity of individuals, groups and communities at large. Integrity is the key to good biosocial research, as discussed in Chap. 1. This of course means that suitable methods of research must be used and that the researcher's social responsibilities be continuously honoured. The ultimate purpose of research should be to maximise benefits for society while minimising detrimental actions. Risk should be balanced

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with considerations of the value of research to be conducted and all risks should be assessed. Researchers must be able to conduct the research and have requisite experience to determine risks and why research should be undertaken in the first place. They should consider how individuals and society stand to benefit if at all.

Anonymity of participants and confidentiality should be respected by careful consideration of what is to be released from a study in terms of sensitive information. Research participants' identities and the findings of any research must be securely kept, password protected and encrypted where deemed necessary. The bottom line is that there must be integrity, transparency, respect for human rights and any participation should ideally be voluntary and fittingly informed. Participants should have some opportunity to view the transcripts of any interviews and also field notes and be allowed to alter the content or interpretation of the data where this is considered to be inaccurately stated. The distinct lines of accountability and responsibility need to be unmistakably demarcated. Researchers have a moral duty and obligation to consider and practise research ethics during the lifespan of their research projects.

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Chapter 3

Considering Africanist Research Ethics Practices in Social Science Research in Africa

Puleng Segalo and Lien Molobela

Abstract Research ethics forms a fundamental and critical aspect of any research endeavour. It therefore becomes pertinent to pay close attention to our understanding of research ethics and ways in which ethical principles are applied. The need for constant revisiting of how we define and apply ethical principles will assist in ensuring that research conducted by both emerging and established scholars is in line with and upholds ethical standards. With the aforesaid in mind, this chapter aims at focusing on ethical practices and principles within the tertiary setting and the accompanying complexities relating to these. Research ethical principles aim to assist in ensuring the "protection of the rights and dignity" of prospective participants. In this chapter, we reflect on and grapple with this idea of "protecting" others by showing how this may be a challenge as it sometimes assumes powerlessness and a lack of voice. We deem this reflection as critical as it affords us the opportunity to imagine the future and engage with ways in which we can contribute towards how future generations of researchers approach the notion of research ethics. We draw briefly from two studies we conducted wherein we highlight some of the contradictions and challenges we sometimes face when it comes to ethical practices within an African context, and we offer possibilities of how these could be tackled.

Keywords African ethics · Ethics of care · Universalist · Decolonial ethics

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3.1 Introduction

> Here the emphasis is on recognising that research is conducted in a world of wide disparities of wealth and health, and as part of much longer term social and political processes; and that much research within this context involves vulnerable people but is not immediately applied for their benefit. (Molyneux and Geissler 2008, p. 686)

Research Ethics forms a fundamental part of any human participant research study as its underlying aim is to ensure that the rights and dignity of prospective participants are acknowledged and respected. This chapter draws on the discussions in Chaps. 1 and 2 that engage the history of how the need for formal research ethics codes came about. The codes include the Nuremberg Code, which resulted in the Declaration of Helsinki, and the Belmont Report (Striefel 2001; Fischer 2006). These codes have over the years in many ways become the universal determinants of what ethical research practices entail. These research ethics codes were initially intended mainly for medical practitioners (and related fields) who in the past would conduct unethical (and often evasive and life-threatening) experiments on people without their consent or knowledge. The application of these codes is through local (institutional) and national bodies who oversee the various Research Ethics Committees (RECs) put in place, as discussed in Chap. 1. This entails social science researchers having to “convince” REC members that the study they propose will follow the prescribed ethical guidelines as specified in the ethical frameworks and guidelines. These include well-defined procedures and explanations of how the project will unfold (e.g. how the data will be collected, from whom it will be collected and the analysis thereof).

While these research ethics guidelines are important, the process of obtaining research ethics could benefit from ensuring that contextual implications linked to research being conducted are central to what is entailed in the guiding principles. This is a point also highlighted by Molyneux and Geissler (2008, p. 686) in their assertion that “abstract principles of existing codes are very hard to apply in practice: history, geography, culture, gender-relations and economic status can have important implications for the way in which ‘universal’ ethical principles and guidelines are prioritised and applied in different contexts”. Furthermore, RECs impose a prescriptive and narrow ethical research framework that often does not take into consideration contextual moral and ethical principles that communities live by. “The checklist approach in research ethics require reconsideration and needs to be informed by cultural practices, values and morals of each studied community” (Adu-Gyamfi 2015; Molobela 2017; Smith and Stillman 2014). Smith and Stillman (in Molobela 2017, p. 75) further assert that “the discrepancy in the universal uncritical application of ethics emanates from the fact that conventional ethics are derived from a particular world frame and discourses that serve as regulator technology of governance that favours the research body instead of the researched community”. It is therefore critical to engage and problematise what ‘ethics’ (within a research context) mean. A point to which we shall now turn.

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According to Chuwa (2014, p. 33) "[e]thics is a generic term covering different ways of examining and understanding moral life, it informs our acceptance of what is just and unjust, right and wrong, good and bad". Most people acquire ethical norms through their lived experiences as they mature in different stages of their lives. This may lead us to the thinking that ethical norms and values are common sense; however the vast evidence on ethical disputes as well as contraventions in society illustrate that ethics are not to be taken for granted especially since ethical norms and values are multidimensional and contextual. This makes ethics an important issue to grapple with, in recognition of the fact that different individuals and groups understand, interpret, apply and balance ethics differently with respect to their values and lived experiences (Resnik 2013). It is in this breadth that we should interrogate who's lived experiences and values of understanding ethics are given authority in academic research within the Social Sciences. To this end this chapter engages a number of factors that we deem as challenges and opportunities towards the reimagining of research ethics within the Social Sciences; and here we specifically look at ways in which we can protect our future generations of researchers and contribute towards what socially ethical practices could look like. The idea is not to reinvent the wheel, but rather to reflect on some of the shortcomings and engage in ways in which we could have principles that take seriously the context within which ethical codes are applied. Following this background we have offered in the introduction, the next section moves towards providing a review of the history of what we call "universalist academic ethics" wherein we engage the shortcomings of the Eurocentric framework of applying research ethical principles.

This will be followed by two case studies which we provide to highlight some of the challenges we personally encountered when we conducted research and having to apply prescribed institutional ethical principles. We point to what is useful and also engage the problematic aspects of the process. We go on to suggest ways in which we could rethink and respond. To this end, we call for the African ethical framework as suggested by a number of scholars whose works we draw from. We conclude the chapter by calling for an Africanist decolonial ethical practice, which we believe will contribute towards socially responsible ethical practices.

3.2 A Brief Review of the History of the Notion of "Universalist Academic Ethics"

Mutenherwa and Wassenaar (2014) assert that there is no doubt that ethical considerations are imperative in every research study; however, the problem currently faced in tertiary academic institutions is the uncritical adoption of a narrow prescriptive Eurocentric approach to ethics which in turn is posed as universal ethics. Drawing from Descartes, Grosfoguel (2012), argues that the "universal is an eternal knowledge beyond time and space… and this situates the subject in a 'non-space' and 'non-time' (p. 88). Grosfoguel (2012) further points to how this universalistic

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approach assumes that knowledge produced in the West (Global North) can be applicable everywhere in the world regardless of context. This is problematic as history, culture, class, race, and other related factors play a critical role in how people engage with the world. Drawing from the Botswana context, Chilisa (2011) argues that African institutions of higher learning and research councils use ethical research codes and guidelines that are "founded on the culture, history and philosophies of Euro-western thought, thus are indigenous to Western academy and institutions" (p. 1). These ethical guidelines often position the philosophies and epistemologies of non-Western communities in the periphery even when conducting research with indigenous African communities. Consequently, it is vital to unpack the history of this universal ethics approach and its adoption by global academic institutions, particularly African academic institutions.

The history of research ethics suggests that the ethics currently employed in academic research were developed as a result of Western institutions and academics' observations for the need to protect research participants from exploitation, malpractice and misconduct in scientific research (Kuschel 1998), as detailed in Chap. 2. As stated earlier in this chapter, violations of human rights are noted in the history of biomedical scientific research that undermined participants' dignity, integrity and humanity (Orb et al. 2001). Some examples that startled the academic institutions were the misconduct and abusive research experiments conducted during the Nazi massacre which required strengthening and regulation of ethical guidelines in research practices. These abuses of human beings have played an important role in the development of current research ethical norms (Ndebele et al. 2014). Within Social Science research, a number of disciplines developed their own ethical principles that were aimed at ensuring that those trained within these fields adhere to agreed upon codes. For example, Psychologists formed the American Psychological Association (APA) while other Social Sciences disciplines such as Sociology (American Sociological Association) and Anthropology (American Anthropological Association) also adopted their own ethical principles in the quest to ensure the safety and respect and acknowledgement of the need for the well-being of their research participants (Kuschel 1998; Ndebele et al. 2014). It needs to be noted again that these principles originated from the West and consequently based on the general western ethical outlook on their professions, members, and communities.

Africa has fallen victim to exploitative unethical research experimentations and clinical trials involving human subjects that have potential for physical harm. Such exploitations were enabled by unmonitored research practices and inept Research Ethics Committees (Ndebele et al. 2014). Although interesting to note that most of exploitative studies were biomedical in nature, it would be unwise to believe that unethical social science studies do not take place in the so-called underdeveloped nations (Mutenherwa and Wassenaar 2014). However, due to the bastardisation of African traditional values and moral views in scientific research, there has been an intensified silencing of meaningful discourses on African ethics, from both the researchers as well as the communities affected, which alienates the appropriateness of the Universalist academic ethics (Murove 2005). This alienation and silencing of other ethical systems cause unintended harm to the marginalised groups that do not identify with the dominant ethical framework. To this end, we call for a pluri-versal

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approach to ethics which acknowledges the contextual and multiple understanding of ethical principles (Grosfoguel 2012). This would be a shift from a universal understanding of ethics and the application thereof.

Below we offer two case studies that aim at highlighting the aforementioned challenges inherent to the application of research ethics guidelines by RECs where *Western* principles are imposed on Social Science Research in Africa.

3.3 Two Case Studies

The first case study explains how African women with legal capacity to consent were deemed (by the REC) vulnerable by virtue of them being *black women* from a *rural community*. This perceived vulnerability status was accelerated by the study's intention of exploring socio-cultural constructions and perceptions of the contentious, public and private topic of abortion. As researchers, we argue that categories such as *vulnerable* and *sensitive* when applied out of context by the members of a REC are problematic as they take agency away from the participants and assume people as being unable to make decisions for themselves. The second study also focused on black South African women who grew up during the Apartheid era. The focus is on the women's lived experiences with a specific focus on the notion of collective suffering. One of the ethical dilemmas faced by the researcher was the use of pseudonyms.

The two studies draw from our individual postgraduate studies and they are used here to assist in pointing to some of the ethical dilemmas that we had to contend with before, during and after the completion of our research projects. Furthermore, we would like to engage the lessons learned and implications for how ethical codes/principles as prescribed by institutions of higher learning are applied.

Case 1

I (second author) provide here an instance where the Universalist approach proved insufficient in its applicability in a Social Sciences research study involving how women from a rural community socio-culturally construct the practice of abortion.

This study aimed at highlighting the marginalised African-centred epistemologies that lack voice in academic literature while playing a significant role in the contestation of abortion. In recognition of rural communities' communal structure, it was a necessity to seek consent for research participation from the gatekeepers of the community as well as the individual participants whom I was to recruit at my own discretion. These gatekeepers consisted of individuals elected to be leaders in the community by community members. This process of gatekeeping (to act as guardians of communities) fosters justice by allowing different voices to be represented in decision making that concern the community.

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As a prerequisite for human participant research studies in the particular higher education institution, I applied for ethics clearance before commencing with the fieldwork. The Research Ethics Committee deemed the focus and methodology of the study problematic. They perceived the population of the study as vulnerable, the topic of the study sensitive and the gatekeeping process dubious. The committee perceived women of legal age for consent as vulnerable by virtue of them being based in a rural community. They further expressed the concern that the gatekeeper might ostracise the women for taking part in such a study. Reflecting on these assumptions made by the committee, I was uneasy as to me it came across as "othering" people and in many ways denying them agency. Furthermore, "the categories, *vulnerable* and *sensitive* are complex, because they take agency away from the participants and assume that they are unable to make decisions for themselves" (Molobela 2017, p. 67). These concerns from the REC left me questioning the criteria used to determine a group's vulnerability especially in the involvement of rural black women. "Such prescriptive measures tend to limit and somewhat silence people who would otherwise want to have their voices heard without imposed restrictions" (Molobela 2017 p. 67).

This poses problems as it keeps women living in rural areas at the periphery and denies them the opportunity to contribute to knowledge production on topics that are relevant for their lives. I perceive this as problematic because women and men based in urban areas and with access to resources and "formal" education are not easily classified as vulnerable. I argue that a person's context or positionality should not be looked at in isolation when decisions about whether they can or cannot freely participate in a research study are made. RECs should not limit themselves to principles that may not be applicable for people's contexts; they should be open to the possibility of rural women not perceiving themselves as vulnerable. Such power dynamics influence what and how researchers conduct research, often leading to research projects/focus that were not the initial intention of the researcher.

It is critical to acknowledge that community members who offer researchers their time and insights are knowing subjects who are knowledgeable and should not be boxed as vulnerable and in need of being spoken for.

Case 2

As part of my (first author) PhD studies, I conducted research wherein I collaborated with a group of women from a township in Gauteng (one of the provinces in South Africa). My engagement with the women focused on them making embroideries that visually depicted their lived experiences under the Apartheid regime. The women made individual embroideries which were later exhibited both locally and internationally at conferences and other

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similar events. Additionally, the embroideries are used as teaching tools for studies on visual methods.

Because of the personal nature of the embroideries made by the women, they each left an imprint of their names on the individual embroideries. This was done as a way to personalise the work and for the connection between themselves and the work they produced. As part of my ethics review agreement/requirement with the institution, I indicated the use of pseudonyms when writing up my report as a way of "ensuring anonymity" and "protecting the participants'" identities. Additionally, as we often assure the participants, upon completing the writing up of the report I went back to show my research collaborators what I had written and to check whether what I had written was a true reflection of the engagements we had.

One of the things they enquired about was the strange names (even though this was discussed when consent forms were signed) they saw next to their narratives. By giving them pseudonyms, the unintended harm was that I had *taken their identities away* and that was a problem for them as their names form an integral part of who they are. This is a critical point to engage with as most RECs require researchers to use pseudonyms as a way of "protecting participants".

We should interrogate the notion of protection and think critically about the contexts within which we conduct research and how people view the world (including "invisibilising" people by bestowing pseudonyms on them). The process of naming is sensitive (and very important) in many African contexts and this needs to be taken seriously when conducting research. While it may be necessary to use pseudonyms for certain members of the population for their protection; this should be used on a case-by-case basis and not as an ethical expectation of all research conducted.

3.4 Challenging Institutionalised Research Ethics Procedures: Moving Towards an African Ethical Framework

The main principles that REC's utilise in evaluating research protocols and proposals are based on "respect for personal autonomy, beneficence and justice" (Mutenherwa and Wassenaar 2014). According to Mkhize (2006, p. 26) "respect for persons requires that research participants be treated as free and autonomous subjects, while protecting those whose autonomy is diminished such as children, the elderly and mentally challenged". This principle also requires the recognition of participants' rights to be informed about the study, its objectives and the methods to be used and the implications of the study (Kuschel 1998). Participants have to be informed of their right to freely volunteer or to refuse to participate in the study or to withdraw at any given time without disadvantages, such consent should be given

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preferably in writing. This principle of autonomy and respect for persons is entrenched in the Euro-Western individualistic view of the person defined by internal psychological attributes (Mkhize 2006). This principle of the autonomous research participant is problematic in a societal context where the concept of personhood is considered to be a communal nature. In such societies consent is supposed to be sought from family members and the community at large rather than the individual. Communal consent can be viewed as a challenge to the Western ethical perspective as it appears inconsistent with the principle of respect for persons. We would like to argue that the principle of respect should be extended to respecting the said society's cultural traditions (Mkhize 2006). The continuous importation of Euro-western ethical protocols speaks to the deafness and refusal to accept and acknowledge the contextual understanding of human relations. While there have been attempts to make the protocols applicable to the contexts wherein they are applied, these are still benchmarked on the assumed universal principles. Issues of justice, ethics, respect and confidentiality manifest very differently in many of the African cultures. This is a notion a number of African scholars have highlighted (Mkhize 2006; Nsamenang 2007; and Remose 2007, to name a few), however, these scholars continue to be absent in many of the ethics training courses. We call for a move towards ethics that are negotiated and agreed upon by community members and the researchers.

Different ethical traditions have to be acknowledged when applying ethics as for instance in Ubuntu ethics the principle of respect relates to the ethics of care through recognising the individual's right to be recognised as a human being deserving respect and reciprocal caring human relations (Chuwa 2014; Metz and Gaie 2010). Additionally, the issue of informed consent as an ethical practice is debatable in instances where participants are suspicious of giving written consent as a consequence to previous exploitation caused by signing official papers they had limited understanding of (Salaam and Brown 2013; Wasunna et al. 2014). Furthermore, informed consent may cause problems in issues related to participants' psychological self-instruction where they may be afraid to say no to participate in a study in fear of negative treatment as a consequence of saying no (Kuschel 1998). (See Chap. 12 by Visagie, Beyers and Wessels in this book for a discussion of informed consent and a comparison of individual vs. collective autonomy in the context of Social Science research in Africa.)

The principle of beneficence recommends securing the well-being of participants by maximising possible benefits and minimising possible harm in order to protect participants (Molobela 2017). Although Social Science research often poses a unique risk to participants which are related to emotional distress, violations of privacy and confidentiality, the magnitude of the harm that may emanate from the study is difficult to estimate (Mutenherwa and Wassenaar 2014). Furthermore, some Social Science research methods are exploratory in nature and as a result the most appropriate ethical codes are usually espoused during the process of fieldwork. This is in relation to the fact that the interaction that unfolds between the researcher and participants may redirect and change the nature of the research and its potential harm (Mutenherwa and Wassenaar 2014).

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According to Orb et al. (2001) the principle of beneficence is closely linked to paternalistic ideologies where the ethics committee may take decisions against including a particular population on the basis that they are considered a vulnerable population. Although marginalised and vulnerable people can benefit from the research and have the potential to contribute significantly to knowledge production and in expanding researchers' understanding of a social or health phenomenon (see Chap. 15 for a more in-depth discussion), such contributions are silenced by the ethics committee's decision (Smith and Stillman 2014). Also, the idea of a vulnerable population is problematic as its classification is embedded in Euro-Western bio-medical traditions which may differ from other non-Western traditions (Molobela 2017). According to Molobela (2017, p 75) "[t]he definition of vulnerability in the Western framework includes poverty, class status, homelessness, age, gendering and landlessness among others; and these are issues that tend to be the norm in the so-called developing contexts as these axes of inequality affect and have a great influence on the affected populations' lives". The Euro-Western ethical principle of justice implies equal share and fairness of burdens and benefits of research (Orb et al. 2001). This is meant to reduce inequalities by fairly distributing risks and benefits in research through an inclusion of all groups irrespective of age, gender, culture, ethnicity and socio-economic status while taking caution of vulnerable groups (Simwinga and Kabero 2014). This aspect of the ethics principle is open to different interpretations and as a result pose challenges when applied in non-Western contexts and particularly on Social Sciences research. For instance, it advocates for the inclusion of marginalised populations while at the same time require sensitivity towards vulnerable populations causing confusion in terms of who to include and who to exclude in a fair manner in knowledge production. Categorisation of vulnerability is dependent on social and cultural context, thus requiring familiarity with alternative ethical systems.

Another issue in Social Science qualitative research methods that RECs need to take into consideration is the requirement of a dense description of the research location being given as a measure of trustworthiness, which infringes on the ethical code of confidentiality (Kaiser 2009). Furthermore, expanding on ways in which research designs can influence notions of ethics, Sagoe (2012) reflects from the Ghanaian context that designs such as focus groups do not provide guarantee of confidentiality due to the fact that some of the members who participate in the group may disclose information revealed by other participants in the study. Another research methodology to pay attention to is Participatory Action Research (PAR). In many ways PAR does not fit neatly with the ethics principles that require anonymity as it is geared towards emancipation and empowerment of participants who are acknowledged as co-researchers and may thus want their real names to be published (Mutenherwa and Wassenaar 2014; Saunders et al. 2015). The above examples highlight some of the shortcomings of a Universalist approach to ethics that aim at transcending cultural and traditional boundaries (Mkhize 2006). As observed by Mutenherwa and Wassenaar (2014, p. 118), "the blanket application of universal so-called western ethical principles to all communities may thus be inappropriate, unfair imperialistic and insufficient to address ethical issues in Africa and other non-western countries".

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A Nigerian scholar, Onuoha (2007) has made great contributions towards the rethinking of ethical principles and his work challenges us to move towards an African ethical framework that reflects on the African worldview's main values of humanity, community, morality, respect for life, solidarity, and justice. This framework has not been operationalised in many academic spaces by Research Ethics Committees, irrespective of its relevance and appropriateness for the African context (Mutenherwa and Wassenaar 2014). We pause at this point and move to our call for African Ethics which take the unique positions of people and their contexts seriously. We suggest that a move towards an Africanist and decolonial ethical practice could assist us to reimagine our ethical codes and principles.

3.5 A Move Towards an Africanist and Decolonial Ethical Practice

> While formal ethical guidelines play an important role in regulating research practice, implicit day-to-day social relations and engagements between people are fundamental to the research process. (Molyneux and Geissler 2008, p. 688)

We draw to a close by calling for ethics grounded in African ways of seeing the world. We acknowledge that Africa as a continent has vast cultures, traditions and beliefs which have all (albeit differently) been marginalised by the Euro-Western ways of viewing and engaging with the world. This marginalisation as we have pointed out, has bled into the academic space and thereby contributed to education playing a role in "invisibilising" people's histories and ways of being. We align ourselves with Chilisa (as cited in Molobela 2017, p. 73) who argues that "Western academy frameworks exclude the knowledge systems of the historically colonized, oppressed and marginalized from knowledge productions by signifying them as 'the other" which further silences them and future generations.

To this end we call for the decolonisation of research methods in general and the research ethics principles in particular. This would mean avoiding further harm to the historically oppressed through providing a space for them to revive and recuperate their culture, history, language and identity by allowing women, the elderly, disabled, and children the agency to define themselves and their reality as well as what can be spoken and written about them (Chilisa 2011). Doing this would be a move towards ethics of care. According to Parton (2003, p. 10) "the notion of care is often devalued due to the dominance of a universalist conception of ethics which attempts to construct a totality of rules, norms and principles which are to be equally applicable to everyone, and which should be recognizable and acceptable to every rational thinking person". An ethics of care focuses on fulfilling the needs of others and to maintain harmonious relations.

The ethics we call for is "a situated ethics *that* considers the relevance and application of ethical principles and guidelines for different studies and contexts, and

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takes into account the realities of complex individual institutional and national imbalances in power and resources" (Molyneux and Geissler 2008, p. 687). This would assist us and future generations of researchers to shift from engaging with people as if they are ahistorical beings without lived experiences and with little to contribute towards knowledge production. Socially responsible ethics are decolonial ethics that speak to the importance of acknowledging the multiple spaces people occupy and the knowledge they carry with them. To decolonise ethics is to acknowledge the multiplicity of understanding the world, to see community members as knowing beings with lived realities that contribute to how they engage with each other and their environment; to have the humility to step back and not impose ethical principles that may not be relevant/applicable to people. Future generations of researchers would benefit from Africanised and decolonial ethics that do not alienate people from their histories, beliefs and overall worldviews.

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Chapter 4
An African Perspective of Benefits in Social Science Research

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Abstract This chapter focuses on the African perspective of benefits in Social Science research with the aim of defining benefit sharing, describing benefits as a social construct and explaining how benefits are constructed in communities. Also discussed is the importance of weighing risks and benefits for avoidance of exploitation of participants. Benefits are discussed at different levels to show that the concept is fluid and is determined by geographical location, needs and group dynamics. Benefit sharing in research is an ongoing concern in developing countries. Foreign researchers sometimes conduct "helicopter" research in Africa to address their research agenda in communities without assurance of benefits. This oversight by these researchers has previously led to suspicion and mistrust. This chapter has been written based on collective experiences in collaborative research in low-income countries, class discussions in health research ethics and related desktop review of literature. The ensuing discussion reveals that the perception of benefits varies at individual, institutional, community level, participants' and researchers' perspectives. The chapter has been guided by the social construction process which views benefits as a social construct. The fact that benefits is a construct brings afore the need for researchers to respect community values, circumstances, culture, social practices and that fair benefits accrue to host communities. To deal with the challenge of benefit sharing, a benefit sharing conceptualisation model has been proposed to guide researchers in identification and prioritisation of benefits for trust and acceptability.

Keywords Benefit · Benefit sharing · Construct · Distributive justice · Perception of benefit · Social construct

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4.1 Introduction

The historical perspective leading to the universal acceptance of benefits as a key component of research is crucial when discussing research ethics in Social Science research. The concept of benefits, which include various dimensions but is focussed on benefits for all shareholders (research participants, the community, researchers and research organisations), has over time affected perceptions on benefit sharing in collaborative studies, in the African context. The social construction processes in resource limited settings should be understood in relation to anticipated research benefits. Distributive justice in Social Science research as an ethical concept is still a challenge in many African settings. It is worth noting that sometimes generalizable knowledge is not realised or important knowledge that is developed is not generalizable, but may otherwise lay the foundation for future studies. However, the challenge faced is how to identify and measure research that gives beneficial societal impact. It is easier to assess and appreciate the societal benefit accruing from applied research such as drug development than what accrues from social research. It is not always easy to link the scientific rigour in a research study to what the society will finally gain from it. Several concepts have therefore been introduced to define how such a research is perceived to impact society. Terms such as “what benefits”, “improves quality”, “is useful”, “adds value”, “transfers knowledge” or “is relevant to their daily lives” have been proposed. Ideally, the ultimate goal of research would be a tangible product or an idea that offers social, cultural, environmental and/or economic returns. However, societal impact often takes long to become apparent, for example in behaviour change, population studies and policy development.

There is therefore need to engage in discourse and conduct studies on benefits of research in the African context and develop models that can guide benefit sharing in collaborative international research. We begin by exploring various definitions of benefit to help in understanding the concept.

4.2 Benefit as a Concept in Research

Benefit is defined as that object of social value and scientific usefulness with a positive impact that arises from research. Some authors consider benefit as that factor which eventually improves human well-being through the utilisation of the generalizable knowledge realised from research (Emanuel et al. 2004). Having considered these definitions and the Social Science research scenario, the authors want to propose that benefit should be defined as that which brings a positive change in status, behaviour and attitudes leading to improved lives and community empowerment. In multisite study protocols, emphasis on the evaluation of the site-specific addendums allows for defining the specific benefits to the concerned community, institution or individuals. However, the challenge is that the realisation of benefits from research

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carried out in low-resource settings is not always as obvious and underlines the importance to develop socio-cultural models that will guide researchers and communities in the evaluation of benefits, as proposed by Lairumbi et al. (2012).

The impact of research benefits can either be direct or indirect to an individual, institution or community. Direct benefits to a participant may include free treatment for clinical studies, individual psychological therapies or gain at personal level from social improvement programmes that come as part of research activities. Indirect benefits are for the larger community and may be informed by knowledge generation to address specific local needs like employment and trainings that can augment the social well-being of the entire community. Research participation should therefore, improve lives by bringing advantages to participating individuals and the society at large. The motivating factor however should be the new knowledge generated through respectful and safe engagement with study participants.

Furthermore, the impact of benefits can be short- or long-term, specific for the concerned community or generalised for the global community. Social science research can shape society and culture by contributing towards finding resolution to cultural and social dilemmas and conflicts. This can be achieved by giving space for critical thinking about, listening to and looking at different perspectives of issues at hand and bringing on board new innovative ideas. Luc and Altare's work (2017) is one such an example where social research on female genital mutilation (FGM) had an influence on cultural practices. Their work advocated for harm reduction through better human rights of the study population who had been socialised to consider FGM an important cultural rite of passage for the girl child. The aspect of human rights and physical harm was not initially well received but with time and persistent advocacy their work has been important in making the international community aware of the issue, a move that is directly benefitting the research population through change of attitude and knowledge on less harmful alternative rites of passage. This has shown that well-managed community engagement and participatory practice can be more beneficial than merely being an avenue to facilitate interventional research.

Long-term sustainable relationships with participating communities should be built for benefits to be felt long after termination of the study. An example to illustrate this is the establishment of a school programme by researchers at the Kilifi Kenya Medical Research Institute-Wellcome Trust Research Centre in a strategy that fully engages the host community. Secondary school students, teachers and the scientists mutually designed and implemented a programme that promotes awareness of local research activities and enhances positive attitudes by students towards learning science and research as a future career (Alun et al. 2012).

Due to the global impact of crises often arising from natural disasters, diseases or social challenges such as mass migration from the Middle East and Africa in 2015 due to warfare and drought, international collaboration in research has become a necessity. Collaborating partners are often from high-income-countries (HICs) and low-and-medium-income countries (LMICs). In such situations, researchers from LMIC countries benefit from the opportunity to be involved in advanced and innovative research, authorship credit and intellectual property rights (Emanuel et al. 2004), which they will often not have had access to in their current positions.

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In some circumstances, collaboration is the only avenue through which access to research funds is possible with LMICs contributing in terms of the social and health setting to answer the research questions (Parker and Kingori 2016).

It is the opinion of the authors that research benefit should contribute to knowledge production, stimulate innovation in handling emerging societal trends or in shaping public opinions and policy formulation. The *DaktariAfrica* (n.d.) study which involved knowledge development, integration of indigenous knowledge and the use of social innovations to improve the community socio-economic status is a good example. The technology advocated by the *DaktariAfrica* group is widely used in provision of healthcare services via voice calls and short text messages.

4.3 Research Benefit Versus Risks

According to the Universal Declaration of Bioethics and Human Rights, the ultimate benefit of participating in research is to increase life expectancy and improve quality of life by participants (UNESCO 2005). However, during the course of research the dignity, human rights and fundamental freedoms of the participant must be upheld which means that benefits should be maximised while any foreseeable harm is minimised.

In collaborative studies attention must be paid to the needs of participants from developing countries, where often participants may bear more than equitable burdens (see Chap. 13). Participants in this position must be cushioned from any further risk or harm by implementing the distributive justice concept where there is an equitable distribution of study burdens and benefits while ensuring protection of participants against exploitation or exclusion without good reason, as discussed in Chap. 15. A very good example, to illustrate the aforementioned, is where sex workers in Majengo (Kenya) were provided with high-quality health care and access to health education to improve their health and self-worth, in exchange to being research participants in a study (Tukai 2017). The improved health and self-esteem as benefits balanced well with the potential risk of stigma and social ridicule.

Risk and benefit analysis for the African population largely, necessitates special attention. As discussed in various other chapters of this book, the notion of individuality and benefit for the self only, is not an easy concept to relate with. The identity of an African is profoundly collective and associated with gender and community norms. It is the responsibility of researchers to understand study benefits and risks in the local context which might go beyond the individual and will influence the bigger social group (clan/family) of which the person is a member. A favourable benefit to an individual may cause a larger society risk by being intrusive to the larger community. The San people's case, as discussed in Chap. 2, is a good example where information provided by participants during interviews once reported may be found to be embarrassing and discriminatory causing collective psychological damage to an entire community (Chennells and Steenkamp 2018).

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Another good example of collective benefit vs. risk is the right to intellectual property of indigenous knowledge where information about plants/techniques have led to discovery of valuable products, technologies and services of human, agricultural and environmental benefit (Morel 2010). This is illustrated by the commercialisation of *Prunus africana* where the bark has been used in the manufacturing of drugs to treat prostate illnesses. It has been suggested by authors (Cunningham et al. 2016) that study collaborators can consider supporting the local community by providing programmes where farmers can be encouraged to diversify their income sources to supplement earnings from harvesting of the species as another benefit (Cunningham et al. 2016).

Definition and perception of benefits vary in different contexts depending on social construction processes involved. Social constructionism proposes that human life exists as it does due to social and interpersonal influences that work together with inherited and social factors to create concepts (Cottone 2004). Benefits are viewed in African culture as constructs that emerge as a result of individual and interpersonal relationships influenced by social factors (Galbin 2014). Therefore, in Africa, constructs such as culture, traditional belief systems, socio-economic status, literacy levels, the immediate environment and gender affect perception of research benefit. A recent genetic epidemiology study conducted in Ghana, illustrated the notion of group beneficence when all the participants involved were asked to comment and decide on the perceived benefits their immediate group should get in respect to their specific social set up (Poku et al. 2011).

4.4 Benefits as a Social Construct

Since research is a product of social and historical processes it constructs benefits through active involvement of people and their worlds which requires interaction and negotiation between groups of people. This raises the need for researchers to understand the local context in terms of language, culture and history of individual communities (Galbin 2014). The aforementioned is illustrated by alluding to a study conducted among a Kenyan community where male adult initiation took on a different form which involved the removal of six lower teeth as opposed to penile circumcision. The success of this study was achieved through participatory involvement of the community using the Community Advisory Board (CAB) approach, as well as cognisance of the local language, culture, tradition and religion (Mwandi et al. 2011).

However, involvement of community representatives previously placed emphasis on engagement of communities and participatory practices which was largely addressed through community representation in project teams and implementing sites. These entities have been required to have CABs or similar mechanisms in place. The disadvantage of this approach is that these mechanisms are not supported in ways that are commensurate to the support given to laboratories and clinical components. Over time there has been a change of the meaning of ‘engagement’, how to effectively engage stakeholders and how context influences engagement

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practices. These questions have culminated in the recommendation that there ought to be more use of participatory practices such as utilization of existing or creation of independent groups (Macqueen and Auerbach 2018). Similarly, 'The Good Participatory Practice Guidelines for Biomedical HIV Prevention Trials (GPP)' offer advice for promotion of participatory practice which will be useful in the benefit sharing conceptualization model (Allman et al. 2014). It is paramount for successful social research in Africa that collaborative partners need to be aware of local traditions and norms before conducting their research. Focussing only on ethical tenets as would be required by their own Research Ethics Committees'(RECs) in High Income Countries(HICs), would cause disrespect to the population under investigation, as discussed by Segalo and Molobela in Chap. 3, and could possibly create risk for those who feel compelled to participate. To illustrate this, the African concept of customary law and religion, which construct their belief system and moral judgment, would ascribe different roles and responsibilities to different members of the family based on their status, age and gender. Therefore, should a collaborator only want to obtain consent from a married woman without her husband's knowledge, or buy-in, it may marginalise the woman in her culture and even cause harm to her. In such a case the informed consent form would have to accommodate this cultural requirement in order for females to participate in research in order to prevent social harm.

The set limit of engagement would involve obtaining consent in the presence of the spouse for married female participants. To buy in husbands, they can be engaged in other activities like guidance and counselling programmes, capacity building or sensitisation on other topical issues within the study site. This would be a reconstruction of benefits to address additional concerns such as need for awareness in understanding health research, knowledge translation, prevention of stigma and accommodating needs of members of the community who are not participating in the specific trial (Anzala 2014).

Coordination of research activities like obtaining informed consent, recruitment of participants, capacity building and provision of benefits culminate into multiple constructions of benefits which emerge from interaction and socialisation. Perception therefore changes through multiple relationships between researchers and communities.

4.5 Benefit Sharing Conceptualisation Model

In view of benefit and research as constructs, a benefit sharing conceptualisation model anchored on the principles and practice of project management has been proposed to guide the benefit sharing process in international collaborative research set in LMICs. The model has five phases and is based on the Deming Wheel Model (Plan, Do, Study and Act).

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The first phase involves planning for community engagement during the conception of the research project as part of integration of activities in the research cycle. The planning phase of the study needs to include a search conference to understand and set ground rules for trust and acceptability. Community representatives or gatekeepers need to be part of this process in order to align benefits to individual and collective needs and priorities. To prevent misconceptions about research benefits, stakeholders should be involved in identification and prioritisation of community needs within the research agenda. This provides an opportunity to express and discuss conflicting discourses. Researchers and other stakeholders should construct benefits using agreed and well-meaning communications. Constructed benefits ought to be a product of interaction and agreement allowing for continuous communication, creation, destruction, construction and deconstruction of benefits. Communication mechanisms can be developed to remain active even after the life of the project. This will increase acceptability and trust among the partners and create an environment that generates knowledge and products (Luc and Altare 2017).

Phase 2 will involve the development of site-specific protocols to incorporate cultural values and local needs. For example, in some African cultures where women are not allowed to address gatherings in the presence of men, provision for different forums would be useful for community-based research engagement. To prevent discrimination, the recruitment strategy would be defined to equitably cater for those who will be excluded from the study with regard to study benefit.

Phase 3 will involve establishment of CABs, advocacy and independent groups as deemed appropriate within respective research studies and communities, groups expected to represent the interests of communities (Allman et al. 2014). The community representatives may include professionals, community health workers, social workers and known gatekeepers who are not directly involved or to be benefited by the research. More importantly, the composition of participatory groups must be determined by all parties in the collaboration (Macqueen and Auerbach 2018; Allman et al. 2014).

Phase 4 involves actual participation through direct involvement in research activities. This phase provides information that can be used to evaluate the process from the onset for evidence based decision making. Resultant information can be used to define and to redefine benefits.

Phase 5 is the ultimate outcome of the whole process which will culminate in knowledge, interventions, improved livelihoods and empowered communities. The result of the benefit sharing process will be a community that trusts and accepts researchers while the researchers will be successful in their research. This will avoid situations like the socio-anthropological study on health-seeking behaviours in an African community with acute malnutrition and low literacy in which FGM was the traditional "treatment" for diarrhoea in girls. However, the researchers missed an opportunity to impart a long-lasting benefit to the community in the form of education on basic hygiene and sensitisation on the retrogressive cultural practice to avoid further harm to the girls (Luc and Altare 2017).

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Fig. 4.1 Benefit sharing conceptualisation model for collaborative research

To ensure relevance and continuous improvement in process management of sharing benefits, the Deming Wheel Model (Plan, Do, Study and Act = PDSA Cycle) (Tague 2005) can be used to guide implementation and evaluation of community satisfaction levels by the use of evidence-based data (Fig. 4.1).

4.6 Conclusion

Benefits as a concept are dynamic and unique to various players in social science research in Africa. It is constructed through the social construction process based on social and historical perspectives and may thus have different meanings in different societies and/or groups. The African setting is that of resource scarcity with individual needs and desires closely being linked to the entire community's cultural and social norms. As benefits are reaped, the level of study-related risk to participants must always be assessed and minimised. To benefit from collaborative research the local communities must always be adequately engaged. The proposed engagement model requires involvement of individual research participants, researchers and respective communities through the creation of a platform for discussion and negotiation of locally specific research benefits to protect participants, reduce harm and maximise benefits at various levels of engagement.

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Chapter 5
Social Responsibility and Health-Related Social Sciences Research

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Abstract Africa continues to be burdened by widespread poverty and endemic diseases, with huge inequity in accessing healthcare services. Health research in all its forms is essential to address the numerous health systems challenges in Africa, using complementary biomedical and social sciences approaches. There is, however, a risk of exploitation from the traditionally hierarchical, Western world-centred and -funded approach to health research in Africa. Care must therefore be taken to ensure health research, including health-related social sciences research, is ethically sound, responsive to local need and respectful of local cultures and values.

This chapter provides a background, history and context to socially responsible and responsive health-related research in the African context. It presents the fundamental ethical principles (beneficence/non-maleficence, respect for persons and justice) for health-related research, and describes how these interface with social responsibility and responsiveness. The roles of Research Ethics Committees in promoting socially responsible and ethically sound health-related research is discussed; and a framework for conducting socially responsible and responsive health-related research in Africa is proposed, applying the principles of "Responsible Research and Innovation (RRI)". RRI encompasses a research approach which explicitly considers the potential impacts of the research on society in a responsible and responsive way.

In order to properly address and mitigate the fundamental health concerns throughout Africa, it is essential that a socially responsible and responsive research approach be adopted, considering accepted ethical principles. By including the community as stakeholders, using a participatory RRI model, the specific needs of

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diverse communities across the continent can be identified and addressed, in a culture of respect, tolerance and mutual responsibility.

Keywords Social responsibility · Ethics · Integrity · Health-related research · Africa · Responsible research and innovation

5.1 Introduction

> We can only find the right answers to the challenges we face by involving as many stakeholders as possible in the research and innovation process. Research and innovate ion must respond to the needs and ambitions of society, reflect its values, and be responsible … (Máire Geoghegan-Quinn 2012)

Africa continues to be burdened by widespread poverty, poor access to health services and serious endemic diseases; and in most cases the premature deaths in these countries are due to preventable causes (World Health Organisation 2013). The problems that these countries currently face include a complex disease burden, poorly functioning health systems and inadequate research to identify health delivery gaps and challenges in order to design improvement strategies. Innovative approaches are needed to address and mitigate, among others, the devastating impacts of disease, poverty and poor access to healthcare services in Africa. Health research in all its forms (applied, basic and policy research) is an essential component of such health promotion strategies (Resnik 2007), in order to identify, implement and determine the effects of preventive measures and interventions for diseases endemic to Africa. Health-related social science research is one form of health research. Health-related research has a different focus to purely biomedical research, the latter being primarily concerned with biological/clinical outcome measures, and usually using quantitative research methodologies. According to the National Institutes of Health's Office of Behavioral and Social Sciences Research, health-related social sciences research aim to explore and understand how the interactions among human behaviour, the environment and physiology/biology may influence health outcomes and/or predict health risk factors, using a range of quantitative and qualitative methodologies. Both health-related social sciences and biomedical health research are essential in order to develop a holistic and comprehensive understanding of the complex factors affecting health and health systems in Africa (Bachrach and Abeles 2004).

Although relevant health-related research is essential to improve and promote the good health status of the African people, this population may be particularly vulnerable to exploitation, for example when research is driven and funded by external high-income countries and pharmaceutical companies. There is historical evidence of a number of examples of human research abuses that have occurred in Africa, and these unethical research practices need to be prevented at all costs. Health-related social sciences research may seem to afford lower "risk" to participants than biomedical research. However, we argue that all human research affords

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a degree of risk to participants. In the absence of adherence to accepted ethical principles and rules and the community's active participation in the research process, there is also the risk of inappropriate research being conducted in resource-scarce African countries, which does not ultimately benefit the population. In this context, emphasis must be placed on applying the many available international and local research guidelines, policy documents and regulations to the African context.

This chapter aims to provide a framework for scientifically, ethically and legally valid health- related research so that such research can be conducted in Africa in a socially responsible, responsive and respectful manner, in order to improve the health status of the African people and address specific societal needs.

5.2 Conceptual Clarifications

All research aim to ultimately lead to improved living conditions, health, social interaction, science. The focus or aims of health-related social sciences research and biomedical research do, however, differ (although there may be substantial overlap). Whereas biomedical health research tends to focus on biological predictive and outcome measures of disease, the social sciences approach aims to understand complex bio-psycho-social inter-relationships, and how these mechanisms and processes may impact on health promotion, disease prevention, disease management and palliative care. Health-related social sciences research may be basic or applied, includes research from an individual to a societal or even population level, and may include a range of research methodologies from surveys, focus groups, observational studies, epigenetic studies, economic analyses and statistical modelling, through to randomised controlled clinical trials (for example evaluating the impact of a social intervention on disease progression or adherence to medication), traditionally seen as being the domain of biomedical research (Bloom and Canning 2008; World Health Organisation 2013)).

Responsible conduct of research and social responsibility are interrelated (Owen et al. 2012), focussing both on the scientific and societal merits of research. It is generally accepted that all scientists have the responsibility to address the social implications of their research (Resnik and Elliott 2016). Social responsibility refers to the responsibility of the researcher to the society at large, to make a "real world" difference as opposed to conducting research for research's sake (Owen et al. 2012) As an ethical framework encompassing health research in Africa, social responsibility requires that researchers act in society's best interests in the fulfilment of their professional duties (Bird 2014). Ideally, researchers should be integrated within the larger society, and act according to societal priorities, needs, interests and expected outcomes of the research programme. The dignity, rights, safety, health and wellbeing, for example physical, emotional and/or financial of the public, as well as the individual research participants, must be the priority of any health-related research conducted in Africa; and researchers should address any moral, political, social and policy issues that arise from or during their research (Resnik and Elliott 2016). The

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concept of "community engagement" in research has been highlighted in recent years. This refers to the "process of inclusive participation that supports mutual respect of values, strategies, and actions for authentic partnership" in order to address issues affecting the wellbeing of the community (Ahmed and Palermo 2010; Holzer et al. 2014).

There is clearly a need to balance health research focused on specific biomedical interventions for endemic disease processes (at an individual level) and research focused on communities or populations (e.g. health systems/epidemiological research), which may influence health sector/system reform and policy development on a wider platform. The two research approaches (social science and biomedical/clinical) can, and some argue, should be integrated, using mixed-methods, interdisciplinary, and multi-level research studies (Bachrach and Abeles 2004) in order to provide more rich and contextualised data. There are a number of examples of successful models that integrate healthcare, biomedical and health-related social sciences research, training and advocacy in a comprehensive approach to disease prevention and control in African countries, such as the Sickle Cell Disease programme in Tanzania (Tluway and Makani 2017). This programme includes biomedical (clinical and basic sciences), social and behavioural (e.g. social determinants of health, science communication) and population health (e.g. health policies) research themes, integrated into healthcare provision, education and advocacy in sickle cell disease.

The conditions in which people are born, live, work and age (including social, economic, cultural and environmental factors) all contribute to health and healthcare-seeking behaviours, and are collectively termed the "social determinants of health" (SDH). Through socially responsible and responsive health research, incorporating health-related social science research, effective measures can be identified to optimise healthcare access and adherence, redress health inequalities, and improve the SDH in Africa, in order to provide a framework for accessible, equitable, effective and affordable healthcare; and to inform and influence regional public health policies (Bachrach and Abeles 2004; Commission on Macroeconomics and Health 2001). Avoidable and persistent health inequities across population groups, based on differing socioeconomic status, is not only unfair but also hinders the realisation of the all-inclusive sustainable development goals. Generating evidence on health inequalities (and iniquities) represents the first step to plan and implement remedial actions. The World Health Organisation's Commission on the Social Determinants of Health (SDH) recommended integrated and multi-sectoral actions on the SDH for improving health equity in 2018 (CSDH 2008). Subsequently, the Rio Political Declaration (RPD), pledging for action on the SDH, was adopted by 125 member states in 2011 (World Conference on Social Determinants of Health 2011). Furthermore, the Sustainable Development Goals (2030) require countries to implement Health in All Polices (HiAP) to sustainably improve the social, economic, health and living conditions and reduce health inequalities in all its forms.

While in recent years there has been considerable progress towards tackling the burden of diseases through development of medicines and medical equipment, at

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the same time the concept of "health services research" is also relevant as a component of health-related social sciences research. This concept is defined as a multidisciplinary "field of inquiry, both basic and applied, that examines the use, costs, quality, accessibility, delivery, organization, financing, and outcomes of health care services to increase knowledge and understanding of the structure, processes, and effects of health services for individuals and populations" (Lohr and Steinwachs 2002). Essentially this research approach aims to make health care affordable, safe, effective, efficient, equitable and accessible, which is in keeping with the concept of socially responsible and responsive health research.

5.3 The Need for Socially Responsible Health-Related Research in Africa

> Many have argued that the unfettered promotion of science and innovation is necessary to the economic vitality, public health, and national security of any country. At the same time there are those who maintain that neither science and technology nor the market can be left to operate wholly on their own without societal guidance and regulation. (European 2012)

As summarised by Benatar (2002), at the turn of the twenty-first century tens of millions of people worldwide were dying each year from preventable conditions, including malnutrition, infectious and parasitic diseases, as well as non-communicable diseases, trauma and malignancies. Low-income countries, including many across Africa, still bear more than 80% of the global burden of disease (Benatar 2002). The Global Burden of Disease Study (2016) reported that although global health is improving, there remains huge inequities. For example, in sub-Saharan Africa infectious diseases, childhood illnesses and maternal causes of death account for approximately 70% of the burden of disease; whereas the same conditions account for less than 20% to one-third of the burden in other regions across the globe (Global Burden of Disease Collaborators 2017).

In response to the numerous health challenges throughout Africa, there has been an appropriate increase in health-related research on the continent, often focussing on health services research, however much of this is funded and initiated by well-resourced nations beyond the African continent (Benatar 2002). The lack of local funding for research makes foreign-funded research attractive to African researchers, however special care must be placed on protecting against exploitation. Many African countries have inherently weak health systems, the potential for fast and cheap recruitment of participants (many of whom have low educational levels and are extremely impoverished) and in many cases have less stringent ethical, regulatory and legal oversight of clinical research; factors which may predispose to the exploitation of the African participants and local researchers (Wemos Health 2017).

There are a number of documented cases of unethical biomedical health research practices in Africa. Further, there are many clinical trials, current and completed, which have been extensively debated regarding the ethical appropriateness of their conduct in Africa, particularly where placebo controls are used; where post-trial

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access to experimental products by the population being studied is unlikely; and where the trials would not be approved in developed countries such as Europe and America (Wemos Health 2017). The use of social sciences health-related research, to inform the appropriateness and methodological approaches of clinical trials prior to implementation, as well as complementary, integrated health-related research run in conjunction with clinical trials, may mitigate participant risk and improve acceptance and ultimately clinical outcomes by better understanding the context, relevance and social implications of the clinical interventions, at a level beyond that of individual risk.

There are ethical challenges and risks associated with social sciences health-related research. In general these risks do not involve physical harms such as those which may result from clinical intervention trials. However social, psychological and economic harms may be a direct or indirect consequence of health-related research (Gurzawska and Bencin 2015). Other ethical concerns may relate to issues of justice, for example, compensation for research activities and involvement may be seen as a benefit of the study, with perceived injustice in terms of participant selection (Molyneux et al. 2009).

In poorly developed countries, many research participants or communities may volunteer to enrol in health-related research in the hope of receiving ancillary benefits, including superior health care, when part of the research study. It has been noted that in the most impoverished regions in Africa, health research studies may provide the *only* access to healthcare services in the region (Wemos Health 2017). This potential inequity of healthcare provision is a serious ethical concern, but if considered as an incentive for participating, may be considered reasonable as long as the research stands to benefit the population in the longer term (Benatar 2002) and extra protection from research-related risk of harm is afforded to vulnerable, socio-economically disadvantaged participants.

"Leave no one behind" is a fundamental principle of the 2030 Sustainable Development Goals (SDGs). In order to realise SDG 3, which strives to achieve universal health coverage across the globe, including those living in impoverished African communities, new approaches using mixed-methods health research and quality assurance studies are needed to identify and address inequities in health (Stone 2016), strengthen health systems, improve the SDH and develop a healthy population.

Global health initiatives, often with researchers from high-income countries working in low-income countries, offer huge potential benefit to health care in Africa, by bringing in clinical and research knowledge and expertise, expertise in health policy and planning, and financial, human and physical resources (Chu et al. 2014). However, such collaborations also have the potential for power imbalances and exploitation, of African researchers and healthcare providers, for the research participants and the population in general. If international research priorities are not aligned with regional needs, projects may not benefit the local population; in some cases researchers from high-income countries may get a greater share of recognition (in terms of authorship, grant income, etc.) than the local research team and health

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research conducted in areas with inadequate infrastructure and staff may actually have a detrimental effect on standard healthcare delivery (Chu et al. 2014).

Considering the potential for exploitation, corruption and misconduct in health research in Africa, it is essential that all stakeholders in the research enterprise adhere to internationally recognised standards of ethics, foster a culture of transparency and be sufficiently flexible to cater for different cultural and social norms, such that neither the health and well-being of participants are compromised, nor the integrity and truthfulness of the data itself (Egharevba and Atkinson 2016). Health-related research should be firmly rooted in an ethos of social responsibility and responsiveness. Socially responsible research should ultimately benefit the health of the regional public; therefore research should be targeted at better understanding and managing prioritised health conditions prevalent in the region.

5.4 Ethical Principles

The three fundamental ethical values common to both biomedical and health-related social sciences research are: beneficence/non-maleficence, justice and respect for persons (Gurzawska and Bencin 2015). In addition, responsible research practice, scientific integrity, investigator competence and independent ethical review are further considerations to prevent research misconduct and ensure socially responsible research practice. Whilst the fundamental ethical principles governing human research are common to all research methodologies, their nature may differ between biomedical and social-sciences approaches to health research (Gurzawska and Bencin 2015).

5.4.1 Beneficence/Non-maleficence

Beneficence speaks to the obligation of research to do good, to have the right impact and non-maleficence speaks to the need to avoid doing harm (both to research participants and the community at large) (Gbadegesin and Wendler 2006). The benefits of the research to the individual and/or community or society should be tangible, may be direct or indirect and may be evident in the short or long term following the study. However in some cases it may be difficult to predict the benefits likely to accrue from social sciences health-related research at the start of the study (Molyneux et al. 2009).

In order to “do good”, health-related research should be locally relevant and responsive to regional health needs and priorities. Beneficence is closely linked to societal value, whereby health research has the potential to directly or indirectly benefit people’s health (Emanuel et al. 2004). Health-related social sciences research primarily aims at benefitting society in the future, through improved knowledge, rather than focussing on individual participant benefit. However, there may be indi-

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vidual benefit, for example there may be therapeutic benefits in sharing traumatic or difficult experiences (Gurzawska and Bencin 2015; Molyneux et al. 2009).

Research-related risk refers to the potential for harm or injury (physical, psychological, social or economic) occurring as a consequence of research participation. Health-related social sciences research specifically carries the potential for social harm, for example in terms of stigma and potential breaches in confidentiality; psychological harm, arising for example when interviewing participants about sensitive or traumatic subjects, and when using deception in research; and economic harm, for example in lost wages (Gurzawska and Bencin 2015; Molyneux et al. 2009). Research risk should be evaluated at both an individual participant level and at a community level, with considerations for potential impacts on healthcare delivery and sociocultural harms, for example as might be seen in genetic research studies (Gbadegesin and Wendler 2006). Social scientists should reflect on the potential impacts of their research on the individuals and communities they are studying, and their research should stem from a culture of respect for local culture and tradition (Gurzawska and Bencin 2015).

In order to properly protect research participants, their level of vulnerability to potential exploitation or coercion must be considered. Specific groups are often considered particularly vulnerable and unable to sufficiently protect their own interests. These groups include (but are not limited to) those with cognitive impairment, children, foetuses, pregnant women, those with poor levels of education, impoverished people, those with severe medical conditions and incarcerated people. However, vulnerability should be considered in terms of context (both situational and individual factors) and is a relative rather than an absolute term. People with identified vulnerabilities should not necessarily be excluded from research (in the interests of justice), but extra protections should be implemented to protect them from potential exploitation and research-related harms (Bracken-Roche et al. 2017).

Researchers' scientific integrity is important as a fundamental responsibility to avoid research misconduct and exploitation and to ensure research outputs are accurate, relevant and original, and therefore more likely to make a positive impact on health when research findings are translated into practice (Gurzawska and Bencin 2015). When evaluating the risk-benefit ratio for individuals and communities involved in health research, the issue of regional post-study availability of any tested intervention (whether this is biomedical or social/environmental in nature) needs to be considered where appropriate. Failure to ensure provision of the intervention after the study (if shown to be effective), may lead to exploitation, with an unfair burden of research-related risk of harm, without any benefit to the community, even though individual participants may have benefitted during the research itself (Gbadegesin and Wendler 2006). Indirect benefits of health research could include improved infrastructure (e.g. clinics, medical equipment), local research capacity development, training of on-site medical personnel, public education (e.g. health promotion) and advocacy (e.g. to improve access to essential medications and vaccinations) (Gbadegesin and Wendler 2006).

In order to be socially responsible, all types of health research must be transparent and accessible, by consumers and healthcare workers alike. Communities that

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are expected to be involved in the research (providing the participants, infrastructure and local research team, for example), should also be involved in the development and conduct of that research. Five requirements have been proposed for the protection of communities involved in biomedical health research (Weijer and Emanuel 2000) and these are equally applicable to social sciences health-related research:

1. consultation with the community;
2. community consent and disclosure;
3. community involvement in the conduct of the research;
4. community access to data/results; and
5. communication and dissemination of research results.

Researchers are therefore obliged to make the process and results of their research accessible, known and understood within the community at large (Gbadegesin and Wendler 2006). This process provides some protection to communities, however exploitation remains a distinct possibility, particularly if the research offers the potential for ancillary benefits/otherwise unavailable health care and the community feels it has no option but to provide permission (Gbadegesin and Wendler 2006).

5.4.2 Justice

Justice speaks to the requirement to evenly distribute both the potential burdens and benefits of health research within the community and population at large. It also speaks to equity in terms of access to health care, which is an ongoing challenge in many African regions, and equality, without discrimination according to race, gender, culture, socioeconomic circumstances, educational level or religion (among others).

Exploitation of a community may occur when others receive an unfairly large proportion of the benefits of the research, for which individuals or the greater community bore the most risk (Gbadegesin and Wendler 2006). Perceptions of injustice may also occur when selected participants, households or communities appear to accrue benefit from the health-related research (for example in terms of compensation for time or better access to healthcare services), whilst those not selected receive nothing (Molyneux et al. 2009). Such perceptions of injustice could be mitigated by community consultation as to the best and fairest way to select participants for enrolment. For example. in general, the greater the risks of the research borne by a community, the greater the benefits should be received (Gbadegesin and Wendler 2006). Justice also speaks to potential disproportionate financial and prestige benefits (among others) to external investigators and sponsors of research, than that of the community and local investigators (Gbadegesin and Wendler 2006).

Within Africa, fair selection of which participants from countries, cities, villages, tribes and regions will be recruited must be carefully considered, taking into account the wide diversity of cultures, economies, resources, religions and political struc-

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tures across the continent. In order to fairly select research populations, consideration must be given to scientific validity, for example high local prevalence of the condition to be studied, risk must be minimised and development and sustainability of collaborative partnership between the community and the research team must be possible in order to ensure societal value and acceptability of the research (Emanuel et al. 2004). Once a population has been identified, the level of vulnerability of that population must be evaluated, with the addition of research-related safeguards to protect the participants and the community where needed, to prevent coercion and promote voluntariness of participation.

5.4.3 Respect for Persons

The principle of respect for persons and their autonomy requires consideration and respect for individual and societal needs, values, customs and choices during the entire research process, from development to translation of results into practice. This requires active engagement, involvement and inclusion of the community, including community advisory boards, civil society organisations, industry and policy makers, in a concept of participatory health research prioritisation and development. In addition, vulnerable persons or communities should receive additional protection (Tindana et al. 2012; Wasunna et al. 2014). Biomedical health research places particular emphasis on individual informed consent, but there is often less weight given to this aspect in social sciences health-related research and other models of information sharing and permission may be considered (Gurzawska and Bencin 2015). In participant observation research, for example, it may not be possible or appropriate to obtain consent from all individuals being observed, and in selected cases an element of deceit may be justifiable in the interests of obtaining reliable data (Gurzawska and Bencin 2015).

As discussed in Chap. 9, communitarianism as a philosophy may impact on the rights of the individual, who may be made subservient to the interests of his or her community. This approach is prevalent in Africa, with the philosophy of *Ubuntu* expressed in the phrase, “people are people through other people” (loosely translated). Individual informed consent is important for interventive health research, based on the concept of independent personhood. However, in some African cultures this concept may be more communitarian in nature and this needs to be respected in health research, particularly for public health/policy oriented research (Tindana, et al. 2012; Wasunna et al. 2014), whilst ensuring that individual autonomy is respected and the potential for coercion is minimised. The communitarian model of consent involves decision making through discussion and consensus, often among the elders or leaders within the community (Mkhize 2008). Other barriers to the traditional model of informed consent relate to language, culture, education levels and beliefs (Wasunna et al. 2014). It is therefore important to engage the com-

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munity in developing recruitment procedures and locally acceptable informed consent models (Emanuel et al. 2004).

Where informed consent is appropriate, for it to be valid, there needs to be adequate disclosure of research-related information, participants and/or communities must understand the information given (with sufficient time for questions) and the decision on whether to participate must be voluntary, without any implicit or explicit coercion or undue influence (Nelson et al. 2011). The process of information exchange, making and communicating an informed decision (the consent process) must be culturally sensitive and appropriate (Wasunna et al. 2014), including the use of local language/dialect and appropriate analogies to describe concepts that participants will properly understand (Emanuel et al. 2004).

Respect for persons does not end at obtaining informed consent, but must continue throughout the research process. Confidentiality must be maintained at all times and participants should in generally be able to withdraw from the research, with no consequences. Respect for persons also requires that people experiencing any harm (physical, social, psychological or financial) arising from the study intervention(s) should receive appropriate care and compensation, and that participants and/or communities should be informed about the results of the study and the local implications to health care.

5.5 Roles and Responsibilities of Health Research Ethics Committees in Africa

Independent ethics review is one of the cornerstones of ethical human research. Socially responsible health-related research in Africa requires research oversight and transparency of ethical review (Emanuel et al. 2004) to enhance public trust, ensure accountability and prevent exploitation. To ensure that exploitation of African populations, communities, institutions and countries does not occur in any health research, particularly when research is funded and developed by researchers from resource-rich countries, robust ethical regulatory frameworks must be in place within the African countries being targeted for research (Ndebele et al. 2014). It is not acceptable for any health research project to be reviewed only by the foreign institutional review board, as they are unlikely to have sufficient insight into local nuances, contexts and the unique vulnerabilities of the African people.

African health research ethics committees (RECs) have an important role and responsibility in the promotion and oversight of social responsibility in health research (including health-related social sciences research) at a grass-roots level – ensuring appropriate research in Africa, for Africans (See Chap. 1 for a more in-depth discussion). In addition, local RECs may have a role in overseeing the need to build capacity for research coordination and provide on-site monitoring of ethical adherence to ensure that human participants are appropriately protected and respected in health research processes. Over thirty African countries now have RECs

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in place (see Chap. 9), however there are substantial differences among these RECs in membership profiles, capacity, training levels and efficiency, with resulting disparities in quality of oversight and consistency of reviews (Kasule et al. 2016). Many RECs are primarily responsible for reviewing biomedical, quantitative research studies and may not have adequate experience or knowledge in the qualitative methodologies often employed in social sciences health-related research. In many cases, social scientists are not represented on the REC at all. Thus, particular attention is required to develop African REC capacity in terms of social sciences review, especially where qualitative research methods are employed (Molyneux et al. 2009).

In order to function effectively and create a conducive research environment, RECs should have standard operating procedures (SOPs) in place documenting their mandate, level of authority and accountability, and clear roles and responsibilities of REC members (Kasule et al. 2016). In the context of global, multi-centre transnational research being conducted in Africa, it is important to ensure consistency of ethical reviews among different research sites, including the consistent and rigorous evaluation of qualitative research studies (Molyneux et al. 2009; Theobald and Simwaka 2008). In developing SOPs, there should therefore be consideration of international ethical standards as well as local norms and regulations (Ikingura and Kithinji 2014). SOPs should consider aspects of REC membership, administration, review procedures and oversight (Ikingura and Kithinji 2014). Other functions of REC's may include the protection of researchers from criticism, where research is conducted in accordance with the approved protocol, setting policies and offering opinions on ongoing ethical issues in research.

5.6 "Responsible Research and Innovation" – A Framework for Conducting Socially Responsible Health-Related Research in Africa

> Responsible Research and Innovation is a dynamic, iterative process in which all stakeholders in research and innovation become mutually responsive and share responsibility for both the process and its outcomes. (RRI Tools Consortium)

Responsible Research and Innovation (RRI) encompasses a research approach which explicitly considers the potential impacts of the research on society in a responsible and responsive way. The concept of RRI is relatively new and therefore definitions and components are continually evolving. However, common concepts of RRI include the following (RRI Tools Consortium; Owen et al. 2012):

1. The focus of the research and innovation development should benefit the society and/or environment. The outcomes should align with the values and expectations of the society.
2. The society/community should be consistently involved in the entire research process, such that responsibility for the research enterprise is shared among all stakeholders.

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3. Potential social, ethical and environmental impacts, risks and opportunities should be assessed and prioritised. The RRI project must be both anticipative and reflective, considering both the potential short- and long-term impacts of the project.
4. Oversight mechanisms should be in place, including RECs.
5. The research should be responsive and adaptive to changing circumstances.
6. Openness and transparency are integral to the research process and development of innovations in health care. RRI includes the need to provide meaningful information to all stakeholders across all stages of the research.
7. Responsible research requires honesty, fairness, objectivity, accountability and investigator integrity.

Public or community engagement is a core component of the RRI approach (RRI Tools Consortium). By actively engaging with stakeholders within the community, using a community-based participatory research (CBPR) model, mutually beneficial research programmes can be developed with lasting impact, considering the greater public good (Emanuel et al. 2004). CBPR shifts the community from being the subject of the research, to becoming a participant in the research approach, empowering the community to investigate and implement necessary change and improvements in health care (RRI Tools Consortium). This collaborative, inclusive approach, with researchers, sponsors, health policy makers, educators, business partners, civil society organisations and other important community representatives being full and equal partners in the entire research process (from planning, through conducting the research, dissemination and implementation), has been highlighted as a fundamental requirement for ethical research in developing countries (Emanuel et al. 2004). The concept of collaborative partnership and CBPR require all stakeholders to respect the values, traditions and cultures within the community being studied, as well as aiming to develop local research capacity through these active partnerships (Emanuel et al. 2004). This approach develops a shared responsibility to ensure that the health research does not do harm and benefits the community by addressing key issues facing the society in an ethical and transparent manner (RRI Tools Consortium). Furthermore, an equal partnership requires that the playing fields are levelled between sponsor, researcher and the community – to do this, there may be the need for development of local healthcare resources and support for improving the structures in place for ethical oversight, for example through training. Consideration should also be given to sharing the rewards of the research itself, including authorship, royalties, funding, as appropriate (Emanuel et al. 2004).

5.7 Conclusion and Recommendations

> An action is right just insofar as it promotes the well-being of others without violating their rights; an act is wrong to the extent that it either violates rights or fails to enhance the welfare of one's fellows without violating rights … An action is right just insofar as it positively

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> relates to others and thereby realizes oneself; an act is wrong to the extent that it does not perfect one's valuable nature as a social being. (Metz 2007)

Health research in all its forms is essential to address the numerous healthcare challenges throughout the African continent. The continent therefore has a clear need and ample opportunity for conducting health-related research. There is, however, a risk of exploitation from the traditionally hierarchical, Western world-centred and -funded approach to health and health-related research in Africa. Researchers and RECs have a responsibility to society that transcends the research itself. In order to properly address and mitigate the fundamental health concerns among the African people, it is essential that a socially responsible and responsive research approach be adopted, considering accepted ethical principles. By including the community as stakeholders, using a participatory RRI model, the specific needs of the diverse communities across the continent can be identified and addressed, in a culture of respect, tolerance and mutual responsibility.

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Suggested Further Readings

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Chapter 6
Risk Assessment of Social Science Research in Africa

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> *Organisations are of two kinds, those which aim at getting something done, and those which aim at preventing something from being done.*
>
> Bertrand Russel (1952: 51).

Abstract This chapter responds to the widespread resistance among social scientists against the perceived inappropriate research regulatory procedures applicable to research of a generally low risk nature. Considering the unique collection of risks and opportunities in Africa (such as illiteracy, genocide and corruption), and as risk and risk assessment is socially constructed and subjective in nature, we propose a caring, context informed and dialogical approach to risk assessment in social and human science research in Africa. This chapter suggests that the dialogical approach include various stakeholders, such as universities and researchers, individual and collective human research participants, as well as the diversity of national and transnational societies. Such an approach will care for the diverse interests of research stakeholders in Africa.

Keywords Risk · Risk assessment · Opportunity · Stakeholders · Africa · Research ethics

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6.1 Introduction

Social science research has not escaped the widespread culture of managerialism and the related obsession with risk in higher education (Davis 2017; Tufano 2011; Wessels and Sadler 2015). In fact, the prevention and mitigation of research-related risks have become a central concern for universities worldwide, resulting in an abundance of institutional policies, standard operating procedures, systems, committees and the appointment of dedicated support staff for this purpose (Iphofen 2017; Schrag 2010, 2011; Wessels et al. 2015).

The backbone of research ethics review in universities has shown to be the prevention or mitigation of the risk of harming human participants, animals, molecules and cells through their involvement in research (Dingwall and Rozelle 2011; Horner and Minifie 2011; National Bioethics and Advisory Commission 1999). A study by Dingwall and Rozelle (2011) has shown that this regulatory concern with potential harmful effects of research interventions originated within the context of biomedical research and treatment as far back as 1803. The process of research ethics review has gradually extended to include the social sciences and humanities (Dyck and Allen 2013; Tolich 2016). However, a perceived overestimation of the risks of social science research procedures to harm human research participants (Van den Hoonaard 2001), has caused tension between social scientists and research ethics regulation systems. To this end, several social scientists argue that the low risk of the specific type and nature of research conducted by them, does not justify the costly and time-consuming procedures of regulatory oversight (Bull et al. 2012; Dyck and Allen 2013; Martyn Hammersley 2009; Iphofen 2017; Israel and Hay 2006; Van den Hoonaard 2001).

Furthermore, the implied prioritising of the risks of harm to human participants above the risks of harm to the interests of the researcher, the public or society, is a major concern for social scientists (Sleat 2017). The reason for this concern is because this prioritising seems to neglect the presence and equally important interests of a wide range of other role-players (parties) in this research process (Van den Hoonaard 2001), such as “participant communities, academic journals, professional associations, state and non-state funding agencies, academic departments and institutions, national regulators and oversight ethics committees” (Tolich and Ferguson 2014: 185).

As social and human scientists in Africa, we share this concern. Within the African context research stakeholders include, inter alia, research participants, researchers and research institutions, national and transnational funders of research, and a diversity of social communities. In this chapter we propose an African relevant approach to research ethics risk assessment for the social and human sciences. Core to this approach is an acknowledgement of benefit-risk assessment as a fundamental normative guide. Furthermore, embedded in this approach is respect for the diverse interests of the different stakeholders in the research process. While our proposed approach is not unique to the social and human sciences, the emphasis of our approach is on context (Africa) and disciplinary (social and human sciences) relevance.

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In this chapter, we consequently argue that the interests of the broad range of research stakeholders in our disciplines, require a more nuanced approach to the assessment of Africa- specific risks in research.

We therefore suggest an approach to research risk assessment that optimises ethical research through an embedded respect for the diverse interests of the different stakeholders in the research process. This chapter will specifically focus on the interests of (a) scholarship as represented by individual researchers attached to institutions of higher education, (b) individual or collective human research participants, and (c) society at large as articulated by national and transnational authorities. Such a review system requires adjusted risk assessment frameworks informed by selected risk management theories, the unique nature of ethical social and human sciences research, and a possible risk profile of social and human science research in Africa.

Consequently, the remainder of this chapter contextualises risk assessment as a multifaceted, contextual and dynamic phenomenon in social and human sciences research guided by the principle: “All social science [in Africa] should aim to maximise benefit and minimise harm” (Dingwall et al. 2017, p. 117).

6.2 Risk Assessment: A Risk Management Perspective

It is with unmistakeable sadness that Weinberg and Graham-Smith proclaim that “the university lost its distinctiveness and [has] become just another corporation” (2012, p. 68), one in which knowledge is circumscribed and risk reduced (p. 74). This worldwide corporatisation of the university (Davis 2017; Weinberg and Graham-Smith 2012) and the consequent risk- averseness (Davis 2017; Feeley 2007) is the immediate context of a quest for a sensible risk assessment framework for social and human sciences research. What can we learn from the risk management field to steer away from an unnecessary and expansive risk-averse regulatory regime?

Risk management is not only a well-established field of study within the social and management sciences (See for example Adam et al. 2000; Scheer et al. 2014; Tufano 2011; Wessels 2015; Wessels and Sadler 2015), but it is also a highly standardised practice through the publication of the ISO 31000:2009 as international standard for risk management in 2009 (ISO 2009). The publication of this standard was followed by several studies on its implications for the concept “risk”, as well as for institutional risk management (Andretta 2014; Aven 2012; Leitch 2010; Purdy 2010; Tufano 2011).

These studies revealed a general agreement among scholars on the concept of “risk”, namely that it refers to the effect of uncertainty on the achievement of an institution’s objectives (see for example the discussions by Aven 2012; Leitch 2010; Purdy 2010; Tufano 2011). This effect is usually calculated as the function of the probability and the magnitude of the outcomes (both positive or negative) of an event (Institute of Directors of Southern Africa 2016; Woodruff 2005), and is expressed as an expected value (Aven 2012). The value attached to the risk can be reduced by decreasing either the likelihood of the occurrence of that event, or the

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severe outcomes of the event, should it occur, or both (Woodruff 2005). However, the literature has also shown that the perceived effect of a risk event on the achievement of an institution's objectives, is determined, inter alia, by the risk perception of stakeholders, especially about the severity of the outcomes of a possible risk event.

The perception and assessment of risk is thus subjective in nature. We therefore agree with Slovic (1999) that risk is socially constructed. Studies of risk perception therefore focus on people's subjective judgements regarding the probability and severity of risk events or activities (Sjoberg et al. 2004; Slovic 1987). It is noteworthy that significant contributions on risk perceptions have been made within social sciences such as geography, sociology, political sciences and psychology (Slovic 1987, 1999). Furthermore, research by Scheer, Benighaus, Renn, Gold, Röder and Böl has confirmed that risk is "understood differently according to disciplines" (2014, p. 1272). In the engineering and physical sciences risk is understood as the function of the likelihood and severity of an event, while in psychology as a function of subjective perceptions within specific social and cultural context (Scheer et al. 2014). On the person level, research has also shown that risk perception "varies between respondents, dependent on the particular issue being evaluated and the definition of risk used to elicit responses" (Sjoberg et al. 2004, p. 29). One can reasonably expect that their social and culturally informed perceptions of risk will also determine the judgements of stakeholders on whether a particular risk event is either a critical risk or an opportunity.

The King IV Report on Corporate Governance for South Africa 2016 (hereafter: The King IV 2016) explicitly recognises "the potential opportunities inherent in some risks" (Institute of Directors of Southern Africa 2016, p. 30). Such opportunities may be the intrinsic benefit of a specific risk (Institute of Directors of Southern Africa 2016), such as an opportunity for radical change amid the risk of a weakened established social order (Adam et al. 2000). The assessment of a risk event should thus balance its potential (risk) to derail the institution from achieving its mission, with the opportunity it provides for achieving the institution's mission (Tufano 2011). This balance is recognised by the higher education institution to which we are affiliated to, as evident from an analysis of the Enterprise Risk Management Framework of the institution (Wessels and Sadler 2015). However, although the framework provides for this balance, it depends on the people within this regulatory system whether risk assessment is done with an understanding and caring spirit for the risks and inherent opportunities within the specific cultural or social context of the assessment (Wessels 2015).

Risk is thus generally understood as referring to the subjective judgement of stakeholders about the possible effect of uncertainty on the achievement of an institution's objectives. The upside of this assessment is the opportunities inherent to the same uncertainty that poses a risk to derail an institution's mission achievement. For the purpose of this chapter, "institution" refers to the university as mission-driven corporation within the higher education sector. The assessment of research-related risks, thus, occurs within the broader social and cultural context of a university, the context of higher education at large, the institutional contexts of individual universities, as well as the diversity of disciplinary and paradigmatic contexts.

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6.3 Risk Assessment: A Higher Education Perspective

In a thoughtful contribution on risk in higher education, Tufano (2011) confirmed that universities face a host of risks. Risk and risk management is indeed an integral part of the contemporary university, mainly due to the worldwide corporatisation (Davis 2017; Weinberg and Graham-Smith 2012) and the subsequent risk-averseness of the university as institution (Davis 2017; Feeley 2007). However, Tufano (2011) is concerned that universities are weakened by their inclination to position their risk management strategies too strongly on uncertainties, such as the government's continued funding and the subsequent avoidance of financial losses. While sharing this concern, we agree with Davis et al. (2016) that risks in universities should be carefully managed not to foster a culture of conformance at the cost of innovation. Tufano (2011) warns against focusing only on those risks that might derail universities from achieving their missions, without grasping the opportunity to even take on more risks to advance their missions.

The specific mission of a university as institution "committed to advanced learning" (Tufano 2011, p. 79) has shown within the South African context the discovery, understanding and transmission of trustworthy and cutting-edge knowledge for the ultimate securing of opportunities for social mobility (Department of Higher Education and Training 2013). Furthermore, an analysis of strategic documents of the "African university in the service of humanity" (Unisa 2018), for example, has shown that the institution's mission to produce "excellent scholarship and research" (Unisa 2018), is closely aligned to the government's expectations for higher education (See also the analysis done by Wessels and Sadler 2015). Furthermore, research and innovation is regarded by this institution as its second "core area of business" (Unisa 2018). Failure to achieve optimal research outputs is regarded as one of the institution's strategic risk areas with a high or extremely high rating. Research related risks are thus managed through a university's enterprise risk management framework and the implied research governance structures.

6.4 Risk Assessment: A Research Governance Perspective

Corporate governance practices require universities to not only identify research related risks, but to assess and mitigate these events and actions (Unisa 2016, p. 49). Typical strategic research related risk events for universities are the following: (a) disseminated research outputs that contravene the privacy and consent rights of research stakeholders; (b) researchers not complying with national legislation applicable to health research; and (c) disseminated research that is plagiarised, falsified or fabricated. It is commonly accepted that any plagiarised, falsified or fabricated research publications pose an extremely high risk for the research reputation of an academic institution, as argued by Padayachee in Chap. 8. Universities, thus, encourage scholars through institutional awareness campaigns to voluntary refrain from

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these incidents of high-risk misconduct by, inter alia, using similarity detecting software. In addition they utilise institutional policies and disciplinary procedures as ex post facto risk governance mechanisms (Slovic 1987; Varghese and Michael 2014); ex post facto mechanisms are used after the occurrence of the risk event.

On the contrary, the risks of disseminating research results that may possibly be harmful to the research participants, are regulated in an *ex-ante* manner (before the possible occurrence of the event) by applicable research ethics review committees (London 2012; The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1978). The *ex-ante* approach to research ethics review has shown to be internationally "a means of risk management in research involving humans" (Gontcharov 2013, p. 3). Social science researchers in especially the United States (US) have complained specifically about what they perceived as unreasonable restrictions of the *ex-ante* experimental oriented research regulations on social and human science research designs such as the grounded theory approaches or quality improvement research (Jordan 2013; Potrata 2010; Stark 2010). Within the African context, the findings of a study by Mamotte and Wassenaar (2009, p 76) attribute social science researchers' negative experiences of research ethics review to poor review procedures (Mamotte and Wassenaar 2009, p 76). In a later publication these authors discuss arguments relating to "principled and pragmatic objections" (Wassenaar and Mamotte 2012, p 5). The principled objections include restriction of academic freedom, ethical universalism and the adoption of the biomedical review model. Key pragmatic objections include time delays involved in obtaining ethics review while RECs are also accused of inaccurate risk-benefit assessments resulting in overregulation of social science research (Wassenaar and Mamotte 2012). Subsequently, we support a nuanced risk assessment approach for social and human science research; an approach that balances the diverse interests and risk perceptions of the wide range of stakeholders, as well as the inherent opportunities of the identified risks (see Chap. 4 and suggested further readings at the end of this chapter for a more detailed description of the terminology used to describe increments of risk, in particular Van Heerden, M., Visagie, R.G., & Wessels, J.S. (2016) & Wassenaar, D.R. & Mamotte, N. (2012)).

6.5 Risk Assessment: An African Social and Human Science Perspective

We have argued that risk, risk perception and risk assessment of social and human science research are subjective in nature and socially constructed and context informed. Not only does Africa serve as immediate context for this book, but also for risk assessment of research in the social and humans sciences. Therefore, we fully agree with Thierno Bah that the political, economic and social development of Africa "cannot be understood without the context of regional integration supported by a new paradigm for research and teaching history" (as quoted by the Graduate School of Development Policy and Practice 2016, p. 23). For the purpose of this

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chapter, we have demarcated the African context into (a) a shared vision for Africa, (b) stakeholders whose interests need to be considered, and (c) factors that may inhibit or enhance realising that vision.

The strategic documents of the African Union Commission as well as related research reports (Africa Center for Strategic Studies 2017; Graduate School of Development Policy and Practice 2016; Nshimbi and Fioramonti 2014) reveal a strong vision for an “integrated, prosperous and peaceful Africa, driven by its own citizens, representing a dynamic force in the international arena” (The African Union Commission & African Union Commission 2015). Inherent to this vision are aspirations for shared values and ethics, inclusivity, sustainability, integration, peace, good governance and a respect for the rights of human beings (Africa Center for Strategic Studies 2017; Graduate School of Development Policy and Practice 2016; Nshimbi and Fioramonti 2014; The African Union Commission 2015).

Several stakeholders have shown to share this vision for Africa, namely the African Union, the African Union Commission, the Pan African Parliament, several regional economic and development communities and organisations, various international, regional and national banks, member states, private sector and civil society (The African Union Commission & African Union Commission 2015). Not only are they driving and implementing a shared vision and aspirations, they are also commissioning, conducting and participating in research projects related to this vision. These stakeholders constitute the context of social and human science research in Africa. This context, thus, should be calculated in not only the risk assessment of social and human science research, but also the identification and assessment of the embedded opportunities for achieving the shared vision for Africa.

The Africa context of social and human science research, implies a unique set of risks and opportunities, such as the following: rapid population growth and the challenge of numbers (Sahel and West Africa Club 2006), illiteracy and lack of capacity (Capacity Development Division 2015; Emanuel et al. 2004), political tensions between countries in the region (Capacity Development Division 2015; Ndomo 2009), violence, genocide and crimes against humanity (African Union Commission 2015; Asher 2017), unstable state-society relations (Kiggundu 2012; Knopf 2013), corruption (Knopf 2013; Luiz and Stewart 2014), crime and security (Livingstone 2013). These risks and opportunities may either derail or enhance the achievement of a shared vision for Africa. Collectively they constitute the African context for social and human research risk assessment.

6.6 An Africa-Relevant Approach to Research Ethics Risk Assessment in the Social and Human Sciences

The final section of the chapter provides points for consideration for the diverse stakeholders involved in assessing research ethics risk in social and human sciences in Africa. Our approach is embedded in the principle of care as eloquently formulated by Stiegler (2010, p. 180): “To take care means caring for an equilibrium

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always at the limit of disequilibrium". We thus acknowledge the tension and dialogue implied by a caring risk assessment processes. If dialogue inspires joined action and meaning (Gergen et al. 2015), it would be reasonable to argue that the ideology and practice of research ethics risk assessment cannot be isolated from its macro-, meso- and immediate contexts (see Chap. 7). Hence, a process of research ethics risk assessment in social and human sciences in Africa ought to be context and disciplinary bound.

Furthermore, research ethics risk assessment should be founded on an embedded respect (see emphasis of this value in The African Union Commission 2015) for the interests of diverse stakeholders*,* which are (a) higher education institutions and researchers, (b) individual or collective human research participants, and (c) society at large as articulated by national and transnational authorities. Embedded respect implies a dialogical process of opportunity risk assessment that departs from the notion that both the integrity of science and the dignity of all stakeholder groups ought to inform the outcome of risk assessment.

The risk perceptions of these stakeholder groups are key in informing risk assessment as a subjective process. One can reasonably expect that stakeholders' social and cultural informed perceptions of risk will inform their judgement on whether a particular risk event is either a critical risk or an opportunity. The possibility that one or more of these stakeholders' research- related interests may be compromised to achieve the "common good" in relation to the research agenda in Africa is also not denied. Hence, judgement is guided by "what other social scientists find credible" (Dingwall et al. 2017, p. 134). Contextual factors that may pose either opportunities or risks of harm to the integrity of science, or to the well-being of any of these stakeholder groups, is an integral part of research ethics risk assessment that is inspired and sustained through dialogue between the stakeholders groups.

6.6.1 Research Ethics Risk Considerations for Higher Education Institutions and Researchers

If a university's mission is to advance knowledge, a critical step in research ethics risk assessment is to consider how the institution's risk mitigating strategies can either promote or inhibit knowledge advancement. Some guiding questions include:

- Are researchers free to make their own choices of "research problems and pursuing them in the light of their own personal judgment" as "cooperating members of a closely knit organisation" (Polanyi 1962, p. 54)?
- Do research ethics governance systems, including research ethics committees, function in such a way that researcher autonomy is promoted without necessarily compromising the dignity of other stakeholders?
- Does the university promote research integrity through education, policies, procedures and the provision of conducive work environments? (Resnik and Shamoo 2011)

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Taking the context into consideration, it is evident that some social sciences researchers working in African settings have to consider risk of harm in relation to their own safety and well-being. For instance, researchers that conduct social science studies in conflict-stricken areas must be prepared to face the consequence of their free, informed choices. Hence, a next step is to consider the protection of researchers from risk of harm. To this end, we agree with Gioraud, Cioffo, De Lettenhove and Chaves (2018, p. 3) that researchers ought to be sensitive to the emergent nature of ethical questions that arise as a result of specific situations associated with research sites or the use of particular research designs. These authors argue that the universal adoption of ethical guidelines or checklists may not be of much help in these situations based on the unique realities of social sciences or the fieldwork settings. However, we recognise that guidelines or checklists could be of value in particular for the stimulation of dialogue through the life cycle of a study. RECs and universities should optimise opportunities to create space for dialogue and ongoing reflection, without unnecessarily frustrating researchers.

Some guiding questions include:

- Is there a possible risk for the researcher to be exposed to physical threat, abuse or psychological trauma as a result of actual or threatened violence or the nature of what is disclosed during the interaction? (Craig et al. 2000)
- Is there a possible risk for the researcher to be in a compromising situation, in which accusations of improper behaviour may be made? (Craig et al. 2000)

6.6.2 Individual or Collective Human Research Participants

The focus of research ethics risk assessment has been traditionally on the risks of harm related to human participants' involvement in research. The concept "risk", within the context of research ethics review, denotes the possibility that research may cause varying degrees of harm to human participants and/or their related contexts (Van Heerden et al. 2016). These risks relate to the possible harm to these participants due to their vulnerability, neglect to their privacy or consent rights (Wessels and Visagie 2017). The following questions could guide deliberation between the different stakeholder groups about risk assessment relating to human participants:

- Does the research include the direct involvement of individuals or communities that are considered to be vulnerable? For example, children, persons that might find it difficult to make independent and/or informed decisions for social, economic, cultural, political and/or medical reasons. These individuals or communities can include the elderly, prisoners, those in dependant relationships, women considered to be vulnerable, those that are victimised and/or persons whose native language differs from the language used for the research.
- Is there a likelihood that a person or definable group will be identified during the research process? Is this likely to be of concern?

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- Does the research methods yield risk of harm to individuals or communities? For example the collection, use or disclosure of personal, identifiable information without the consent of the individual or institution that is in possession of the required information, participants that are required to commit an act which might diminish their self-respect or cause them to experience shame, embarrassment or regret (Deibert et al. 2011; ESRC 2015). Furthermore, deception of participants, concealment or covert observation could potentially create a risk of harm (Keane 2014), as well as disclosure of the findings of research that could place participants at a risk of criminal or civil liability or that can be damaging to their financial standing, employability, professional or personal relationships.

6.6.3 Society at Large as Articulated by National and Transnational Authorities

The interests of society are pivotal in assessing the social value of research. Civic engagement is heralded by some scholars as an important step to include the voices of society. Carpenter (2017, p. 9) for example, highlights that "researchers ought to involve members of the public in the designing, planning, delivery, ongoing monitoring and dissemination of research". Involving members of the public in risk assessment could thus add another dimension to the understanding of diverse risk perceptions. However, Hammersley (2017) is cautious in adopting this approach without careful consideration. He argues that civic engagement could lead to a further erosion of the social researcher's autonomy. With reference to the common good, Hammersley (2017) acknowledges that governments may pursue this goal, however, it is not clear what would be the criteria for measuring the achievement of the common good. In a similar vein, Dingwall et al. (2017, p. 117) warns against the "fashionable 'impact agenda' … and governments" approaches to research funding. These authors are curious about the meaning of impact and the possible risk of harm inherent to the aspiration for impact – "If impact is defined in terms of benefit to government or its agents, could the results actually harm those who has collaborated or co-operated in the provision of data?" (Dingwall et al. 2017, p. 117).

6.7 Conclusion

This chapter has been conceptualised against the background of notable resistance among social scientists against the perceived inappropriate research regulatory procedures applicable to research of a generally low-risk nature. While a common consensus exists on the values of ethics and integrity of research, the main concern has shown to be about the contextual validity of risk assessment of social and human research. We approached these concerns from an African perspective. Considering

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the unique collection of risks and opportunities in Africa (such as illiteracy, genocide and corruption), we have argued that risk and risk assessment is socially constructed and based on the subjective, context-informed, judgement of stakeholders about the possibility that a specific event may derail efforts to achieve interests. We have also shown that the same event may simultaneously pose an opportunity to enhance efforts to achieve the interests of stakeholders. Regarding social and human research, we consequently suggest a nuanced and dialogical approach to risk assessment that considers the diverse interests of the broad range of research stakeholders. Within the context of Africa, these stakeholders include universities and researchers, individual and collective human research participants, and the diversity of national and transnational societies. While the widespread culture of managerialism has evidently also infiltrated the immediate context of social and human scientists, we argue for risk assessment in social and human research that cares for the diverse interests of research stakeholders in Africa.

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Chapter 7
The Macro Ethical Impediments in Academic Research: A View from Africa

Tennyson Mgutshini and Genevieve James

Abstract Globally and with respect to research ethics, northern Euro-centric norms have progressively consumed southern Afro-centric-norms and a critical appreciation of this realisation sets the scene for a review of the constitution of socially responsible and ethical science in the African context. Following a description of the three levels (micro, meso and macro) of ethical enquiry, this chapter will provide an African view of macro ethics from the context of higher education and then proceeds to highlight macro-ethical impediments. How research in the South can effectively meet the needs of society, if it is governed by the research culture and ethical codes of the North, is the central dilemma of this chapter. Against this backdrop, the chapter addresses the differing value systems in research ethics between North and South and critically considers "universality" in the social sciences while exploring the complexity in the contextual application of research ethics. The chapter concludes with two aspects. Firstly, a reflexive "in-ward critiquing" section in which the authors consider some of the views that exist in contradiction to arguments posed here. Finally, the chapter ends with an overview of some of the critical necessities for researchers in the South to address the macro-ethical impediments.

Keywords Research ethics · Macro ethics in research · Northern hegemony in research ethics · North-South research

7.1 Introduction

Ethical norms or the rules we adopt for determining right or wrong are, on superficial analysis, common sense because they speak to our sense of right or wrong. Significantly, the application of ethical norms involves interpretations which may differ from person to person, and from one culture to the next, resulting in

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differences that centre on competing frameworks. Globally and with respect to research ethics, northern Euro-centric norms have progressively consumed southern Afro-centric-norms (as argued in Chaps. 2 and 3), and a critical appreciation of this realisation sets the scene for a review of the constitution of socially responsible and ethical science in the African context.

The first part of the chapter will introduce the three levels of ethical inquiry (micro, meso and macro). The focus will then move to the macro level of ethical inquiry, here the chapter will critically analyse the tensions between the research ethics paradigms of the North and South, and will address the differing value systems between North and South. The chapter will proceed to outline necessities for researchers in the South to address macro-ethical concerns in research.

7.2 The Three Levels of Ethical Enquiry

According to Blackstone (2017), ethical enquiry takes place at three levels affecting (a) the individual, (b) the profession/organisation, and (c) the community/society.

The individual is considered at the micro level. Here, the onus is on the researcher to carefully reflect on personal conduct and ethical decision-making thereby protecting the rights and dignity of research participants. At the micro level, universities and research entities provide research ethics training for academics, develop codes of conduct and determine ethical transgressions and their consequences.

At the meso level, researchers contemplate the expectations and rules of their chosen profession, as well as the ethical requirements of entities they seek funding from, or partnership with. Professional bodies have rules of engagement, codes of conduct and ethics polices to guide behaviour and control membership within a profession.

Finally, the macro level concerns the expectations and the needs of the society. Here, researchers consider it their duty to fulfil the expectations of society. For the purpose of this chapter, we have chosen to explore the research ethics dilemmas at the macro or societal level of enquiry. Our primary concern pertains to the macro ethics of research and knowledge production since we observe that much emphasis is placed at the micro and meso levels of enquiry, thus leaving the greater ethical dilemmas of research largely unresolved.

We argue that while researchers ensure the meticulous completion of ethics clearance forms; seek the necessary permissions and check that every source is flawlessly referenced, the greater, macro-ethical concerns of research remain disregarded. We assert that the macro-ethical concerns such as the dominance of the Western research ethics canon and its consequent marginalisation of the South are being ignored. It is our contention, that if university researchers are not sufficiently “conscientised” to macro-ethical dilemmas in the research enterprise then there is a

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present danger of lapsing into banal careerism and blind, uncritical obedience. This will result in the thoughtlessness of researchers to the injustices of their context and the needs of society, while remaining finicky about the micro concerns. At this point, it is necessary to emphatically state that we are not discounting the need for the micro- and meso-ethical considerations, what we seek to do is to raise consciousness about the uneven focus on the micro and meso levels, at the expense of the macro levels.

7.3 The Macro Level: Higher Education Research in the African Context

There is increasing concern pertaining to an apparent disconnect between science and the public. The old images of science, propagated in spy movies, perpetuate a notion of bespectacled men in white coats conducting secret research in high security labs concealed from the eyes of the public. Research produced by higher education simply cannot fit this mould, more especially if it is funded by the public purse. While the public contributes to research coffers and pays the salaries of academics, they sadly seldom see the return on investment. On a positive note, there is a move within higher education towards aligning research to the development needs of society. For example, at the University of South Africa, academics are encouraged to produce engaged research to support the development imperatives of the country. The university has developed niche areas and strategic focus areas to encourage researchers to explore African solutions to African problems (see Chap. 6). While this is an encouraging development in higher education, we are still a long way from fully realising the transformative potential of higher education research on the continent.

If the needs of society are at the heart of the macro level of ethical enquiry, then we need to consider what the expectations for universities on the African continent are. On the continent, there are vigorous calls for bolstering university research as a means of African renewal and progress. The *Continental Education Strategy for Africa 2016–2025 (CESA)* approved by Heads of State in January 2016 at the *26th African Union Summit*, stressed that [African] research is critical to growth and development.

Higher education research is an indispensable catalyst for the African renaissance, yet it cannot realise its potency if it continues to suckle on the breast of its colonial masters. According to Zeleza (2016), higher education plays a critical role in the resurgence of the African continent. He proposes critical priorities for higher education on the continent among them being the “relevance of knowledges produced, disseminated, and consumed to economy, society, and the times, [this] entails sustaining the project of decolonizing knowledge from the historic epistemic stranglehold of Eurocentricism” (Zeleza 2016, p. 11). This brings us to the crux of this chapter, which is the macro-ethical impediments of research.

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7.4 The Macro-Ethical Impediments of Research: A View from Africa

As indicated earlier, academics and researchers alike, may overlook the larger ethical questions about research when they focus solely, or too closely, on the micro-ethical level. At the macro-ethical level there is a plethora of questions that require our attention. These questions include, but are not limited to: Who sets research ethics rules? Who develops our research ethics training? Who shapes our research methodology? Who decides our research agendas? Who publishes our research? Who decides who gets access to the research? Is the research conscious of the specifications of our context, worldviews and cultures? This chapter attempts to explore some of these questions by identifying key ethical impediments or obstructions at the macro level thereafter providing necessities for researchers to address the status quo.

7.4.1 Research Culture: The Search for Knowledge vs. Knowledge for the Public Good

A recurring macro-ethical concern relates to the adequacy of our research pursuits to meet the needs of African society. We doubt if Western modes of research adequately prepare us to understand, discern and respond to African realities. If society is at the heart of the macro-ethical level of enquiry, then a critical impediment at this level pertains to the motivation behind our search for knowledge. The reason why we research, is for us, an ethical concern.

We concur with Armstrong (2012) who suggests that a fundamental motivation for research has been "intellectual ambition" which he describes as "the desire to know and understand the word, to appreciate the best that has been said and thought on the topics that grip our imaginations". Apart from our observation that membership to the club of the intellectually ambitious is restricted and carefully controlled, Armstrong (2012) states that intellectual ambition is "accompanied by indifference to public opinion, lack of concern with buy-in from the wider world, hostility to winning over hearts and minds in large numbers". The pursuit of knowledge for knowledge's sake is coming under fire, in part, due to the scarcity of research resources in a tough economic climate, where many universities have introduced austerity measures. Illuminating the prevalent ideology of scientists in the modern period (which has its roots in Western Europe), Vessuri (2008, p. 119) paints the following picture:

> They refuse to see that, in practice, values other than the search for knowledge prevail. This corresponds to the form of education and professional training that excludes any link between the scientific endeavour and social concerns.

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7.4.2 The "One-Size Fits All" Approach to Ethics in Research

Against the backdrop of the Western normative discourses influencing higher education, a chronological exposition of the genesis and growth of ethics in research invariably leads back to four declarations, namely the Nuremberg Code (1947), The Declaration of Geneva (1948) and more seminally, the Declaration of Helsinki (1964) and the Belmont Report (1978) (Miracle 2016). Seen as the formal theoretical basis of modern ethical principles, each of these provisions were developed in either America or Europe and set forth the ethical codes that represent the cornerstone of modern research ethics. Seminally, the Nuremberg Code (1947) and the Declaration of Helsinki (1964) continue to be seen globally as cornerstones to ethical practice in research.

Most notably, the Declaration of Helsinki has grown in status as a guideline for medical research involving human participants that much of the global ethical standards, principles and practices are founded upon. So ingrained is its influence that it has been revised no less than seven times over its existence, the most recent being in 2013 (Emanuel 2013). Even though the primal principles are founded on 1964 blueprint, they remain current by virtue of their continued review.

Dominant ethical principles are founded on micro ethics, which is the primal concern of respect for the individual, their right to self-determination and most significantly, their right to make informed decisions regarding participation in initial and progressive aspects of the research. Within this conceptual framing of ethical practices, the researcher is primarily duty-bound to their study subject with the interests of science and society occupying secondary importance. These tenets are at the core of the way in which the Helsinki Declaration and resulting theoretical positions have been communicated. Although broadly acceptable, the prioritisation of the subject's interests (the micro concerns) above that of the wider society (the macro concerns) is juxtaposed to African sensibilities where communal priorities often occupy higher priority than those of the individual. Within that determination, the researcher's intentions and practices should primarily answer to society above all (Jermias and Gani 2004).

Predecessor contributors including Ndlovu-Gatsheni (2013) and De Oliveira Andreotti (2011) provide a thematic and construct analysis of the key principles within ethics in research, most of which represent extensions and confirmation of the original Helsinki Declaration and other related declarations and reports.

Much like the rest of the world, African scholarship has modelled its ethical standards and expectations on Western foundations, namely the Biomedical, Newtonian and Cartesian-form principles that remain central philosophical underpinnings within Western research domains (McDowall and Ramos 2017). This norm represents the status quo for the way research ethics is conceptualised, applied and evaluated. Critical perspectives at the forefront of key indigenisation movements such as decoloniality, Africanization and the African Renaissance, have broadly presented critiques of the way Western norms and episteme have been and continue to be the central driving forces for the way in which practice across society

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and more specific to academia – how academic norms continue to be westernised and colonially-influenced to the detriment of local preferences and expectations (McDowall and Ramos 2017).

Several reviews of current ethics in research allude to wide-ranging concerns about the way in which a “one-size-fits-all” application of ethical principles and interpretations appears to be the practiced norm, even by those who have taken on the mantle of decolonising knowledge production (De Oliveira Andreotti 2011). These reviews conclude that ethical analyses should also include an exploration of factors such as cultural, gender, ethnic and geographical considerations. In summary they assert the view that traditional moral norms should be subjected to ongoing re-evaluation on a case by case basis (see Chap. 3). For example, contestation continues over the ethics and regulations of research involving human subjects as a direct result of ongoing debates about the meaning and priority that American guides such as the Belmont Report have attributed to widely used ethical principles such as, respect for persons, beneficence and justice. Significantly, the specification of how these ethical principles should be weighted or prioritised, should be locally determined. At its most basic, there is a need for localised decision-making about whether key principles should be viewed as an obligation that society must undertake on behalf of its members or if it should be viewed as giving absolute priority to respect for persons’ autonomy over the general good of society (Mignolo 2011).

7.4.3 The Notion That “West Is Best”

The continued reliance on Western conceptions of morality and ethical correctness remains the norm across ethics in research globally, largely because of the view that depicts Africa and other emerging continents as brain-drained entities where their most prolific thinkers have either been exported to the West and/or have been educated within Western educational systems. 82% of all graduates with postgraduate degrees report “migration to Europe and the Americas” as the most noteworthy aspiration that they have as far as professional progression is concerned (Oluwajodu et al. 2015; Venhorst 2013). Similarly, they cite “access to highest levels of expert knowledge within their profession” as the key determining factor behind their justification for their migratory ambitions.

The notion that “the best resides in the west” further marginalises the contribution that emerging countries can make in shaping conceptions of morality and ethics in research. Venhorst’s (2013) study of the culture of professionalisation shows that images of professional behaviour tend to be aligned along Westernised norms and it is asserted that it is these practice determinations that shape ideas of what best practice and/or research behaviour should be like.

An example of what we describe above is the experience of Mahmood Mamdani of the Makerere Institute of Social Research, who was one of the beneficiaries of a

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US scholarship at the time of the Ugandan independence. He explained what ensued on the completion of the scholarship:

> Those who came with me divided into two groups. There were those who never returned, and then those who did, but were soon frustrated by the fact that the conditions under which they were supposed to work were far removed from the conditions under which they were trained. In a matter of years, sometimes months, they looked for jobs overseas, or moved out of academia into government or business or elsewhere. (Mamdani 2017, pp. 85–86)

For Mamdani (2017, p. 86), the lesson gleaned from this experience, was that was that "the old model does not work". He asserts that postgraduate students must be trained on home ground "in the very institutions in which they will have to work. We have no choice but to train the next generation of African scholars at home" (Mamdani 2017, p. 86).

We are in agreement with Mamdani's assertion, since researchers in the South are often regarded as second-class citizens in the world of research requiring the mentorship of their more adept counterparts in the North (Baijnath and James 2015). A case in point is the suggestion that Karolsson (2002) offers to increase knowledge in the area of environmental and human systems in the South. For Karolsson (2002, p. 13) the solution lies in "increasing the number of northern scientists working on the South" and "to strengthen the scientific community of the North for the South, by increasing the number of Northern scientists who conduct field studies in the South". While Karolsson laments the research inequalities between north and south and suggests that governments of the South have a role to play, the benevolent solution offered, is the continued research capacity building of the South, by the North. Karolsson (2002, p. 13) offers a transactional benefit to the researchers of the North: "When they carry out their work in close partnership with local scientists, they benefit in their own research from local knowledge and experience while also contributing to the capacity of their Southern partners."

7.4.4 *Northern Ethics in the South: A Square Peg in a Round Hole*

As a direct result of the by-products of the industrial revolution, colonisation and other related historical developments, the history of progress has favoured the Northern Hemisphere over the Southern Hemisphere. Examples of this can be easily evidenced in areas such as "developments in Information and Communication Technologies"; "the development of University-culture" and "developmental efforts in poverty alleviation". Generations-long advantage for the North continues to be perpetuated in all walks of life with earlier works suggesting that "morality and civilization" are unquestionably more advanced in the North than in the South (Nedeau et al. 2003). The development of the first universities in Europe and in North America established them as the gold standard against which all scholarship is measured. Even within the context of determining ethical correctness and morality, they

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have historically provided the guiding light to their global peers. At the superficial-objective level, this is acceptable but closer analysis highlights the limitations of such an approach, not least because of the differing social and politico-ethico contexts that exist in other areas of the globe. As a casing example, Southern Hemisphere conceptions of the individual autonomy versus collective action differ markedly from those of their European and North American counterparts. By virtue of this and other significant differences, it is reasonable to assert that; Northern episteme is incongruous with Southern hemisphere norms.

7.4.5 Research Ethics: Uncontested Vade-Mecum

The dominance of Eurocentric codes of ethical practice within the global research context translates to a wider domination in other spheres of life. The challenge related to a disproportionate adoption of Northern Hemisphere norms is not exclusive to the research ethics domain but instead, extends across many domains. Mendoza (2016) and Ndlovu-Gatsheni (2015) allude to this and suggest that the total colonisation of African life has often meant that all important areas start from a position of accepting Northern ontologies as superior norms. Accepting this, it comes as no surprise that research ethics continue to be dominated by Northern modes of conceptualisation. The prioritisation of it as an area worthy of corrective decolonisation has been negatively influenced by a lack of activism in challenging prevailing academic norms. Ndlovu-Gatsheni (2015) further supports this view and strongly argues that academic contexts are surprisingly compliant and often show the most significant lag in challenging the status quo within their area(s) of practice.

7.5 North-South Polarisation: A Crude Over-Simplification of Complex Societal Dynamics?

It is necessary to state that the arguments and positions posited within this chapter are not to promote a simplistic polarised depiction of the North as “bad/wrong” and the South as “good/right”. By contrast, we argue that the differentiation between the North and South is based on a more complex relationship in which a primal realisation is that, for the South’s true potential to be realised, there is a need to acknowledge the knowledge legacies of colonialism and the dependency on Northern canons. Similarly, there is acceptance that in many current African societies, the infiltration of Western influence is for the most part, substantial but yet discreet, at times latent and but often visible.

Costa (2017) and Floya (2016) identify the dilemma that exists from the fact that, even decoloniality theory and praxis often benchmark their successes or failures on

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western norms. This chapter sheds a singular light on this issue. We have tried to communicate the extent to which African society is influenced by its colonial histories. Discussions around research ethics, or put simply, doing the right thing in research, cannot take place without an understanding of the disequilibrium in knowledge power and influence. Some including Boone (2003) and Mignolo (2017) believe that the complex nature of any type of power-transfer transition must, at some level involve the "taking" of power from current holders of that power who are seen as ill-placed to remain in power. Within the African context, this motivational basis is by its very nature, about liberating the South from the vice grip of Northern legacies, dependencies, power systems and structures that impinge on research praxis. This liberation is necessary to build new African research consciousness and consciences.

7.6 Addressing Macro-ethical Impediments in Research: Necessities for Researchers in the South

It is our assertion that the analysis thus far offers a noteworthy articulation of key impediments to developing contextually-based research ethics. As eye opening as this engagement has been, it is critically important that the process of reflection be concluded with a summative overview of practical ways to undo these age-long hindrances. To that end, a number of related "ways of being" are postulated with the proviso, that they should be seen as initial thoughts that each researcher can build on.

7.6.1 Critical Consciousness Should Not Be Considered a "Given" Within Academia

Researchers need high intention to develop critical consciousness beyond the realm of their disciplines and specialisations, to the realm of research culture, codes, canons, management and mobilisation. We assert that the level of critical consciousness will influence the quality and confidence of our research praxis.

7.6.2 Professional Reflexivity Must Be a Critical Research Attribute

Linking to the point above, much of the evidence continues to portray academia as a space whose rules were negotiated historically and the primary purpose of current academics must centre on compliance and emulation above all. The assertion here is that, much as the times have changed, so too must the rules of engagement. It is

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incumbent on all academics to regularly re-evaluate whether or not their modes of cognitive processing and practice remain relevant and whether new contexts require new rules. If this were to be truly adopted by institutions at large, one would expect significant review and revision of ethical standards, many of which have remained unchanged since their conceptual birth some 70 years ago.

7.6.3 Researchers in the South Need Social Impact and Transformation Consciousness

It is our assertion, that academia and by inference, research ethics, have been wrongly motivated by careerism and the perpetuation of individual success with little regard to the social and transformative value of the research produced. It is important to note that the rewards-based nature of research has meant that researchers who comply with the norms, standards, productivity levels and ethics bestowed by the West, will be recognised and rewarded. Recognition will include acceptance around the table of Western experts, invitations to foreign conferences, requests for research collaboration, international accolades and research ratings. This seal of approval will result in rewards, which will include financial benefits and career upward mobility. Researchers have been hardwired to expect these benefits no matter how limited the public good, social impact and influence of their research. This is especially perturbing in contexts where the research skills of academics are in critical need for the development and social transformation of society.

Research excellence indicators have often been skewed in favour of simplistic quantitative measures (Ferretti et al. 2018). These measures primarily included the number of articles produced (outputs) and number of citations etc. In addition to scientific rigour, there is now a growing move to consider research excellence in terms of impact and influence. There are increasing concerns for research to contribute to transformation of people, places and polices. According to Tijssen and Kraemer-Mbula (2017) in a survey on perceptions of research excellence in the African context, respondents were asked to list relevant dimensions of research excellence, while most indicated ‘scientific merit’ (91%), notably 81% indicated ‘impact and influence’, and 68% ‘relevance’. Tijssen and Kraemer-Mbula (2017) note, “a distinction should be made between intrinsic characteristics of the research or the researcher (merit), the final effect of the research outcomes on others (impact), and a value judgement regarding the external usefulness of those outcomes (relevance)”.

Against this backdrop, within research ethics, it is important that the prioritisation of social good and public contribution, become the mainstay of research activity without contest. Establishing social value-add as a primal imperative within research practice needs to be a critical aspect that differentiates research practice within Africa from our Western counterparts, not least because we live in societies that have longstanding disadvantages that can only be eradicated through the use of knowledge as a tool for public development and not for just, for knowledge sake.

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7.6.4 Context Must Matter

Given that research cannot take place in a vacuum, a prime necessity for researchers to address the macro-ethical impediments is contextual awareness, which concurs with the arguments of Roets and Molapo in Chap. 10. Researchers must learn how to read and analyse context. An acute understanding of setting will aid in greater relevance, and transformative impact *on* particular problems *for/with* particular people *in* particular places.

7.7 Conclusion

The chapter began with an introduction of the levels of enquiry, and then focused on the macro-ethical impediments in research concluding with the critical necessities for researchers in the South to address the macro-ethical impediments.

While it was necessary to offer a dissident view on research ethics by exploring the macro-ethical impediments, it was not our intention to be controversial or subversive just for subversion's sake. It is our contention that researchers in Africa and the global South need to move from weakness and vulnerability to greater agency, impact and influence. We do not seek a new research centre of gravity or a Southern hegemony. What we seek is self-determination and self-actualisation, which will make us stronger partners in the global research enterprise. We need the confidence to interrogate and revision the research enterprise, its codes, canons and methods in order to construct an inclusive research world order that recognises us as competent, equal partners. The ability to do this will result in us progressing from mere factory workers in the production of research, to critically conscious owners, leaders, partners and innovators in research. This *New Jerusalem* of research, will have to be created by the higher education and research sector, supported by the increased commitment and will of governments, and in dialogue, with research partners around the world.

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Chapter 8
Unethical Authorship Deals: Concepts, Challenges and Guidelines

Keshnee Padayachee

Abstract This chapter examines the lesser vilified issue of “unethical authorship deals”. Unethical authorship should be afforded the same status as other forms of research misconduct such as plagiarism, as it is a form of deception and it often involves the exploitation of lesser acclaimed authors. Unethical authorship deals occur when authors collude to misrepresent the true authorship of a paper and this form of misrepresentation makes it difficult to assess the credibility and validity of a work against possible bias. The true authorship of a paper may be misrepresented in several ways. Authors may bestow authorship upon an individual who has not substantially contributed to the work or an author may take full credit for a paper that was co-written by a ghost author. While honorary authorships or ghost authorships are clear infractions, the authorship order issue is an underrated contravention. The aim of this chapter will be to draw attention to the concept of ethical authorship deals and explore the prevalence of unethical authorship practice. While there is a dearth of studies with respect to unethical authorship in Africa, these limited studies indicate that the problem is of significance within the African continent.

Keywords Unethical authorship · Authorship order · Authorship guidelines

8.1 Introduction

In the academic field, there has been a surge of multi-authored scientific papers within the social sciences where multiple authorship is considered to be a norm (Macfarlane 2017). It is conceivable that there may be sound justification for the increase in multiple authorship publications, which may be due to knowledge sharing and increased visibility. However, it is more likely due to the pressure to publish, coupled with the prestige and the opportunism associated with being an author on numerous publications. The problem with multiple authorship, where an author is given undue credit on a regular basis, is that these deceitful authors become power

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players in academia. Their power is enhanced and propelled by the acquisition of funds, obtaining positions of seniority and being recruited as editors and reviewers (Gasparyan et al. 2013). They become science politicians (Santos et al. 2015) canvassing for more publications. This perpetuates the culture of unethical authorship, which is often rewarded. This culture is marked by bullies who use their power and influence to obtain undeserved credit by exploiting the vulnerabilities of others. Awarding unmerited authorship is often seen as a victimless crime (Osborne and Holland 2009). A person who exploits junior members of staff is often aware that the incident will go unreported (Kwok 2005), consequently a vast majority of unethical authorship deals do go unreported (Sandler and Russell 2005). Hence it is important for institutions to create an environment where vulnerable groups (e.g. junior staff, students, etc.) are empowered to advocate for authorship if it is warranted (Osborne and Holland 2009) and to report it when an infraction has occurred.

Typically, the guidelines for authorship stipulate that in order for an individual to claim authorship, he/she must make a substantial contribution (ICMJE 2009). It appears unlikely that where there are multiple authors on a paper each author has made a substantial contribution (Kwok 2005). For instance, an article from the PubMed database was found to have 3040 authors in the by-line (Marušić and Marušić 2013). Although this situation is unlikely to occur in the social sciences, there is evidence that multiple authorship is growing in the discipline (Macfarlane 2017). Authorship patterns in South Africa show that multiple authorship is on the rise (e.g. the average number of authors per article in the discipline of Biotechnology is 5.91 per article (Singh 2017)). Another issue of concern is when an author publishes in excess of what is feasibly possible to publish within a specific timeframe (e.g. an academic who produces in excess of 40 articles within a single year). It is inconceivable that an author with this level of productivity could have made a substantial contribution to all 40 articles. However, institutions tend to reward this level of productivity instead of viewing it with the suspicion it deserves.

The challenge with unethical authorship is that it is a commonly occurring and acceptable standard practice, particularly within collaborative research teams. This form of research misconduct may be attributable to the "publish or perish" maxim. It is often endorsed and enforced by senior researchers, which compounds the problem. The returns on unethical authorships are far greater than the repercussions of reporting such occurrences. Therefore, we should be mindful of these unethical practices as a primary step towards addressing this challenge.

Consequently, the aim of this chapter is to raise awareness of the issue regarding unethical authorship deals. We explore the pervasiveness of unethical authorship practices and its associated influencing factors in Africa and globally. It has been recommended that unethical authorship may be prevented if the entire scientific community challenges and prevents unethical authorship collectively (Santos et al. 2015). Furthermore, this chapter presents a guiding framework for identifying, understanding and addressing unethical authorship. The aim of the guideline is to raise the awareness of all stakeholders and to empower junior researchers and students who may be vulnerable to this form of exploitation by senior researchers. Towards this end, we explore the adequacy of extant ethical guidelines.

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8.2 Terminology and Challenges Associated with Unethical Authorship

This section explores the terminology and challenges associated with mitigating unethical authorship. The term "unethical authorship deals" requires a comprehensive examination by means of providing an overview of concepts underlying unethical authorship deals. Foremost, it is important to understand what the term "authorship" means and the implications of being listed as an author on a publication. There is no standard definition for the term authorship that can be used to easily resolve disputes (Marušić and Marušić 2013). The Vancouver Protocol which originated at the biomedical sciences, was defined by the International Council of Medical Journal Editors (ICMJE) in 2009 (ICMJE 2009) and is now being applied by a number of universities (Macfarlane 2017). The American Sociological Association's (ASA) criteria for authorship is also included in Table 8.1, for comparative purposes. The Vancouver Protocol is composed of four criteria and all four of them must be met in order for an individual to claim authorship.

Osborne and Holland (2009) reviewed authorship criteria among various associations and noted that only the ASA makes provisions for student authors. The authorship criteria for the ASA is composed of three criterions (~1), (~2) and (~3) only. The fourth criteria (~4) is a related point on the ASA Code of Ethics and was included for completeness, however, it is not specifically listed under the criteria for authorship.

Table 8.1 Authorship criteria guidelines

The Vancouver Protocol (cited from ICMJE 2009)	The American Sociological Association (cited from ASA 1999)
(#1) "Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work"	(~1) "Sociologists take responsibility and credit, including authorship credit, only for work they have actually performed or to which they have contributed"
(#2) "Drafting the work or revising it critically for important intellectual content"	(~2) "Sociologists ensure that principal authorship and other publication credits are based on the relative scientific or professional contributions of the individuals involved, regardless of their status. In claiming or determining the ordering of authorship, sociologists seek to reflect accurately the contributions of main participants in the research and writing process"
(#3) "Final approval of the version to be published"	(~3) "A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis"
(#4) "Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved"	(~4) "In cases of multiple authorship, sociologists confer with all other authors prior to submitting work for publication and establish mutually acceptable agreements regarding submission"

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The term authorship may be defined as “an author is the originator of both information and written work” where the “intellectual creativity and originality are the primary basis for scientific authorship” (Vučković-Dekić 2003, p. 211). Often the term used to describe authorship is “one that makes a substantial contribution to the manuscript” as described by the Vancouver Protocol, but this can be a grey area and open for exploitation. Strange (2008) suggests that there must be two thresholds to authorship – (1) all authors must be able to describe their contribution within the *intellectual context* of the manuscript and (2) an author must be able to take accountability and responsibility for his/her contribution. Consequently, threshold (1) cannot be satisfied by a funder, technical advisor, statistician or editor who does not engage intellectually with the manuscript and such a person must be acknowledged (Strange 2008). Threshold (2) which is also stipulated by criterions (#4) and (~1), becomes significant when there are criticisms levelled at a paper. The author cannot claim ignorance or apportion blame to the co-authors for problems such as falsification, fabrication or plagiarism if he or she met threshold (1), as they would have been aware of such infractions. Osborne and Holland (2009, p. 4) also assert that the term “substantial contribution” should be defined more expressively as it could contain one or more of the following: (1) conception or design, (2) data collection and processing, (3) analysis and interpretation of the data, and (4) “writing substantial sections of the paper”. However the criteria proposed by the Vancouver Protocol should not be maliciously used to deny authorship to deserving individuals by not involving an individual in criterion (#2) or (#3) (ICMJE 2009), however the criterions (~2), (~3) and (~4) from ASA (1999) appear to be mechanisms to prevent power differentials and thereby also prevent an individual’s contribution from being undermined.

While it is imperative to understand when a contribution to an article is given authorship credit, it is also equally important to understand when a contribution should not be credited. The following contributions do not warrant authorship credit – administrative assistance, clerical or mechanical assistance, general supervision over the research project, acquisition of funding, data collection and sharing of materials or samples (Osborne and Holland 2009).

Honorary authorship is the act of bestowing authorship to an individual owing to their “authority or prestige, or as a courtesy”. According to Marušić and Marušić (2013, p. 2) there are two types of honorary authorship:

- **Guest authorship**: This type of authorship is characterised as an author that did not contribute in any way to the research. However, the credit is endowed, as there is an expectation that the author’s eminence may increase the likelihood of a publication.
- **Gift authorship**: This type of authorship is characterised as an author who has “marginal relationship to the study” such as a figure of authority (e.g. Head of Department).

However, in some instances, honorary authorship can be characterised as **coercive authorship** which involves the exertion of pressure from a person in a senior position over junior researchers (Strange 2008). Coercive authorship is a very serious

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infraction and is analogous to the White Bull Effect. Kwok (2005) proposed the term **White Bull Effect** (derived from Greek mythology) to describe an academic who exploits the ambiguities in ethical guidelines to obtain unmerited authorship credit. The White Bull effect is a "premeditated way to avoid the accusation" associated with honorary authorship (Kwok 2005, p. 555). The White Bull is insidious and careful to keep within the rules of ethical practice while not making more than a token effort by showing public displays of involvement in the concept, design, data collection, analysis and undertaking to proofread the drafts (Kwok 2005). Consequently, the White Bull technically satisfies all criteria for authorship, however at no point in time "is the White Bull compelled to make more than a token effort" (Kwok 2005, p. 554). Kwok (2005) suggests psychological profiling for such individuals. These individuals may exhibit certain narcissist behaviours that may be used to identify them. Perhaps White Bulls can be socialised to understand the impact of their behaviour on the scientific community.

Honorary authorship can also involve relationships, which are not coercive but mutually beneficial, which is characterised as **mutual support authorship,** where two or more authors in a symbiotic relationship conspire to list each other's names on their individual efforts in order to feign higher productivity (Strange 2008). Other types of authorship which are forms of plagiarism include **duplication authorship** (i.e. submitting the same article multiple times) (Strange 2008).

In contrast to honorary authorship, a **ghost authorship** is when an author is not given authorship credit while contributing substantially to the manuscript (Marušić and Marušić 2013). Essentially ghost authorship can be defined as excluding an individual from the by-line even though they meet the authorship criteria (Vučković-Dekić 2003, p. 211). This typically happens with commissioned research where a well-renowned author is commissioned by an organisation to conduct research. The well-renowned author plays a minimal role in the research, and an insider(s) does the write-up. Neither the company nor the insider(s') credentials are revealed. Using what appears to be an independent expert adds credibility to the research. Ghost authorship occurs as a means to hoodwink the scientific community as revealing this bias in a study will devalue the scientific merit of the study. This typically occurs within the pharmaceutical industries, where the benefactors of the research obscure their relationship with the authors of the research (Marušić and Marušić 2013) to avoid revealing conflicts of interest. This bias would limit the scientific merits of the study. It can also occur within academia where junior members who have contributed substantially are not given authorship credit (Marušić and Marušić 2013). The ICMJE (2009) recommends that authors should avoid agreements with sponsors where there will be limited access to data or where there is interference with their ability to work independently. Another form of ghost authorship is **"denial of authorship"** which occurs when authors assume that they have participated in a legitimate scientific endeavour and they will be given due credit, however, their involvement is deliberately obscured which is a form of plagiarism (Macfarlane 2017).

Vučković-Dekić (2003, p. 211) lists several reasons for the prevalence of honorary authorship – "pressure to publish", a "sense of obligation", "fear of offending"

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an individual, “pressure from another co-author” or “explicit demand”. However, the act of honorary authorship may not always be a reaction to negative pressure. For instance “crediting an influential scientist” can “increase publication chances and prestige of publication” (i.e. guest authorship) or crediting a senior or junior colleague as a “gesture of amicable relationships” or to receive a favourable response (i.e. gift authorship) (Gasparyan et al. 2013). The **Matthew effect** which was coined by sociologist Merton (1968) which implies that eminent scientists get more credit in collaborative works than lesser-known scientists and consequently that eminent scientists get more visibility than lesser-known scientists. This is based on the Gospel of Mathew, which is based on the aphorism that “*the rich get richer and the poor get poorer*” which perpetuates inequality in academia. This phenomenon plays a role in explaining why honorary authorship occurs as a junior researcher will include a more seasoned researcher in order to give the article more prominence. On the flip side, when a junior academic publishes with an eminent scientist, the question of who contributed substantially will become an issue during promotions for example, as naturally it will be assumed that the eminent scientist was largely responsible for the output (Strange 2008). Hence, it is not always advantageous to exploit the Mathew effect.

Santos et al. (2015) describe the term unethical authorship as taking the form of coercive, honorary (gift and guest) and duplicated authorship. The term should also include forms of ghost authorship and denial of authorship. The denial to put the names of real contributors on papers is unethical conduct (Gasparyan et al. 2013). Using authorship as a form of currency in academia (Santos et al. 2015) which undermines the scientific process is wholly unethical. Unethical authorship deals are the unethical practices of using authorship as a currency in exchange for repudiating the quantity of the contribution of the legitimate authors involved in a publication.

8.3 Prevalence of Unethical Authorship Deals

Unethical authorship is highly prevalent globally and “particularly in small, non-mainstream science journals and in journals representing highly productive scientific fields” (Gasparyan et al. 2013, p. 279). Sandler and Russell (2005) conducted a study on American Psychological Association (APA) members (n = 604) and student members that were involved in student-faculty collaboration where it was found that 27.3% of the participants believed that they had been involved in an unethical authorship deal. Wislar et al. (2011) sampled the corresponding authors (n = 896) who had published a piece in six general medical journals; they found 21% of articles published in 2008 had evidence of honorary authorship while 8% of articles had evidence of ghost authorship. There has been a decline in previous years, which could be attributed to more stringent policies adopted by journals (Wislar et al. 2011).

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Sandler and Russell (2005, p. 77) hypothesised that “perception of unethical or unfair authorship assignments” can “vary by gender, collaborator status, faculty collaborator tenure and facility seniority”. It was found that non-tenured faculty members and women are more likely to perceive an authorship as being unethical. No statistical significance was found with respect to status and seniority, however, these might be due to limitations in the study as conceded by the authors. They also found that incidents go largely unreported; only 3.7% of respondents reported the incident to an authority figure.

According to Sandler and Russell (2005, p. 71) the possible reasons for why unethical authorships go unreported could be as follows: (1) “fear of negative consequence”, (2) “ignorance of rules or options available”, (3) apathy, (4) “disagreed with guidelines” (in this case by the APA), (5) “event was unfair but not unethical”, (6) “respondent instigated the event, so did not report”, (7) “incident did not reach the level of importance for reporting”, (8) “respondent blamed himself or herself for the event”, (9) “issue was resolved without authority intervention”, (10) acceptance of the norm, and (11) powerlessness. The “fear of negative consequence” (24.5%) was the most highly rated reason for not reporting incidents while “disagreement with the guidelines” was the least cited reason (1.5%). It appears that the power differential plays a significant role in the lack of reporting.

Marušić and Marušić (2013) conducted a meta-analysis of surveys (n = 14) concerning issues of authorship which included sociology papers, where there was an average of 30% of author-misuse cases reported. They found that authorship misuse was more prevalent among countries such as France, South Africa, India and Bangladesh (55%) than with countries such as USA and UK (23%). They found the most common types of authorship are related to honorary and ghost authorship. Okonta and Rossouw (2013) aimed to determine the prevalence of scientific misconduct among researchers in Nigeria (n = 100); they found that the most common type of misconduct was unethical authorship deals (36.4%) – omissions of contributors, the inappropriate order of authors listed and honorary authorship, see Chap. 9. However, they did not determine the specific forms of unethical authorship deals.

The problem of unmerited authorship is exacerbated in South Africa, as authors who publish in accredited journals, books and conference proceedings receive a state subsidy (Louw and Fouche 1999). The policy does not take into account authorship order nor the quantum of the contribution (Department of Higher Education and Training 2015). Incentivising research can lead to perverse research practices such as deliberately publishing in predatory journals for monetary gains (Mouton and Valentine 2017). A cursory scan of the research integrity policies in South African universities reveals that most traditional and comprehensive universities subscribe to the Vancouver protocol or to the Singapore statement on research integrity regarding authorship. A recent study by Breet et al. (2018) on authorship practices in South Africa revealed that most South African researchers (n = 967) are familiar with the dimensions of the authorship criteria (87.9%) as described by ICMJE or the Committee on Publication Ethics (COPE). However, only 51.8% of respondents found it easy to implement the criteria. Therefore, the gap between the

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knowledge and the implementation of the authorship guidelines need to be closed in order to "end questionable authorship practices" (Breet et al. 2018, p. 418).

Research misconduct is an under-researched area in Africa. Clearly, the lack of research in this area shows that in the developing world issues of research misconduct and specifically issues around authorship are not given due attention and this could undermine the credibility of research efforts emanating from Africa. There also needs to be more research done with respect to how post-colonialism affects the culture of authorship particularly within countries such Zimbabwe and South Africa. There is evidence that culture may affect one's perception of authorship (Smith et al. 2014).

8.4 Guiding Framework

Louw and Fouche (1999) assert that clear guidelines for authorship are vital to ensure that researchers get warranted recognition and also to prevent conflict and possible lawsuits. Osborne and Holland (2009, p. 3) found ten themes from a review of several organisational guidelines, which may be used to compose a policy, which should contain the following descriptors. First, there must be a list of elements that compose authorship criteria (e.g. intellectual ownership). Second, there must be a list of elements that specify which of those roles do not fulfill the authorship criteria (e.g. reviewing, editing, gathering and capturing data, providing resources and maintenance of equipment). Third, there must be regulations to protect student authorship and vulnerable groups (i.e. junior staff). The rights of the student must be defined with respect to papers that emanate from their theses and dissertations. Fourth, the policy must provide regulations to acknowledge those contributors who do not meet authorship criteria. The guidelines from Osborne and Holland (2009, p. 3) may be used to compose a memorandum of agreements among authors. Agreements must include: (1) conditions for authorship among collaborators, (2) acknowledgments of assistance or funding, (3) authorship order, (4) responsibilities to prevent unethical practices such as plagiarism, (5) mechanisms to prevent misuse of power differentials – senior members are expected to protect the rights of junior members, (6) timelines, and (7) disclosure of conflicts of interest.

8.4.1 Authorship Order

In most fields, the authorship order is dependent on the quantity of the contribution, ranging from most to least, where typically the first author contributed substantially more than the other contributors while the last place is usually reserved for the

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senior researcher or the head of the research project (Marušić and Marušić 2013). However, the order in other fields may be alphabetical which may vary according to the discipline. In some disciplines, the last authorship spot is reserved for persons of prestige. It is vital that authorship is not determined by power differentials based on the ranks of researchers which are often used to control authorship orders (Osborne and Holland 2009) known as power ordering (Macfarlane 2017). This is particularly an issue among students who are often misused by supervisors.

8.4.2 Supervisor-Student Authorships

Louw and Fouche (1999) provide the following guidelines for determining the authorship order between supervisors and students:

- The authorship order between a student and supervisor could be determined by the initiator of the concept, however, it is advisable that supervisors should play a supportive role (Lategan 2012).
- Including a supervisor or co-supervisor as a co-author should not be an automatic process but should rather be earned by the supervisor making a substantial contribution, or if not, the supervisor could only be acknowledged.
- If an article is the product of the student's thesis/dissertation then the student should be listed first, however, the student must show "initiative, responsibility and dedication". As in some instances, the supervisor endures a substantial rewrite to convert the thesis/dissertation into a publishable format (p. 148).
- There are a few instances where the student may be omitted from the paper due to the lack of interest on the part of the student. However, this cannot apply to derivative works of the thesis/dissertation, as it remains the student's intellectual property.

It is clear that the default standpoint is that a student must be listed as the principal author on derivative works of their thesis or dissertation unless there are compelling reasons to do so otherwise. Moreover, within the humanities discipline, a student assumes sole-authorship of graduate-related work while supervisors are acknowledged (COPE Discussion Document 2015). It is recommended that students are socialised in the process of authorship and there should be signed agreements spelling out the roles and responsibilities of the lead author vs. the co-author. It can also be problematic when the supervisor co-ops colleagues as co-authors who were not part of the original studies, hence it is important for students to keep records of their contributions. Supervisors should refrain from encouraging students to publish in predatory journals, which undermines the scientific careers of their students (Mouton and Valentine 2017).

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8.4.3 Creating a Culture of Ethical Authorship Deals

Sometimes unethical authorship is the norm and often individuals see nothing wrong in attributing authorship to a senior person. Therefore, it is critical that a culture of non-tolerance towards unethical authorship deals is fostered. A culture of ethical authorship may be achieved by acculturating researchers through awareness and policy (Albert and Wager 2003). The following table shows the responsibility of each entity in the cycle of research, the research institute, authors, reviewers, editors, publishers and professional bodies. As shown in Table 8.2 based on Gasparyan et al. (2013), each entity can play a role eradicating the scourge of unethical authorship. Research institutes should be primarily responsible for instituting policies and implementing deterrent controls such as a hotline for reporting research misconduct. Authors must self-regulate and have agreements in place to prevent authorship disputes. Reviewers of journals should report instances of unethical authorship and disclose conflicts of interest. Editors should resolve authorship disputes, adhere strictly to authorship guidelines and disclose conflicts of interest. Publishers should ensure that there are regulations of authorship criteria. Professional bodies can regulate the academic profession per discipline.

It is evident that if all stakeholders play a role in eradicating unethical authorships, it may become an indiscretion that no longer influences academia in the future. The enforcement of authorship guidelines is essential, as the culture of unethical authorships will spread to the next generation (Santos et al. 2015) unless it is regulated.

8.5 Conclusion

The scant studies on research misconduct in Africa do not imply that research misconduct is not an issue in Africa. In fact, it demonstrates that issues such as unethical authorship deals are discounted due to the lack of application and hence the prevalence of unethical authorships may be rife. This chapter highlighted the fact that the maxim of "publish or perish" that influences all researchers irrespective of their country of origin is a major factor in promoting unethical authorship deals. The axiom of "publish or perish" has severe consequences on the integrity of the research process. This adage in academia has allowed the industry of predatory journals to flourish. Evidently, research integrity and incentivisation of research are contradictory processes. In order to maintain the veracity of the research process, research integrity should also be incentivised.

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Table 8.2 Guidelines to inculcate a culture of ethical authorship

Entity	Roles and responsibilities
Research institutes	Institute policies to include: authorship criteria, non-criteria, rights of authors, acknowledgment criteria (Osborne and Holland 2009)
	Create awareness through courseware (Gasparyan et al. 2013) and professional development (Osborne and Holland 2009)
	Professional development to prevent the misuse of power of junior researcher teams, prevent dishonesty and conflict (Osborne and Holland 2009)
	Institute a hotline for research misconduct
	Institute an authorship dispute resolution team (Strange 2008)
	Identify White Bulls through profiling or surveys (Kwok 2005)
	Create an environment where vulnerable groups (e.g. junior staff) feel empowered to discuss authorship deals (Osborne and Holland 2009)
	Publically disseminate authorship guidelines (Osborne and Holland 2009)
	Orient new staff and students to the guidelines (Osborne and Holland 2009)
Authors	Must self-regulate and be aware of authorship guidelines (Gasparyan et al. 2013)
	Confirm in writing authorship roles and responsibilities before any research endeavour: conditions for authorship among collaborators, acknowledgment of assistance or funding, authorship order, prevention of unethical practices, misuse of power differentials (Osborne and Holland 2009) and timelines, disclosure or conflicts of interest
	Individuals who are asked to be involved in unethical authorship deals should report it to the hotline
	Authors must be publically responsible and accountable for their contributions (Strange 2008)
Reviewers	Must be aware of authorship guidelines
	Report suspected authorship deals to the editor (Gasparyan et al. 2013)
	Disclose conflicts of interest (ICMJE 2009)
Editors	Should strictly adhere to authorship criteria (Gasparyan et al. 2013)
	Resolve authorship disputes (Gasparyan et al. 2013)
	Request an authorship verification document which attests each author's role and responsibility (Strange 2008)
	Disclose conflicts of interest (ICMJE 2009)
Publishers	Provide regulation on authorship in the guidelines for authors
	Require authors to list their contributions as a footnote in the paper (Strange 2008)
	Institute an authorship dispute resolution team (Strange 2008)
Professional bodies	Institute policies and authorship criteria (Gasparyan et al. 2013) members

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Chapter 9
Research Integrity in the Context of Social Science Research in Africa

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Abstract This chapter will provide an outline of the concept of integrity pertaining to social science research. An inclusive definition is proposed where integrity is seen as both a value as well as a virtue. Developments on the continent of Africa are listed which support the notion of research ethics and integrity, but the question is also asked, against the backdrop of well-known cases of misconduct, on how integrity can be developed. An approach is described where integrity should be internalised by social science researchers themselves and then questioned against the presentation of serious misconduct data. This chapter asserts that integrity policies in Africa are underdeveloped and need to be addressed. The final part of this chapter describes the importance of individual honesty and putting the benefit of the people of Africa as the primary function of social science research.

Keywords Research integrity · Research ethics · Honesty · Misconduct

9.1 Introduction

The concept *integrity*, although used as early as 1633 by Sir Thomas More, has gained legal tender in the scientific arena since the 1980s (Horbach and Halffman 2017; Nillsen 2005). Although widely used within scientific literature for the past four decades the term and concept is not without disagreement and still a source of great debate. It is important to assert at this point that integrity has varied definitions based on the vantage point and source of science under study. On the one hand integrity could refer to procedures which are articulated in order to trace and punish misconduct, while on the other hand it could refer to moral standards which

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academics and scholars need to ascribe to in order to produce good science (Horbach and Halffman 2017). The debate is further fuelled by the influence of the environment, population and/or culture under study. As such, some conduct would be regarded as acceptable in the specific context, while the same conduct would be deemed unacceptable in a different setting or culture.

In 1633, Sir Thomas More (an English lawyer and well-respected humanist) described the concept of integrity as that which defines wholeness or completeness (Nillsen 2005). The idea of wholeness is derived from the Latin etymology of the word *integrare* which is translated as "to make whole" (Callahan 1995; Green 2017). As such, Horbach and Halffman (2017) argue that integrity should be considered as a concept having attributes associated with being a value and virtue; both are closely related to ethics and form the basis for good scientific practice. Therefore, for clarity's sake, although we value definitions by international bodies such as the National Academies Institute of Medicine (USA) who regard integrity as the aspirational standards of scientific conduct rather than simply the avoidance of questionable practice (Grinnell 2013), integrity in social science research is a question of both what one does (virtue) as well as how one does it (value).

In 2010 at the Second World Conference on Research Integrity in Singapore, a group of international scholars discussed the importance of integrity and collectively developed four main principles embodied in 14 responsibilities for researchers in science at large, which is commonly known as the Singapore Statement (Singapore Statement 2010). These four agreed upon principles include:

- **Honesty** in all aspects of research;
- **Accountability** in the conduct of research;
- **Professional courtesy** and **fairness** in working with others; and
- Good **stewardship** of research on behalf of others. (Singapore Statement 2010, p. 1 – *bold as per original*)

These principles have been internationally adopted into many funding organisations' codes of research ethics, such as the National Institute of Health's Office of Extramural Research. Some universities in Africa have already incorporated the Singapore Statement as part of their organisational integrity policies that inter alia aims to foster integrity development among staff and students (HSRC n.d.; University of Stellenbosch n.d.; University of the Witwatersrand n.d.; University of KwaZulu-Natal n.d.).

9.2 Why Is Research Integrity Important?

In contemplating the question regarding the importance of integrity as both a value and a virtue in research, Drenth's (2012) explanation of the influence it can have on science itself and the negating effect of effectiveness and trustworthiness on society is valuable. Drenth (2012) argues that if incorrect theories are not falsified and false insights are not invalidated then deceptions and falsehoods in science can continue, which could in turn greatly influence other researchers in the field and even nullify

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their research (Stern et al. 2014). According to Drenth (2012), it may also result in the defence of wrong applications of scientific knowledge, misconceptions, stigmatisation as well as wrong decisions. The latter is illustrated by socio-anthropological research conducted in a community in Northern Africa where female genital manipulation is culturally relative (Luc and Altare 2018), see Chap. 4 for a more in-depth discussion. However, the published results which identified the practice as against the values of society at large have led to misconceptions and stigmatisation of the group (Luc and Altare 2018). Another example is the 2010 research project, as mentioned by Rakotsoane and Nicolaides in Chap. 2, on genomics entitled “Complete Khoisan and Bantu genomes from southern Africa”, where conclusions were drawn that the Khoisan people had a great feeling of inferiority – results which were far removed from the genomics project (Chennels and Steenkamp 2018).

Drenth’s (2012) final argument is that the general public’s trust in science will be undermined and as such society will lose confidence in science as a dependable base for decision making and knowledge. Another argument levied as to why integrity is important is that it assists in the advancement of knowledge to safeguard participants, groups and communities against harm and abuse, but also to foster trustful collaborative relationships between researchers (Bonn et al. 2017).

During its colonial past the people of Africa were often subjected to power relation abuses. These abuses are sadly often still prevalent in research methods employed by researchers from other parts of the world, especially developed countries. This notion is supported by Willyard (2007) who reports that since the late 1990’s there has been an increase of clinical trials run by pharmaceutical companies in countries with limited public health resources or few regulatory prohibitions. Regardless of the fact that guidelines of CIOMS and the World Health Organisation (WHO) intend to guarantee that participation in research should be characterised by the same standard regardless of where a participant may live, the reality is that it is up to a specific government to ensure the honouring of those guidelines. Often developing countries do not have the means to adopt and enforce guidelines and make sure research is done ethically (Willyard 2007).

Making sure that social science research has as its main focus the best interest of individuals, groups and/or communities at heart in the development, execution and reporting of proper research, brings us to the last question in this chapter, namely how can research integrity be developed in social science research in Africa?

9.3 How Can Research Integrity Be Developed in Social Science Research in Africa?

Lyn Horn (2013), a bio-ethicist and integrity officer from South Africa, contemplating about whether integrity can be developed in researchers, refers to Aristotle’s position that quality of character can be acquired by the process of moral training. This training, which begins at home, should be developed by formal education (in

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Aristotle’s case the Academy in Athens) which tasks itself not only with teaching theory to young people (value), but also to teach them how to be good people (virtue) (Horn 2013). Nussbaum (2003) also draws on ancient Greek philosophers such as Cicero, Seneca and Aurelius when she argues that according to them people across the world hold a common humanity and have therefore a moral obligation towards each other. Nussbaum (2003) is therefore of the opinion that good researchers need to be aware of their own personal bias and perceived objections when conducting research involving persons, groups and communities foreign to their own. This notion of respect is supported by the seminal article by Beecher (1966) where he argues that a reliable safeguard for ethical (and consequently integrity driven) research lies with having an intelligent, informed, conscientious, compassionate and responsible researcher.

Often, a monitoring authority for collaborating research across borders does not exist, with a subsequent reliance on the individual integrity of the researcher. Ahmad (2001) thus supports the need for an internalised modus operandi. This internalised modus operandi, according to Thomassen, Strand and Heggen (2017) can be developed as a psychological phenomenon where it is associated with a psychological state of being which focuses directly towards the experience of integrity itself. Integrity therefore should focus on an individual’s moral consciousness as well as responsibility in order to make the right choice and do the correct thing (Bauman 1993).

Although this approach to cultivate researcher ethics may appear to be a plausible initiative, some worrisome results have surfaced regarding social science research practices in Africa, as discussed by Padayachee in Chap. 8. In research conducted by Okonta and Rossouw (2013) in Nigeria, 69% of the survey participants (researchers) admitted to some form of scientific misconduct; it included infringements such as falsification of data and fabrication of data. This is significantly higher than the 33.7% reported by researchers in the USA and the UK (Okonta and Rossouw 2013). Another growing concern to the development of researcher integrity is the findings of Van Zyl and Thomas (2015) for a student cohort of “millennials” at a university in South Africa. According to them there is reason to be alarmed as millennial students are challenging the traditional notion of doing research and of what proper research conduct would entail, as honesty and dishonesty have fluid definitions for the millennial. Part of the challenge is that this young generation of upcoming researchers interpret the idea of what is “acceptable” against their belief in open source media as well as the free availability of information on the world wide web, which transcends claims to any ownership.

If one is to argue that universities in Africa need to task itself with the development of integrity among researchers in their institution, it would be wise to also take note of Horn’s (2013) report that institutional integrity policies, specifically in Africa, are in general underdeveloped. In this regard Kombe et al. (2014) argue that two strategies can be followed in Africa to develop research integrity. Firstly, there should be a renewed focus on capacity within institutions and also of the individual researcher through developmental initiatives to encourage the value of integrity; and secondly, there should be a focus to develop preventive and remedial tools as well as disciplinary measures to mitigate misconduct.

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Whether punitive measures will effectively mitigate misconduct and develop integrity in research is debatable, however various authors argue that professional conduct among professionals are dependent on role-model mentoring by respected senior researchers (Godecharle et al. 2014). Shephard et al. (2015) support this strategy by stating that students' view on research ethics and integrity is greatly influenced by participating in academic communities and observing the conduct of teachers, mentors and researchers. Ultimately, such mentoring can result in the internalisation of integrity scholarship.

9.4 Conclusion

This chapter proposes that all African stakeholders involved in social science research (i.e. governments, tertiary institutions, civil leaders, community groups, etc.) should cooperate to develop and implement context-sensitive customised best-practice research integrity courses, mentoring programmes for researchers working on the African continent, as well as dedicated policies based on international good practices to address integrity violations present in research (Kombe et al. 2014). Taken from the preceding it is imperative that the concept of integrity needs to include both value and virtue perspectives which are not mutually exclusive but rather overlapping; in other words, integrity refers to the notion of good scientific conduct (as defined by the Singapore Statement) done by good scientists and researchers (based on Aristotelian Virtues Ethics) to result in good outcomes for all concerned.

We concur with other authors (Kombe et al. 2014; Nussbaum 2003) that the scientific community needs to be collectively alert and vigilant to prevent, detect and reprimand scientific misconduct. Furthermore, it is imperative for good social science research in Africa that individual researchers develop a moral conscience to invoke the highest standard of behaviour and conduct, especially in a context characterised by ever shrinking space and time due to global integration and the eroding of socio-cultural and socio-political borders by virtue of social media and the internet.

Social science research on the African continent has much to contribute and offer persons, groups and communities, but in order to move forward with integrity it needs to critically engage with the current research challenges. The authors concur with Sibbald et al. (2016) that social science researchers in Africa need to be cognisant and respectful of culturally sensitive practices through careful consideration of local contexts, engaging with communities in terms of social value and emphasising solidarity through the development of cooperative relationships with stakeholders, local partners, end-users and research participants. In order to attain the aforementioned it is necessary that researchers realise that no social research is void of context-based norms and that universal norms (as often mandated by sponsoring entities) need to be integrated with culturally sensitive ideas and practices which emphasise a deeper purpose and respect for each group, community and society.

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Chapter 10
African Social Sciences Research Ethics – Africa as a Conversation and Methodology

Leon Roets and Matsheliso Palesa Molapo

> *I am an African.*
> *I owe my being to the hills and the valleys, the mountains and the glades, the rivers, the deserts, the trees, the flowers, the seas and the ever-changing seasons that define the face of our native land.*
> *Mbeki (1996) ("**I am an African**" was a speech delivered by previous Deputy President of South Africa, Mr. Thabo Mbeki on behalf of the African National Conference on 8 May 1996 in Cape Town. The event was the passing of the new Constitution of South Africa. This poem forms the methodology of this chapter and different phrases were used to organise the chapter and research as an African methodology. It should further be noted that the poem should be read in its completeness to fully appreciate the depth of this chapter. See http://www.soweto.co.za/html/i_iamafrican.htm)*

Abstract The aim of this chapter is to initiate a critical conversation on the need to question the applicability and appropriateness of the use of a predominately biomedical framework for research ethics review in social sciences research, especially within the African context. Firstly, it focuses on unpacking the current status and application of international research ethics approaches and frameworks and their influence on social sciences research ethics in Africa. Secondly, a deeper conversation on the indigenisation of social research within the African context is done by sharing some examples of innovative practices from similar scholarly work as well as the authors' own lived experiences as practicing social sciences researchers in Africa. The last part of the conversation draws upon some lessons learned and mak-

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This title is inspired by a lecture presented by Prof Siphamandla Zondi on *Africa as a Method: An upsurge!* delivered on 17 January 2018 at the College of Human Sciences: Decoloniality Summer School at the University of South Africa.

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ing recommendations for the application of ethical considerations in social sciences research within an African context.

Keywords Research ethics · Integrity · International bioethics frameworks · Indigenisation · African context

10.1 Introduction

Through a critical conversation with the reader, this chapter seeks to problematise the current research ethics and integrity content and practices within the African context. This it does by raising the concern about the use of predominant biomedical ethical frameworks, mostly developed in Western-European countries, for social sciences research and the lack of indigenising social sciences research within the African context, as alluded to in Chap. 2. In most African countries the relationship between the participants and the researcher is unequal due to the socio-cultural, socio-economic and socio-political diversity of communities, especially in social sciences research (see Chap. 13). The current research practices and ethics are furthermore problematised by analysing the ethics of power relationship between the indigenous knowledge systems, participant and the researcher, when it is particularly presumed that the participant is merely an object/subject to the research findings rather than an active, equal team member and co-creator of the research project (Tikly and Bond 2016; Ndlovu-Gatsheni 2013). Although in some cases the participants are part of the research team there is always an unequal social-power relationship on the application and management of the research which raises critical ethical concerns (Simwinga and Kabelo 2014; Tikly and Bond 2016). Multinational organisations, which often provide funding for collaborative research with African researchers, use so-called international research ethics frameworks, which are mostly biomedical and in most cases, do not apply in a local context and the existing indigenous knowledge systems, and thus contribute to the aforementioned inequality (Kruger and Horn 2014).

Some efforts have been made to unpack these ethical considerations and also to discuss the nearly impossible task of applying universal ethical standards for social sciences research according to Council for International Organisations of Medical Sciences (CIOMS 2016). However, there needs to be a deeper conversation on the authenticity and indigenisation of social sciences research within the local context in developing countries like in Africa. This should be done not in isolation but also within an understanding of the tension between local versus global contexts. This chapter highlights these challenges and endeavours to provide some guidelines with practical examples on how to ensure a more indigenised African understanding of ethics in social sciences research.

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10.2 Current Status and Application of International Research Ethics Approaches and Frameworks and Their Influence on Social Sciences Research Ethics in Africa

The vulnerability of politically, socio-economically, racially and ethnically disadvantaged populations (see Chap. 15 for more on vulnerability), has over an extended time made these populations fall prey to research ethics transgressions all around the world, particularly in Africa (Ndlovu-Gatsheni 2013; Gyekye 2011).

In the twentieth century such transgressions in Europe date back to the Nazi war crimes involving invasive biomedical and psychological experimentations conducted among the prisoners of war; the resultant outcome to prevent such atrocities from happening again was the establishment of the Nuremburg code in 1947, the first modern code governing ethics of research (Nuremberg Military Tribunal 1996). In the United State the infamous Tuskegee Syphilis study conducted among the poor African-American sharecroppers by the National Institutes of Health from 1932 to 1972, revealed the harrowing experiment about the progression of syphilis, which led to the demise of its victims who did not get treatment. The discovery and outrage stimulated legislation and regulations in research ethics, which ultimately led to yet another development of an ethical principle to never cause harm to human participants; this was the Belmont Report of 1978 (Kelty 2008).

In the twentieth century Africa, a combination of the legacy of colonialism (and Apartheid in South Africa), racially divided health systems and unequal power relations between government and later donor organisations and local populations and biomedical research and its frameworks has had notable ethical and social implications with a spill over effect on social sciences research. In the colonial context and by design, the current disparity in health care services between former white and black areas stems from a system that concentrated and promoted clinical research and its capacity in few predominantly white institutions with the consequent unethical biomedical research practices among the less represented population in South Africa (ASSAF 2002). For instance, the history of mining and labour migration in South Africa, largely driven by governments and the mining industry came with a huge burden of communicable diseases, which impacted mainly black migrant workers due to the system of racism, oppression, unequal and unethical health care practices. Health care services were urbanised, industry based and provided care to only migrant labourers for as long as they were employed, and excluded their families who remained in rural sites. The spread of tuberculosis from urban industries to rural populations in southern Africa is a case in point (Packard 1989).

Likewise, in post-colonial and post-apartheid era, Africa continued to be a testing ground for biomedical research, and in many cases, accompanied by unethical human research practices. For example, in the early 1990s a British anaesthetist,

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Dr. Richard Gladwell McGown, was charged with conducting unethical human experiments without the knowledge and consent of 500 patients in Zimbabwe. He was found guilty for professional negligence by the courts in Zimbabwe, mainly for conducting interventional studies using new medications and anaesthetics without the approval of the National Drugs Authority. It was established that six patients died during these experimentations (Ndebele et al. 2014).

In recent years, the advent of the AIDS pandemic and its opportunistic coexistence with tuberculosis and other infectious disease, including the outbreak of Ebola in Africa, came with increased research interests from the West accompanied by some unethical practices by some (Schroeder et al. 2018). For instance, clinical trial sites outside of the US more than doubled between 1995 and 2005 while the proportion of trials conducted in the US and Western Europe decreased (Glickman et al. 2009). However, the growing interest from the West in conducting research in the African countries came with an increase in biomedical research ethics and practices that are in many cases incompatible with African cultural and social diversity. Specific guidelines had to be developed by CIOMS (2016) and UNAIDS (2011) to ensure the involvement and participation of all stakeholders including the indigenous communities must be one of the key ethical drivers in implementing social sciences research on specifically health-related research and HIV trails involving humans. These guidelines are an effort to incorporate the socio-cultural diversity within communities by mobilising local key role-players and stakeholders to participate not only in conceptualising but also in each step of the research to ensure the community take ownership and stay intact after research.

The attraction of low-income countries as a site for researchers by the Western and European countries was influenced by many factors, some of which included funding and resource support provided by the national or federal governments to do external research in developing countries. In some other cases, strict ethics measures in the home country as opposed to lax government, and institutional regulations that provide easy access to research populations in developing countries with dysfunctional institutions or unempowered ethics committees (Muwanga-Zake 2009). Furthermore, the general poor state of health care services in developing countries make disadvantaged communities vulnerable to opt for perceived health benefits that come with participation in global health research and incentives or food provided in research sites (Moodley and Rennie 2011). Although these transgressions were mainly in biomedical research, there are also evidence of other transgressions which impact if it was social research including cultural insensitivity and applying research ethics which do not reflect the local understanding of ethics within the indigenous knowledge system. According to Tindana and Wasunna (2014), this is often an ethical conflict between the community and researcher when conducting ethnographic and narrative research, especially in rural communities in most African countries.

It is important to recognise that in most social sciences research in Africa there still lurks a colonial and global context (Zondi 2018; Odora-Hoppers 2002). This is mainly due to two reasons: the institutionalisation of colonialism in social sciences research; and the internationalisation of social sciences research.

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Despite a shift in conducting collaborative research with hosting institutions, the predominately biomedical research ethics frameworks and ethics codes for social sciences research are mostly developed by developed countries from the West and Europe. They depart from the point that ethics and guidelines can be standardised and structured to universalism and often the research process has to fit a logic and systematic way of doing research which is not always possible at community levels (Onyemelukwe-Onuobia 2018; Schroeder et al. 2018; Khomba and Vermaak 2012). Furthermore, the universalistic approach to the nature of these frameworks often paints a picture of equality or sameness across the world which then makes it easier for a standardised social sciences research ethics framework and practice, and yet Africa still suffers the long-lasting effect of dominance and oppression caused by colonial histories. The post-colonial and global contexts are based on these histories and legacies, and have not yet incorporated and centralised African knowledge production as their key research outcomes.

The predominately biomedical research ethics frameworks developed within the European-American context often remove the researcher from these realities of indigenous communities and groups by dehumanising the research process in order to achieve so-called objectivity (Onyemelukwe-Onuobia 2018). Seeing the research process as objective does not only disembody the researcher from the community and existing indigenous knowledge systems, but also devalues the findings or results which are supposed to enable communities to help themselves. Instead, research becomes so distanced from the community, and decision making is based on these so-called universal ethics and standards, which is often not applicable and appropriate to the different socio-cultural and religious contexts of the community and existing indigenous knowledge systems in Africa. This kind of research and ethics still construct relations of power between the researcher and the community, among researchers and research institutions and the research and social realities (CIOMS 2016).

Social sciences research in Africa is also shaped by current socio-political agendas such as ethnicity, gender and race (Kruger and Horn 2014). Through these categorised lenses, the researcher is seeing the community as an object rather than as a subject, and the whole research process is being formalised by implementing universalism towards research ethics and guidelines, as discussed by Segalo and Molobela in Chap. 3. These agendas also play out in the selection of the research topics as the researcher would rather do popular than localised research with limited global impact (Schroeder et al. 2018). This approach goes against the basic concept of beneficence where the benefits of research should be relevant and useful to improving the quality of life of participants as well as to outweighing risks and also contribute to indigenous knowledge.

Also, the hegemonic presence of the European-American understanding of social sciences research in Africa limits the application of adequate indigenous research methodologies and theories to address the diversity and uniqueness of communities (Onyemelukwe-Onuobia 2018; Gyekye 2011). It further limits the understanding of indigenous communities and lived experiences as the research frame is often far removed from these realities and challenges. These understandings often problematise or psychiatrise African issues and, thus, portray a sense of hopeless-

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ness of which the researcher should act as a rescuer or saviour (Higgs 2015). It is from this understanding that it is often hoped that social sciences research should lead to some kind of intervention to help people and communities. This undermines the social and moral structures in communities in Africa to help themselves if they encounter a problem. A need to see Africans as able bodies through research must be one of the core agendas for any ethical consideration and practice (Kruger and Horn 2014; Menzies 2006).

Another challenge is language and translation of concepts from English to African languages according to Monwabisi et al. (2017); usually Africans speak four to five languages and English would be the sixth language. For instance, in many African communities, the concept or word “research” does not exist and often translating it into a local understanding leads to confusion. Yet social researchers in Africa conduct their studies among indigenous communities without exploring what they understand not only of the word, but all the complex terminologies coming from the predominant European-American framework as mentioned in the previous discussion.

The matter of language contributes to the unequal relationship between the researcher and communities is the use of English. This often positions the researcher as the expert and is higher up in the social hierarchy of knowledge (Kline et al. 2014). Understandings lost in translation not only predisposition researchers in relationships of power over communities but also leads to confusion among researchers and misrepresentation of finding or results. Researchers often struggle to get similar social research concepts or terms in the local languages and existing indigenous knowledge systems to describe what they intend to do with the outcomes of their research. For many social researchers the English version of language leads to a memorised knowledge and not to an internalised knowledge embedded in their own indigenous knowledge (Zaman and Nahar 2011).

This unequal relationship also plays out in the community perspective that social sciences researchers are professionals and their knowledge is superior to the local indigenous knowledge (Ndlovu-Gatsheni 2013; Odora-Hoppers 2002). This is usually due to the colonial and oppressive history of education where such high value is being placed on an “educated” person. The researcher then becomes more than the research itself and is often seen as an advisor, counsellor and even an educator. This is also due to the long history of social research in Africa which was mainly done by “educated” people or graduates and professionals from development aid agencies. It is a history of dependency where people and their communities depend on the expertise of this person on social sciences research to decide what is right or wrong (Menzies 2006). Throughout history there has been very little done to ensure people and their communities receive at least feedback on the findings or results of the research on them; let alone participate in each step of the research process. However, as previously mentioned UNAIDS (2011) and CIOMS (2016) developed guidelines for community and stakeholder engagement during every step of research on the clinical HIV trails especially in socio-economic unequal societies like in Africa. This has been further developed in the notion of community engagement research and narrative inquiries where the indigenous community is the custodian of

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the research process and product and the social researcher becomes part of a greater team consisting of key role-players and stakeholders in a community (CIOMS 2016). However, there is often a misalignment between these set of guidelines from CIOMS and consistent and practical implementation of them.

10.3 Some Examples of Innovative Practices Around the Application of Ethics in Social Sciences Research in Africa

In moving forward, social sciences research and research ethics within the African context ought to be more indigenised to recognise the complexity and diversity of the interconnection and social relations between people and their communities to locate the researcher as well as the research participants (Horsthemke 2017; Gyekye 2011; Odora-Hoppers 2002). Social sciences research should not only adhere to some universal ethics frameworks but should be more embedded in the lived experiences of people and their environment to negotiate a long-term engagement between the researcher and the community towards co-creation of knowledge. Meaning that a process of indigenising social sciences research ethics should include dialogues with and participation of community members in every step of the research decision making.

Social sciences research can only be adequate within a local context where it reflects the existing indigenous knowledge systems and understanding of the local people and their communities including their own indigenous methodologies and theories. Affirming the African culture, traditions and value systems according to Odora-Hoppers (2002) should foster the African understanding of social sciences research and ethics. It is therefore critical for the researcher(s) to not only be familiar with, but to learn about the cultural practices and local indigenous knowledge system of the targeted population long before embarking on any form of research. For instance, conceptualisation and the design of the study should be a collaborative effort with the prospective participants/community long before institution-based processes of ethical clearance and research permission (CIOMS 2016; UNAIDS 2011).

Research ethics should also be localised through processes of emerging into the indigenous knowledge creation and production. It should raise consciousness of the social researcher to link research to community understanding, culture and identities as platform for justice and dignity, which is supported by the arguments of Amugune and Omutoko in Chap. 4. In this process, social sciences research should transcend individual identities into interrelated relationships of commonalities and diversity within communities in Africa (Kline et al. 2014). The interrelatedness between people and their communities (indigenisation) should form the core of the research process; and the interpretation and understanding of research findings or results should be applied to contextualise that process both at a local and broader or global level. This means that the researcher must recognise the interrelatedness with people and communities in the pursuit of securing an authentic African voice, without ignoring the global context (Kruger and Horn 2014).

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Furthermore, the indigenisation of social research and ethics within the African context means the understanding of the African experience from an authentic lived experiences of the past, present and future by people and their communities (Onyemelukwe-Onuobia 2018; Higgs 2015). Even debates about the indigenisation of social sciences research and ethics should be flexible to accommodate the day-to-day lived realities of people and apply to all existing and new knowledge to construct and re-construct social realities. Using the Ubuntu ethics (*I am because we are*) in social research will assist the researcher to position Africa as the central point of departure and localise understandings even within a global context (Gyekye 2011) (also refer to Chap. 12). The Ubuntu concept according to Muwanga-Zake (2009) is a reminder that human beings are social and are shaped by their communities; hence, an individual is who they are because of the community that they come from. In that context an individual embodies his/her being and existence to the community and will always have the interest of the community at heart. For example, the greetings between two people in Africa is in plural form because the inquiry is not only about the individual person and his/her health but it is about the clan and the community at large. Indigenous knowledge systems should therefore be used to locate the research and its source of knowledge as the base for knowledge production.

The role of research institutions and universities is also key to raising consciousness in indigenising social sciences research within the local context. One key element in doing this is to promote the use of African languages in explaining the research process to local communities (Monwabisi et al. 2017). As stated above, many African people may not fully comprehend the word “research” as it is not a recognised term in their own languages and the closest resemblance might be a phrase rather than one word (Menzies 2006; Horsthemke 2017). To further complicate the understanding is unpacking the different concepts and terminologies taught to students at these institutions and universities within a local context including language. Not only should students learn how to engage with communities and indigenous knowledge systems within given localities but also staff who are responsible for the teaching of social sciences research and ethics. This should happen through practical applications of social sciences research ethics where the communities are, on what they identify as their own identities, and the social location to explore local knowledge with them (Muwanga-Zake 2009). It should, furthermore, recognise the legacies of colonialism and oppression on these communities, and how they play out in the relationships among each other and the researcher.

According to Higgs (2015: 40), the location of the researcher as an African is key to not only transfer the African experience and knowledge but to also communicate them through research findings or results. He defines an African as someone who has a common geographical origin in Africa with others as well as a spiritual attachment through an ancestral history on and of the African continent. This description of being an African then not only goes beyond any ethnicity or racial understandings, rather, it calls upon all who see themselves as Africans to start working together toward the African Renaissance or rebirth in order to ensure Africa is the centre of all social research and ethical considerations (Nkrumah 1964). Being located thus

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allow social researchers to authentically and ethically engage with communities on an equal platform to the benefit of all people living in Africa. Hence,

> Today, as a country, we keep an inaudible and audible silence about these ancestors of the generations that live, fearful to admit the horror of a former deed, seeking to obliterate from our memories a cruel occurrence which, in its remembering, should teach us not and never to be inhuman again.
>
> I am formed of the migrants who left Europe to find a new home on our native land. Whatever their own actions, they remain still part of me. (Mbeki 1996)

It is critical to establish an equal relationship between a researcher and the participant in the process of indigenising social research. Social sciences research is often received with suspicion and mistrust as it was used as a vehicle to oppress or spy on communities during colonial eras (Ndlovu-Gatsheni 2013). Simwinga and Kabelo (2014) highlights the following research elements or steps as critical in order to establish trust at community level, including, community consultation with all relevant role-players and stakeholders over a period of time; facilitate a space for community collaboration at each step of the research including the conceptualisation of the research process and suggested theorising; and establish a partnership with the community to ensure not only successful implementation of the research but also ownership of its findings and/or results as well as the implementation of recommendations. This mistrust is further enforced with the research being conducted over very short periods of time and without providing any feedback. Communities give themselves to the research process as it is within the Ubuntu values to do so; researchers should make real effort to live in the lived experience of these people over longer periods of time (Caracciolo 2009; Swanson 2007). This requires a different attitude towards research than merely an intervention or problem-solving outcome towards a deeper understanding of the lived experiences of the community and indigenous knowledge systems.

It is therefore essential that both the researcher and the researched communities should decolonialise their minds in order to participate equally in any social research process. Decolonialising the mind according to Higgs (2015) is to mentally and socially deconstruct the meaning and process of research outside the predominately Western epistemologies and ontologies and explore the existing indigenous knowledge systems with communities to produce meaningful engagement (Muwanga-Zake 2009). The same applies to research ethics committees which have to spend time to decolonialise their ethics frameworks and indigenise them with communities within the African context. The Ubuntu ethics lenses give us an opportunity to embrace a critical yet reflexive narrative and methodology that will assist in creating opportunities for disruption and resistance against any form of colonial legacies. It is through the Ubuntu belief system that the community becomes the centre of the research process embracing the interrelatedness and interdependency of people and their communities with the other elements of the cosmos yet recognising the diversity of lived experiences and finding common solutions within an African context (Gyekye 2011). These beliefs or ethics should facilitate a dialogue between the social researcher and the communities under investigation about the nature of indigenous knowledge and identities to transcend any personal, political or social agenda

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of oppression. The end goal would be to make the researcher human first and then reconnect him or her to the community before conducting research.

Social sciences research ethics should not be seen as universal but indigenised within the African context as the diversity of the socio-cultural, socio-economic and political contexts have to construct agreed upon ethics and values between the researcher and the community (Khomba and Vermaak 2012; Schroeder et al. 2018). This requires an engagement between the researcher, research ethics committees and the communities to establish a deeper understanding of the indigenised epistemologies and ontologies to locally contextualise such existing ethics and values. It should be an ongoing engagement with dynamic and flexible scope to allow common understanding and diversity within each party. Cultural hierarchies should also be considered in establishing social research ethics as the European-American Research Ethics Framework's universal ethics focus does not accommodate indigenous knowledge and the interrelatedness of people and communities. Local cultural and religious beliefs and values should be taken into consideration in responding to the application and adequateness of research ethics within a local context (Tikly and Bond 2016).

As mentioned previously and elaborated by Hendricks and Donnir in Chap. 13, the unequal relationships between researchers, communities and research institutions form a basis for a hierarchical relationship and power discourse. This plays out right at the beginning of conceptualising research and its goal. Research according to whom, for whom and with what knowledge system, should be the central questions to engage with communities according to Onyemelukwe-Onuobia (2018) about the goal of the social research and the application of ethical considerations. This should also be the question when a social sciences researcher engages with an institution and its research ethics committees to ensure there is a continuous awareness of the indigenisation and localisation of research as well as the need for equality within social justice and dignity of all people in Africa (Odora-Hoppers 2002; Menzies 2006). There should also be an understanding that there are no universal human rights on which research ethics can be presumed, and rights should rather be localised within specific socio-cultural and religious contexts of indigenous knowledge and value systems.

The emphasis of research ethics committees should not only be to keep social sciences researchers publicly accountable but also accountable to the communities within which the research was conducted. Guidelines 1–3 in CIOMS (2016) also talks about an equitable relationship between researcher, research institutions and communities including potential risks and benefits. Social research should restore the inequality among the researcher and the communities through the indigenisation process as well as serve a social justice agenda to redress the long-term consequences of colonialism and oppression. But instead, social sciences research, like many other types of scientific research, has become commercialised and industrialised removing the human side from both the researcher and the community in the pursuit of objectivity. Often bureaucratic processes within research institutions and universities create structural gaps and bottlenecks between the researcher and the community, like complex processes to review

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research proposals and ethical clearance from research ethic committees. Power relationships then also further contribute to the complexity of social research as non-African frameworks are used to review the appropriateness and adequacy of the research; and often without consultation with the communities (UNAIDS 2011). Inadequate research methodologies and theories are used to deal with the local context; this further alienates the researcher from the communities. This is done to adhere to universal standards and terms set by the predominately biomedical research ethics frameworks applied to social sciences research.

Theoretical bias towards traditional European-American social theories, even when exploring African theory, maintains these unequal relationships between the researcher, community and research institution (Ndlovu-Gatsheni 2013). Most existing social theories do not inform or properly explain local situations or even relate to indigenous knowledge systems which often limit research application (Kruger and Horn 2014). This limits European-American research methodologies as they are not adequate to facilitate research of social settings in communities and indigenous knowledge systems within Africa (Zondi 2018). Guideline 7 in CIOMS (2016) concur with the importance of engaging with communities to establish a trust relationship which include the recognition of indigenous knowledge systems and theories as a way to apply research ethics in a more socially accountable way.

As discussed in Chap. 12, informed consent within the African context is more complex due to the hierarchies in social relationships existing in communities. Culture often dictates the hierarchy of who should give consent and what it means to the community (CIOMS 2016). For example, in many communities there are gate keepers like traditional leaders in most African cultures who should first be consulted for permission before entering into a community(Wasunna et al. 2014). In some cases these people have to then explain to the community what the research is all about and obtain permission to proceed in asking for individual informed consent (Zaman and Nahar 2011). Then it is also the question as to what information do they get in order to obtain successful informed consent within a local context according to culture and other beliefs as well as existing indigenous knowledge systems? Information sharing for full consent should also be gender sensitive as in most communities women are in lower socio-economic statuses than men as well as being less literate. Simpler local language is required to ensure full comprehension in most communities for informed consent than is currently practiced (Schroeder et al. 2018). This also includes culturally and socially sensitive words within the local context.

Some other case studies explaining the complexity of informed consent within the African context include the understanding of community hierarchies of power, especially around age and gender lines (Onvomaha Tindana et al. 2006); and the importance of traditional leaders as gate keepers like in a case study on male involvement in maternal health care in rural and urban settings in Malawi (Kululanga et al. 2011). In Botswana, according to Shaibu (2007), there are certain cultural practices and rituals which must be considered before entering into negotiating consent including submitting a gift to the tribe. A more in-depth discussion on this topic is done in Chap. 12.

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The role of the researcher is often seen as an evaluator or inspector by some African communities due to past experiences with international development aid agencies and research institutions. This kind of research is often done in short periods of time, published somewhere out of reach of the community while the community does not benefit from the research (CIOMS 2016). There is not enough done by both the researcher and research institutes to engage with communities to facilitate co-design and co-production of the research. The practice of research ethics is often more towards the protection of the researcher and research institution rather than what is in the best interest of the community and existing indigenous knowledge systems.

Anonymity and confidentiality also have different indigenous meanings in local African context and are not always practical due to the hierarchical relationships in communities. In small African communities like rural settings and villages it is nearly impossible to secure anonymity as participation is public knowledge and in the interest of the community (CIOMS 2016; UNAIDS 2011). This raises questions on how does one then protect the individual from the community and stigma? Researchers who do not understand the local context and have not spent enough time in negotiating these ethics with communities often rush in and disrespect them. Often this has serious socio-cultural consequences to the participant or respondent. For an example, taking photos for research purpose is very complex and not only a negotiation with various role-players in the community, but it should also be done within the local socio-historical context of self-expression. In some communities it could happen that people have never seen a photo of themselves, let alone a clear image, due to limited exposure to modernity, while in other communities taking photos may be seen as an honour, and in some it can be seen as vanity where the taking of photos is not permissible (Zaman and Nahar 2011).

In most indigenous communities in Africa it is expected that there is some kind of incentive provided to the community during social research. Most socio-cultural beliefs in these communities are based on the understanding of a giving-taking belief system. This makes the provision of incentives complex in the research process as there are also cultural or religious appropriate incentives based on local knowledge systems. Social sciences researchers should spend time to learn to understand the customs of communities in order to ensure the most appropriate incentive is provided (CIOMS 2016; UNAIDS 2011). In urban communities often financial incentives are required due to the high unemployment rate as well as the money value to time. For example, according to South African Department of Health (2015) it is important to take note of the time and inconveniences which participants experience in participating in research including trails and social research. This should be compensated without appearing as a kind of monitory value to buy their involvement in the research but rather compensate or contribute through meals and transport fees. In other cases, incentives are negotiated through existing community and/or family hierarchical structures (Mduluza et al. 2013). When researchers enters into some of these communities like in rural South Africa it is expected that they also bring accepted gifts like livelihoods as a way to compensate for permission to conduct the research. This again, reiterate the importance of social sciences researchers

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who have to emerge themselves into communities before doing the actual research to understand the significance of these kinds of incentives.

Selected research methodologies from Western and European design are not always flexible enough to be applicable and appropriate to facilitate the collecting of data within a local context or within existing indigenous knowledge systems. Some of these methodologies are often so formally designed that they remove the local context and the people who participate in the research from their belief systems (Onyemelukwe-Onuobia 2018). Most of these methods and research designs are reviewed against a so-called academic standard which is far removed from what is really happening and practically possible at community level. Also, these approaches do not always recognise existing indigenous methodologies and theories in local communities which should be considered to either be co-implemented or even replaced. This ensures equal participation by communities as well as to enrich research findings to the benefit of all: both the researcher and the communities.

Sharing research findings or results should be crucial to maintain community trust (Onyemelukwe-Onuobia 2018; Higgs 2015; Odora-Hoppers 2002). This also includes considerations for publication by both the researcher and the community. Publication of these findings or results is often not well-considered by researchers and may contribute to the negative image of Africa in some public spaces or even lead to the exploitation of indigenous knowledge systems. There should also be opportunities for co-authoring with community members to ensure full capturing of and appropriate sensitivity towards the indigenous knowledge systems as well as recognising their equal contribution to the final research product and its outcomes according to Guidelines 4 and 24 of CIOMS (2016).

Some of these abovementioned ethical dilemmas cannot be dealt with within the existing predominately biomedical frameworks of research ethics as the assumption is that ethics are universal and should be adhered to as a practice of academic standards. This limits the engagement between the researcher and the people and their communities to equally and fully participate in the research process as well as to recognise the diverse and unique nature of indigenous knowledge within a local African context. Hence,

> It seeks to create the situation in which all our people shall be free from fear, including the fear of the oppression of one national group by another, the fear of the disempowerment of one social echelon by another, the fear of the use of state power to deny anybody their fundamental human rights and the fear of tyranny. (Mbeki 1996)

10.4 Conclusion: *Seeking Solutions Together Within the African Context*

The point of departure in seeking solutions to some of the research ethical questions mentioned above should be: how to put Africa at the centre while we make sense of the world.

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For social sciences research to make sense to African communities, its ethical approach should be decolonised so as to foster understanding not only among communities, but to researchers as well. Africanisation and decolonisation will thus lead to communities under scrutiny to appreciating the research effort, hence, the exchanges between the researcher and his or her subject(s) will have equal exchange, particularly that the former would appreciate the local ethical values. In this way, it will be easy to deflect the superiority-inferiority attitudes that come with the so-called universal research ethics frameworks.

In order to gain a deeper understanding of the role social sciences research and research ethics within the African context should play, the following aspects should be considered:

(a) A deeper understanding of the African knowledge systems through the indigenisation of social sciences research and research ethics: This requires a more flexible and cross-cultural approach to research ethics rather than a standardised, universal approach to allow an engagement between the researcher and communities for a local understanding and equal participation.
(b) A sensitivity towards the histories and legacies of colonialism and oppression should be present with all social sciences researchers and research ethics committees as it plays out in many spaces and steps of research. The drive to have research ethics should be embedded in the lived experiences of people and their communities to ensure an authentic social sciences research practice which is equal and fair to all.
(c) Use social sciences research and research ethics as a goal to achieve social justice and dignity for all populations living in Africa. This includes ethics, which speaks about the Ubuntu belief system, which reconcile people towards interrelatedness and unity as opposed to individual gain for personal motives.
(d) Humanise the research process by localising social sciences research practices and ethics within communities rather than abiding only to international frameworks or standards. This requires an engagement over longer periods of time between the researcher, people and their communities and research ethics committees.
(e) The importance of African languages to both humanise and localise social sciences research and research ethics: Social sciences researchers should be able to communicate in a local language or use an indigenous translator as a form of social justice and reconciliation and not only as an academic exercise.
(f) Build research methodologies and theories from local people and communities to be appropriate and adequate within the African understanding. This will then allow them to compare and contrast these local methodologies and theories against the predominant European-American theories which do not address the realities of African communities.
(g) Promote subjectivity as a way to conduct social sciences research and practise research ethics. This will allow the researcher to strive towards becoming a more equal with people and their communities and to remove any kind of power relationships between the two. It will also allow the researcher to share own

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lived experiences through ongoing self-reflection within a local context in order to complete a full picture of the research findings or results.

(h) Remove the notion that research is a once-off event standing alone or objective to the lived experiences of people and their communities. Research is an integral part of our interrelations and interconnectivity with each other and our existence in Africa. It should be seen as an exploration of our humanity.

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Chapter 11

Promoting Research Integrity and Avoiding Misconduct – Perspectives on and from Africa

Christa Van Zyl, Francis Kombe, Patrick Okonta, and Theresa Rossouw

Abstract Research in the social sciences provides insights into human behaviour and social interactions. Evidence from such research may inform policies and decisions affecting the lives of many. It requires trust between the researcher, research participants, other stakeholders and the public. To earn trust, the quality and integrity of work done by researchers should be impeccable.

Introducing the concepts of research integrity, research ethics and responsible conduct of research as desirable characteristics of research practice, this chapter also deals with questionable forms of research practice and research misconduct – the latter including fabrication, falsification and plagiarism.

Little is known about the prevalence of, and reasons for, research misconduct in Africa, and there are no national or regional policies, guidelines or structures to promote research integrity on the continent. The voice of Africa and perspectives from African researchers are largely missing in international debates and research about research integrity.

Possible risk factors that may lead to research misconduct or questionable research practices are highlighted, with examples specifically dealing with fabrication, plagiarism and authorship issues. Special reference is made to the risk of unequal power relations in internationally-funded research studies, and the need to

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provide support to research fieldworkers to ensure the quality and integrity of research and research relations.

Recommendations to strengthen research integrity in the social sciences in Africa include networking and information sharing, training and capacity building, research on research integrity (and research misconduct) and the introduction of policies, systems and structures to enhance research integrity institutionally, nationally and continentally.

Keywords Africa · Research integrity · Responsible conduct of research · Questionable research practices · Research misconduct · Plagiarism

11.1 Introduction

The research enterprise, more than many other areas of human endeavour, depends on trust between the researcher, research participants, other stakeholders and the public (National Academy of Sciences, National Academy of Engineering, and Institute of Medicine 2009). Research in the social sciences and humanities provides important insights on human behaviour, including social interactions and cultural aspects. Far-reaching, sometimes life-changing, decisions about government policies, education programmes, public health or economic reforms may be based on research in these fields (Flesch 1995; Hanekom 2014). The integrity of research underpinning such decisions ought to be impeccable.

Trust in research and the research enterprise depends on the integrity, quality and reliability of researchers, research processes and research findings. These obligations form the premise of what can be described as a “social contract” involving researchers, research institutions and the research environment (ALLEA 2017). In 1990, a declaration on intellectual freedom and social responsibility was made under the auspices of the Council for the Development of Social Science Research in Africa (CODESRIA). Although prepared in a context different to some of the world declarations on research integrity, it is worth noting that the claims to academic freedom and support are counterbalanced by acknowledgements of responsibility by academics, i.e.

> *Members of the intellectual community are obliged to discharge their roles and functions with competence, integrity and to the best of their abilities. They should perform their duties in accordance with ethical and highest scientific standards.* (CODESRIA 1990, Article 19)

While individual researchers and research teams carry great responsibilities in their work, discharging these responsibilities is often hampered by lack of goodwill from higher-level decision makers, and an absence of structural support systems. Follow-up reviews on the implementation of the Kampala declaration and a later (1997) UNESCO recommendation on the status of higher-education teaching personnel, suggest that institutional policies and national or regional oversight to promote these principles were generally absent, inconsistent or lacked enforcement. The manner in

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which research and teaching took place depended on the values espoused by individual academics and university departments rather than on guidance from overarching support systems or structures (Altbach 2005; Appiagyei-Atua et al. 2016).

In Africa, there is a notable absence of designated bodies or individuals to promote research integrity. For example, when trying to establish how many institutions in Africa had complied with requirements to submit annual reports on possible research misconduct involving grants funded by the United States Public Health Service (PHS), it was found that only 13 entities in Africa had submitted such annual reports to the Office of Research Integrity (ORI) in the United States of America (USA) – all of them located in South Africa (final response package received via e-mail from the Freedom of Information Act Program Support Centre, 21 September 2017).[1] In contrast, when searching the database of institutional Review Boards registered with the Office of Human Research Protections of the PHS (United States Department of Health and Human Services n.d.), it was found that there are several hundreds of such committees or boards in African countries that had been able to demonstrate compliance with requirements set by the PHS for ethics review of research involving human participants. This seems to imply that institutional support for research ethics is more widely known and established than institutional support for research integrity (database accessed and searched according to country names on 22 September 2017). Apart from the few known institutional points of support for research integrity – appointed to comply with requirements predominantly in the fields of health and biomedical, rather than social science research – there is fortunately also a growing number of individual researchers and research managers interested in promoting the responsible conduct of research within and beyond their institutions. However, there appears to be no national or regional oversight bodies or legislation in place to deal specifically with the promotion of research integrity in Africa (Rossouw et al. 2014).[2]

This chapter aims to address the concept of research integrity in general and apply it to the context of Social Science research in Africa. In the discussion, we introduce principles, roles and responsibilities that underpin research integrity, as well as examples of its negative counterpart, namely research misconduct. The concepts introduced intend to inform discussions of how researchers and the broader research community can help to identify and deal with potential problems, but also recognise and promote research integrity in Africa.

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[1] In the period following receipt of this response package, more entities, also in other African countries, might have joined this group. The authors are anecdotally aware of at least one such instance, in Malawi.

[2] There are, however, some promising developments underway. These include work by the Uganda National Council for Science and Technology on the development of a national research integrity policy (personal communication via e-mail, October 2018) and explicit reference, in the 2019 South African White Paper on Science And Technology, to the need to promote responsible research and innovation (RRI) across the National System of Innovation (NSI), and an intention to develop “the required governance framework to drive the RRI agenda across the NSI” (DST 2019, p. 19).

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11.2 Clarification of Concepts

The concepts “research integrity” and “research misconduct” are clarified in this section.

Research integrity is a term which captures what should be the ideal norm in the research enterprise. The term represents a broad concept which prescribes or evaluates the professional conduct of research. Even though there is no universally accepted definition of research integrity, a well-known definition from the ORI describes research integrity as “active adherence to the ethical principles and professional standards essential for the responsible practice of research” (Korenman 2006, p. 2). Responsible conduct of research (RCR) can therefore be seen as an overarching theme that encompasses the interrelated terms “research integrity” and “research ethics”. “Active adherence”, in turn, is associated with personal adoption and internalisation of those principles and practices, rather than mere compliance with rules imposed by others. (See also Chap. 9 by Nortjé and Hoffmann in this book for an introduction to research integrity in social science research in Africa).

Underpinning the concept of research integrity are fundamental principles of honesty, reliability, trustworthiness, respect, accountability, professional fairness and good stewardship (Second World Conference on Research Integrity 2010; ALLEA 2017). These principles are universal and applicable to good research across all disciplines. As stated in a code of good practice published by the All European Academies, “(t)hey guide researchers in their work as well as in their engagement with the practical, ethical and intellectual challenges inherent in research” (ALLEA 2017, p. 4). The Second World Conference on Research Integrity (2010) adopted the Singapore statement on research integrity, which outlines four principles and 14 responsibilities that are fundamental to research integrity and are entrusted to researchers, research institutions and the research environment. In 2013, the Third World Conference on Research Integrity adopted the Montreal Statement on Research Integrity in Cross-Boundary Research Collaborations. This statement is of particular relevance to researchers in Africa who often collaborate in cross-boundary studies and is discussed in more detail later in this chapter. Reference is made to societal considerations and the need to ethically consider risks inherent to the research in relation to anticipated societal benefits in the fourteenth responsibility of the Singapore statement, but the Montreal statement does not explicitly mention the word “ethics”. This does not mean that research integrity should be seen as unrelated to research ethics. In fact, we propose that one cannot exist without the other.

Research integrity predominantly deals with the relationship between researchers, their peers, and other role players interested in using their research. Peers, policy makers and the public at large should be able to trust the researchers, the research process as well as the research outcomes. Research ethics, in turn, predominantly deals with the interaction between researchers and research participants. Participants should have sufficient information to base their decisions on whether to participate in the research or not. They should also be able to trust the researchers and the

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research process. Research integrity presupposes that the research is conducted ethically, and research ethics presupposes that the research is carried out with integrity.

Some countries, notably the USA, tend to define the concept of research integrity by juxtaposing it against an opposite or contrasting concept, namely research misconduct (Resnik et al. 2015). However, when dealing with actual research practice, it becomes clear that a simple dichotomy between research integrity and research misconduct is not always sufficient or appropriate to categorise the behaviour of researchers and research teams.

Research misconduct is defined in a narrow sense by the United States Office of Science and Technology Policy (OSTP) as "fabrication, falsification, or plagiarism in proposing, performing, or reviewing research, or in reporting research results". OSTP further states that "[r]esearch misconduct does not include honest error or differences of opinion". Fabrication is "making up of data or results and recording or reporting them"; falsification is "manipulating research materials, equipment, or processes, or changing or omitting data or results such that the research is not accurately represented in the research record", while plagiarism is "the appropriation of another person's ideas, processes, results, or words without giving appropriate credit" (OSTP 2000, p. 76262).

Research misconduct is also defined in a broader sense. Beyond the three egregious instances of misconduct – fabrication, falsification and plagiarism (FFP) – research misconduct is deemed to include any deviation from good research practice (Resnik et al. 2015). The Health Professions Council of South Africa (2016) stipulates that scientific misconduct goes beyond FFP and also includes aspects such as: "failure of obtaining informed consent; inappropriate disclosure of research participant data; deviation from approved protocol; falsification of credentials; and deception in the research proposal" (p. 9). The Danish definition of scientific dishonesty (research fraud or research misconduct) also extends beyond FFP to include "other serious violations of good scientific practice committed intentionally or due to gross negligence during the planning, implementation or reporting of research results" (Danish Ministry of Higher Education and Science 2014, p. 21).

If research integrity and RCR lie on the positive end of research behaviour, research misconduct would lie on the negative end, somewhat overlapping with questionable research practices (QRP) – the latter also referred to as "irresponsible research practices" (Second World Conference on Research Integrity 2010) or "detrimental research practices" (National Academies of Science, Engineering, and Medicine 2017).

The table below provides an overview of various forms of research-related behaviour, alongside an imaginary continuum ranging from positive and idealised, to negative and flawed forms of research conduct (Table 11.1).

It should be noted that the various categories and concepts captured in the table, and the inter-relationship between them, all merit detailed further discussion. For instance, mistakes from sloppy or careless work are usually not made intentionally. At the same time, negligence – a form of carelessness, often associated with the idea that the perpetrator "should have known better" – is generally deemed to be a form

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Table 11.1 Shades or degrees of responsible or irresponsible research conduct

	Category	**Concept**
+Positive / Ideal	Responsible conduct of research (RCR)	Research integrity
		Ethical conduct
		Conflict of interest (financial or personal)
? Uncertain / Risky		Conflict of commitment
	Questionable research practices (QRP)	Sloppy, careless, inaccurate work
		Failure to follow accepted research procedures
		Establishing or supporting publications that undercut appropriate quality control of research
		Not retaining or making data, code or source materials available
		Selective reporting of findings; ceasing or continuing data gathering to better fit hypotheses
- Flawed		Authorship issues or disputes
		Maliciously accusing another researcher of misconduct; ignoring or covering up possible and actual violations
		Abuse of power
		Gross negligence
		Failure to comply with statutory requirements and policies
- Negative / Detrimental	Research misconduct (“Research fraud”)	Failure to comply with ethical requirements
		Fabrication
		Falsification
		Plagiarism

Based on ALLEA (2017), National Academies of Science, Engineering, and Medicine (2017), OSTP (2000), and Steneck (2006)

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of misconduct. Conflict of interest in itself is not necessarily good or bad – it exists in life. However, it is a risk factor that needs to be recognised, declared and appropriately managed. Unknown or unmanaged conflicts of interest can unduly influence researchers to manipulate research processes or misrepresent findings to reach a preferred outcome. It is indeed the graded, or shaded, distinctions between different kinds of research conduct and research contexts that require attention when dealing with actual research practice.

11.3 Examples of Research Misconduct

11.3.1 The Prevalence of Research Misconduct

Research misconduct is a global problem which also appears in, and affects Africa. There is a lack of empirical evidence to situate research misconduct in Africa and a dearth of mechanisms to report, mitigate or appropriately sanction research misconduct. Sufficient evidence, anecdotal and reported, nevertheless exists to inform discussion and reflection on Africa's response to challenges in this regard.

While numerous studies have described the prevalence of research misconduct in the natural and health sciences, little is known globally about its presence in the social sciences. A perception exists that such misconduct might even be more prevalent in the social sciences than in the natural sciences. For instance, relatively small studies involving human participants that typically feature in fields such as social psychology are difficult to replicate, making it easier for researchers to manipulate responses or be selective in what they report, without any wrongdoing being detected (Yong 2012). However, the fact that social science research is generally not subject to the kind of regulatory oversight as for the biomedical and health sciences, makes it difficult to prove or refute this perception.

A few studies allude to specific challenges to research integrity, notably plagiarism and authorship disputes, in low-income and middle-income countries (LMIC) or other developing world regions. Hesselmann et al. (2017) reviewed published literature about the occurrence of retractions, as well as possible reasons for retracting journal articles. Whilst retractions are often the result of genuine errors that were detected and reported after publication, many retractions are also occasioned by scientific fraud. It appears that retractions occur more often in the fields of Biomedicine, where the risk of harm in case of misconduct is deemed to be greater, and provision for oversight and corrective action arguably more institutionalised. Retractions in social science research publications are not explicitly discussed. Where lead authors are from "emerging science nations", the ratio of retracted journal articles in relation to published journal articles appear to be higher. Plagiarism seems to be a factor especially in non-English speaking and lower income countries. Based on these studies, Hesselmann et al. concluded that national contexts seem to influence both the occurrence and the detection of scientific errors or research

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misconduct. They referred to Fanelli et al. (2015) who found a lower risk of retraction in countries with an "Anglo-American" higher education model and where national policies to address scientific misconduct are in place.

We also searched the on-line database of *Retraction Watch*, a blog founded by Ivan Oransky and Adam Marcus (http://retractionwatch.com/), to obtain more information on retracted papers from African countries.[3] This database, which was formally launched in October 2018, contains more than 18,000 searchable records. Of 18,142 entries in the Retraction Watch database that had been retracted on or before 14 January 2018, 342 referred to retractions of publications that had at least one author affiliated to an African institution. This constitutes about 1.89% of all retractions listed in the database for this period, which is broadly in line with the share of scientific papers produced by African researchers, relative to the world: According to the 2015 UNESCO Science Report, Africa's share of the total number of researchers in the world was approximately 2.4% in 2013, and some 2.6% of the research output produced globally, in 2014. These aggregated numbers conceal interesting trends and peaks, warranting more detailed analysis and discussion elsewhere. For instance, if the calendar year 2014 is considered in isolation, the total number of scholarly publications for that year that were subsequently retracted according to the *Retraction Watch* database,[4] is 1096 globally, with 44 (4% of the total) involving authors affiliated with African institutions, The global output of journal articles in the same year, according to the UNESCO report, was 1,270,425, with 33,593 (2.6%) involving authors from Africa. For this particular year, then, the relative number of retractions involving African authors, was higher than the global average. Apart from such variances between years, there are also variances between countries, regions, disciplines and reasons for retracting the articles. Closer examination of the entries recorded for the period up to January 2018 revealed that – apart from reasons that could not be associated with misconduct, such as errors by publishers – plagiarism, duplicate publications, authorship issues, lack of ethics review and problems with permission to use data were key drivers for retractions of publications produced by African authors. Fabrication or falsification of data, image manipulation, or concerns about data analyses were also cited as reasons, but to a lesser extent – and not in relation to publications associated with the social sciences or humanities.

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[3] Information correct as at 10 November 2018.

[4] A comprehensive and searchable database of more than 18 000 entries, developed by the *Retraction Watch* research team. The database was officially launched in October 2018, see http://retractiondatabase.org/.

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11.3.2 Issues Around Research Data

When it comes to research data, social science research has been described as "scientifically fuzzy" and "lacking replicability" due to inadequate incentives to replicate studies, difficulties to publish repeat studies, incomplete descriptions of experimental procedures, and the heterogeneity introduced by cultural and social contexts (Stroebe et al. 2012). In contrast to the natural sciences, post-publication audits in the social sciences may be impossible to conduct since requirements for the protection of human participants tend to render them anonymous. The very fact that human beings are participative subjects rather than objects of research, and that they change and develop over time, might also lead to different responses if and when experiments are replicated or perception surveys repeated. Social science has also been stereotyped as being overly interpretive and subjective, with potential to lead to idiosyncratic results (Yong 2012).

A well-known case of prolific scientific misconduct in the social sciences – albeit in Europe – is that of Diederik Stapel, a former psychology professor and dean of the Social and Behavioural Sciences Faculty at Tilburg University in the Netherlands. Stapel was found guilty of academic fraud in work spanning almost a decade. He cited the "messiness of experimental data, which rarely led to clear conclusions" as one the reasons for inventing his own results that were easy to publish due to their elegance and public appeal (Bhattacharjee 2013).

High profile cases such as that of Stapel, fuel the perception of unreported and insufficient management of research misconduct in social science research (Stroebe et al. 2012). The Stapel case was widely reported on in the academic and lay press, with headlines such as "Fraud Is Too Easy in the Social Sciences" (Oud, 2011, as translated by Stroebe et al. 2012, p. 672) undermining public confidence in the field of social psychology research.

11.3.3 Plagiarism

The ownership of ideas is increasingly problematic as millennial students emerge with a tendency to disregard ownership of knowledge (Thomas and Van Zyl 2012), likely due to a post-modern disregard for "the author" and authority. Changing world views on modern notions of individualisation, copyright and intellectual property feed into the increasingly popular idea of intertextuality, together with the perception that information on the internet is freely available and is hence not "owned" by anyone.

An assessment of 279 papers submitted to the USA-based *Academy of Management Learning and Education* journal revealed that 25% contained some degree, and 13% contained a high level, of plagiarism (Honig and Bedi 2012). These authors suggested that plagiarism seemed to be less prevalent in North America than in other countries. Thomas and De Bruin (2015) did indeed find very

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high levels of similarity (pointing to likely plagiarism) in 371 papers submitted to 19 South African management journals: 68.2% were above the cut-off point of 9% that had been set by the authors for the similarity index while 21.3% were found to contain "an excessive amount" (>24%) of similarity.

The availability of similarity checking software products have succeeded in raising awareness of the problem of plagiarism in many African countries. Various articles published between 2008 and 2017 in the *University World News* newsletter, addressed the issue of plagiarism in countries such as Algeria, Egypt, Mozambique, Nigeria, South Africa and Tunisia. Responses to the problem range from the introduction of punitive measures to attempts to raise awareness and provide resources to help reduce the risk of plagiarism. In Algeria, rampant plagiarism led to a ministerial decree in 2016 to criminalise this form of scientific misconduct, apparently to little effect. Academics and university leaders interviewed about the problem proposed further initiatives to raise awareness through media reports on confirmed cases, provision of software programs to help detect and address similarities before publication and the development of university databases of existing publications (Zaghlami 2017). In Egypt, the pressure to publish as prerequisite for academic promotion was regarded as a root cause for many academics plagiarising the work of others, and initiatives to combat this problem included the establishment of university research ethics committees (Khaled 2008). Although research ethics committees do not generally deal directly with matters related to research misconduct (beyond deviations from approved research protocols) this is nevertheless a clear indication of national support for the promotion of RCR. The Tunisian Observatory for Higher Education and Scientific Research (TOHESR) was launched in 2016, to serve as a data repository for university education, science, technology and innovation in the country, and to analyse such data to support evidence-based policy making. At the same time, TOHESR is also expected to be involved in awareness-raising programmes around the high levels of academic cheating, including plagiarism, evident at universities in the country (Sawahel 2016).

A high-level plagiarism case involving Oxford-educated Sociology professor Abebe Zegeye at the University of Witwatersrand (Wits) received media coverage in South Africa and in Australia. Zegeye was dismissed from Wits, but subsequently employed by the Hawke Research Institute at the University of South Australia – only until the circumstances around his departure from Wits became known. Wits was criticised for not making the case public, arguably to protect its own image (MacFarlane 2011; Baker 2011). In reply, the (then) vice-chancellor of Wits wrote a letter providing insights into the process followed to deal with the initial allegation received from "three senior international academics". While the policy of the university allowed for disclosure of full details of such cases upon enquiry, it did not allow for public disclosure of the outcome of disciplinary processes (Nongxa 2011). The Zegeye case opened debate around national guidelines and disclosure standards regarding confirmed cases of research misconduct. Such systems and structures might support a more uniform approach to dealing with allegations across a country or region, while helping to improve levels of awareness, transparency and accountability.

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Plagiarism at undergraduate level is a looming threat, as also described by Nortjé and Hoffmann in Chap. 9. This could significantly derail the academic integrity of institutions of higher learning, especially with the increasing availability of the internet and personal computers that allow copying of large amounts of information. No figures were available for Africa, but many factors, such as of the need to publish in English (which is often a second or even third language) coupled with insufficient mastery of subject-specific English, and inadequate censure of research misconduct could potentially exacerbate this problem on the continent (Ana et al. 2013).

There also appears to be cultural or intergenerational differences in perceptions about what constitutes plagiarism and what the root causes leading to the problem are, although one should be wary of oversimplification and generalisation when specific practices are considered. In many countries, including African countries, the fact that academic writing is done in languages other than the mother tongue of researchers, is deemed to play a role. The free availability of often unattributed information on the internet, and ease with which this can be copied and reused, should also regarded as a contributing factor. For instance, some Brazilian researchers have been reported to regard copying text as a less serious offence than copying data (Ana et al. 2013). A study of Italian students revealed that they viewed the reproduction of large portions of academic material as acceptable, since the facts were already so well expressed by an expert that they could not possibly improve on them in their own words (Sherman 1992). In a study among 139 undergraduate students in South Africa, 30.3% indicated that they plagiarised in order to obtain better marks, while 35.3% attributed it to laziness and/or bad time management and 20.8% to the fact that they did not understand the assignments (Sentleng 2010).

Pennycook (1996) argued that plagiarism is a complex phenomenon that goes to the heart of differences in views about the ownership of language and ideas. Students from countries where rote memorisation is a common pedagogical technique often have difficulty in paraphrasing academic language. The classic example is China but many African schooling systems also reward students for verbatim repetition of facts. Many students therefore are unable to paraphrase effectively and have limited understanding of what constitutes plagiarism when they enter university (Pennycook 1996; Sentleng 2010). Notwithstanding these contextual realities, it is critical to empower African students and academics at all levels with a fundamental understanding of plagiarism as well as the expectations of good academic practice if they are to compete effectively on a global scale.

11.3.4 Authorship Issues

Authorship disputes represent another vexing issue with special importance for LMIC, as discussed in Chap. 8. Instances of unearned authorship include cases where the heads of research units expect to have their names on all papers emerging from those departments, and junior academics who are willing to list more senior, well-published colleagues as co-authors in order to improve their own chances of

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publication (Horn 2017). Okonta and Rossouw (2013) found that authorship disputes were reported by 36.4% of Nigerian researchers sampled, making this the most common form of QRP reported in this study.

11.3.5 Possible Causes of Research Misconduct

A recurring theme in cases of research fraud is the pressure to perform, a phenomenon that could make researchers in LMIC even more vulnerable to QRP in their efforts to compete in the rapidly changing, globalised research enterprise. Intense competition for research funding coupled with the almost exclusive focus on academic research output exacerbate the risk of research misconduct (Rossouw et al. 2014). In addition, national systems that reward academics for quantity of output, such as rating systems or incentive funding, could contribute to a culture of expedience and opportunism. For instance, in South Africa, the introduction of the Department of Higher Education and Training funding system in 2005 saw the number of article units double in the next decade, with many of these published in predatory journals (Mouton and Valentine 2017). The pressure to publish together with the rise of predatory journals and absence of penalties for publishing in such journals, have a synergistic effect on fuelling questionable publication practices. Chapter 8 in this book provides an in-depth discussion of unethical authorship deals.

While many developed countries have well-established institutional and/or national systems in place to deal with allegations of research misconduct, a review by Ana et al. (2013) found little or no in-country discussion of research misconduct and few national bodies tasked with dealing with such issues in most LMIC.

11.4 Researchers in Africa as Potential Victims of Research Misconduct and Questionable Research Practice

11.4.1 Protecting the Interests of Individuals and Teams Involved in Collaborative Research

The Montreal Statement on research integrity in cross-boundary research collaborations (Third World Conference on Research Integrity 2013) lists 20 responsibilities that are entrusted to individual and institutional partners in research collaborations. Looking in particular at the relationships of power and trust between researchers and research teams from different parts of the world, it is indeed very relevant to researchers in Africa whose collaborative research activities often involve cross-boundary teamwork.

Some of the responsibilities refer to enabling principles or “good housekeeping practices”, for instance, the need to build partnerships on shared goals and princi-

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ples of integrity, trust, transparency and accountability; to have proper agreements to govern the collaborative research and good communication between all team members throughout the research process. Other responsibilities listed highlight potential risks to good research practice, especially if there is an uneven balance of power between members of the collaborative team.

Importantly, the Statement calls, among other responsibilities, for

- fair distribution of costs and rewards among collaborating partners;
- clear agreement on roles and responsibilities in planning, executing and disseminating research;
- the ability to account for differences in customary practices and assumptions related to research;
- fair agreements regarding ownership and subsequent management of data, intellectual property and research records emanating from the collaborative work;
- prior agreement on publication plans, including the recognition of authorship and other contributions; and
- having procedures in place for responding to possible allegations of research misconduct or other QRP involving team members.

The abovementioned responsibilities touch on areas where researchers in Africa need to be aware of potential vulnerabilities and ensure that they do engage honestly and clearly with counterparts about roles, responsibilities and recognition.

11.4.2 Dealing with Power Relations

Researchers in Africa often collaborate with international research partners. Because of funding realities – with the international counterparts usually instrumental to funding being secured – there are uneven power relations to deal with. Although the local (African) counterparts are usually much more experienced in terms of local conditions and are able to engage in meaningful ways with both the research topic and potential research participants, they often find themselves relegated to junior roles (Pandor 2017).

Team leaders and project managers might set unrealistic targets and deadlines for survey-related work, not understanding local contexts or even seasonal challenges in terms of access to remote areas. Such pressure placed on local researchers may result in corners being cut in terms of recruitment and ethical guidelines, and pose risk to the quality of data being gathered (Laine and Winker 2017).

As clearly underscored by the Council on Health Research for Development (COHRED) , there is a need for equitable transnational research that will enable researchers to negotiate for more appropriate terms within the African context (Research Fairness Initiative n.d.). The Secretary-General of the African Research Universities Alliance (ARUA), Professor Ernest Aryeetey, underlined this need at the launch of ARUA in April 2017, when he said: "Researchers in the developing world should not merely be regarded as data collection hubs, or wellsprings of

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material waiting to be analysed, or footnotes in north-south collaboration projects" (Kokutse 2017).

For the above expectations to be met, Horn (2017) identified five areas requiring attention. Three of these highlight positive perspectives on research conduct, namely "the promotion of an ethic of responsibility in opposition to compliance and bureaucracy", "collaboration ethics and collegiality especially in the context of North-South collaborations" and "authorship and publication ethics". She also mentioned areas of potential misconduct that warrant attention, highlighting plagiarism in particular. The fifth important area mentioned by Horn was the availability of relevant and useful policies and procedures to promote research integrity. Paying due attention to these important aspects of RCR is expected to enhance the recognition of African researchers, including those working in resource poor settings, and to render a positive influence on the conduct of research in Africa.

11.4.3 Recognising and Supporting the Role of Fieldworkers and Fieldwork Managers

Questions about integrity have also been raised in relation to the role of intermediary research assistants, otherwise known as fieldworkers. Many survey-related studies in Africa are highly dependent on fieldworkers who are able to engage directly with research participants. While capacity-building efforts for African researchers have been receiving attention, the role of those involved in data collection, interviewing and seeking informed consent remains grossly under-recognised and underdeveloped (Kombe et al. 2014). This has the potential to undermine research integrity.

Experiences from Africa have shown that (foreign) principal investigators and research project leaders often lack time and most importantly, the cultural and linguistic competence to interact directly with the communities involved in research or to adequately supervise the fieldworkers they employ for their research. As a result, they tend to employ fresh graduates, lacking in research experience and people management skills, to coordinate the day-to-day activities of fieldworkers and to supervise their work (Participants of an International Workshop in Kenya on the Role of Frontline Staff in Biomedical Research and Kombe 2015). Blasius and Thiessen (2015) demonstrated how pressure to obtain high levels of participation in large international social science surveys seemed to have influenced field workers to fabricate portions of survey returns – especially if the survey instruments cover many questions that will require considerable time and efforts from research participants to complete. Pressure to meet recruitment targets and limited support from more senior project team members tend to be associated with these kinds of engagements – without considering what the effect of such practices might be on the quality and integrity of survey data collected by fieldworkers (Kamuya et al. 2013; Kingori 2013; Molyneux et al. 2013).

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There is therefore a need for research project leaders to come up with some practical local mechanisms or models that will enable them to articulate scientific and ethical requirements in a way that provides training and support to this important cadre of staff. As alluded to by Burton and Wenning (2017), protecting scientific integrity requires the concerted effort of everyone engaged at each step of the knowledge chain.

11.5 Remedies, Possible Resources and Recommendations

11.5.1 The Need to Ensure and Promote Research Integrity

Regardless of the discipline, research that is conducted responsibly, including in social science, has the potential to inform planning, policy and practice. For instance, a former South African Minister of Science and Technology made mention of the value of regular national surveys that covered social, behavioural and medical information for government planning. Evidence from such surveys provided a sound basis for budgeting, plans to roll out antiretroviral treatment programmes, targeted prevention programmes as well as the development and implementation of a national strategy to deal with HIV/AIDS and other sexually transmitted infections (Hanekom 2014).

However, the promotion of research integrity and good research practices cannot depend on the good intentions of individuals only. Political leaders, funding organisations and institutional leaders also have important roles to play in this regard.

11.5.2 Systems and Structures to Support Research Integrity

Many countries and regional entities in the global North have established excellent initiatives to promote RCR and research integrity across various disciplines, and also to ensure that researchers are held more accountable for their actions. Africa is notably lagging behind when it comes to the development of regulatory frameworks, guidelines and initiatives that are aimed at enhancing research integrity. Efforts to build capacity for research ethics have been made, notably in the field of health and biomedical sciences, but little is being done in the area of research integrity. The few African institutions that have introduced policies or statements to comply with requirements set by the ORI tend to operate in isolation from each other and only a few have developed policies that incorporate local requirements that go beyond the minimum conditions set by external funders.

Importantly, the voice of African scholars pertaining to this critical and growing field is missing or grossly underrepresented (Kombe et al. 2014). Opportunities to increase awareness of research integrity in Africa, and of Africa in the context of

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research integrity, need to be identified and pursued. The recent launch of the African Research Integrity Network (ARIN), consisting of committed researchers and practitioners who are dedicated to promoting research integrity in and with Africa, is a promising step in this direction (Kombe 2017). In addition, the Research Ethics Committee Association of Southern Africa (REASA) was launched in 2015. REASA promotes sustainable networks between RECs in Southern Africa and the African continent. A differentiating factor of REASA is its support for a more integrative approach towards research ethics and research integrity (http://www.reasa.africa/).

From the perspective of high-level coordination and leadership, it is encouraging to note that the Science, Technology and Innovation Strategy for Africa (STISA) does contain explicit reference to the need to promote research integrity. Although stated in the context of health research, the sentiments are equally important for the social sciences and other fields of research:

> *In addition, the AU and its Member States must prioritise establishing greater coordination both among health stakeholders as well as with other related sectors contributing to the development of science and technology and building governance structures to promote ethics and research integrity, thus increasing public trust in research* (African Union 2014, p. 22).

11.5.3 Driving the Research Agenda

It can be safely said that researchers and research projects on the African continent are largely dependent on financial support from external sources. This has, without a doubt, greatly influenced research practices and even priorities for research in the region (Pouris 2017). Despite numerous efforts to lobby national governments to invest in and develop more dedicated budgets for research of high local relevance, the scenario has largely remained the same.

Within the context of limited funds for research, even less is currently available to support initiatives towards strengthening research integrity in Africa. As mentioned above, there is a need for national governments to consider the establishment of domesticated oversight and governance frameworks to promote RCR locally and regionally. At the same time, funders and donors who are committed to building capacity in research and research ethics for Africa – currently especially in the fields of health sciences – could consider increasing levels of support for training and research in the field of research integrity as well. It is a fact that good research practices are not limited to protecting research participants.

In this regard, it is worth mentioning the "Amsterdam Agenda" which was agreed to at the Fifth World Conference on Research Integrity. The agenda aims to promote and coordinate research on research integrity worldwide, including lobbying for better financial support for such research. Research on research integrity is needed to better assess efforts to improve integrity in research, and to encourage the use of empirical information to inform the development of research integrity policies

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worldwide (Fifth World Conference on Research Integrity 2017). Researchers and practitioners from Africa should reach out to international counterparts to become part of research consortia in this important field.

11.5.4 Specific Provision for Research Integrity in Capacity-Building Initiatives and Academic Curricula

Over the last two decades, Africa has witnessed a steady growth in the level of support and initiatives aimed at building and strengthening governance and structural systems to support research ethics, albeit with more emphasis on health research ethics. Capacity development programmes funded by the National Institutes of Health (NIH) in the USA, notably through its Fogarty International Center (FIC), as well as the European Union, notably through the European and Developing Counties Clinical Trials Partnership (EDCTP) have successfully built the capacity of research ethicists who are working across the continent (Horn 2017). The European Union, through its Horizon 2020 programme, also offers opportunities from time to time for African researchers to become involved in collaborative projects that deal with research integrity, research ethics and related capacity-building initiatives. Additionally, there are several initiatives that focus on capacity building of African scientists and researchers to acquire knowledge and skills that can enable them to conduct internationally recognised, quality research (Lansang and Dennis 2004). Some of these, including the South African Research Training Initiative (SARETI) and the West African Bioethics Training Programme (WABTP), both supported by NIH-Fogarty grants, include specific modules on research integrity (Ndebele et al. 2014).

There is no doubt that these initiatives have gone a long way in improving the quality of science and research output attributable to Africa in the global arena. However, there is still a need for strengthening research integrity through dedicated training in Africa. This gap has been noted by a few African scholars who have recently been advocating for more inclusivity when it comes to accommodating perspectives from Africa in efforts to promote research integrity (Kombe et al. 2014). It is also important to be more systematic in the approach to promote and recognise good research practice in and with Africa (Horn 2017). Provision should be made for dedicated training in research methods, research integrity and associated potential pitfalls, in under- and postgraduate programmes offered at universities.

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11.6 Conclusion

Because of its focus on examples and risks related to research misconduct and QRP, the chapter might have painted a pessimistic picture around research integrity in Africa. Such a picture would not be realistic or complete. There are many examples of good research practices, with individual researchers, research teams and other role players in the research enterprise showing strong commitment to the principles underpinning research integrity.

What is important, is to ensure that African voices are heard and recognised when it comes to the promotion and recognition of research integrity at all levels – globally, continentally and nationally.

The discussions and recommendations above are informed by existing initiatives and are deemed to be realistic. With support from political champions and decision makers, an enabling environment to promote research integrity on the continent can be created with relative ease. The commitment of individual and networked practitioners remain key to the actual promotion of research integrity and principles underpinning good research practice on, from, across and within Africa.

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Suggested Further Readings

The reference list contains. recent and relevant publications that deal with research integrity in general, as well as research integrity in Africa.

In the absence of formal training. programmes or dedicated workshops, individual researchers and practitioners who are interested to learn or do more about research integrity can already benefit much from online resources. These include rich and dense information made available by coordinating bodies such as the Office of Research Integrity (ORI) in the United States of America, the United Kingdom Research Integrity Office (UKRIO) and ALLEA. The Retraction Watch blog provides topical information and comments about pitfalls of misconduct, but also good and valid reasons for retraction that actually bode well for research integrity. Many university sites also provide excellent sample policies and training materials that can be accessed by visitors. A summary of some of these resources was made by Van Zyl in 2017 (https://drive.google.com/file/d/0B9gcuGd4Fnz2RExWRWdpRVBTblk/view).

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Chapter 12
Informed Consent in Africa – Integrating Individual and Collective Autonomy

Retha Visagie, Soné Beyers, and J. S. Wessels

Abstract Free, prior informed consent is a universally acknowledged ethical requirement for research with human participants. In social sciences, informed consent guidelines are mostly critiqued for its inherent universalism and support of the individualised principlist notion of autonomy. Therefore, social science researchers working with rural communities in Africa cannot ignore the values, concepts and theories relevant to collective autonomy. This chapter advocates for an integrated informed consent approach founded on Afro-communitarianism. We argue that the process of obtaining free, prior informed consent is deeply entrenched in cultural values. A one-size-fits-all approach to informed consent is in itself a form of disrespect for those concerned. The significant contribution of the chapter is a comparative analysis of individual and collective autonomy as it pertains to informed consent from two theoretical perspectives, namely principlism and Afro-communitarianism. We hope to encourage social researchers working in these settings to consider an African perspective on how to preserve participant autonomy.

Keywords Collective autonomy · Individual autonomy · Informed consent · Research ethics · Afro-communitarianism · Principlism

12.1 Introduction

Significant shortcomings in the conduct of biomedical research, in particular, have resulted in the establishment of codes and guidelines to protect human participants against undue risks of harm. Common to all these guidelines is a set of foundational ethics principles that are understood to be universal. The most noteworthy of these guidelines are the Nuremberg Code in 1949 and the Belmont Report in 1978, as

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elaborated by Rakotsoane and Nicolaides in Chap. 2. The Nuremberg Code, for example, lists voluntary informed consent of the human research subject as a universal requirement for conducting ethical research with humans. This requirement originated as a direct response to the abuses committed by the Nazi doctors during the Second World War (The Nuremberg Code 1949). The Belmont Report extends the spectrum of universal principles for conducting ethical research through the establishment of three sets of principles: respect for persons, beneficence and justice (Amdur and Bankert 2011: 21). Within the context of "respect for persons", researchers are morally obliged to obtain free, prior informed consent. This condition emphasises the researcher's moral obligation to preserve participant autonomy.

In spite of strong objections by social science researchers against this form of "ethical universalism" (Keane 2008; Ryen 2016; Shea 2000), the requirement of obtaining informed consent for human participant research has also been imposed on social science researchers, as described by Segalo and Molobela in Chap. 3. In a recently published book, *Finding Common Ground: Consensus in Research Ethics Across the Social Sciences,* the series editor, Ron Iphofen, provides an overview of an array (no less than seven) of codes that currently exist as normative tools to guide the ethical conduct of social science researchers across disciplinary boundaries (Iphofen 2017). Obtaining voluntary informed consent is central to all these codes, thus indicating consensus, also among social researchers, that informed consent as a condition for conducting ethical research is indeed universally accepted (Ahern 2012; Iphofen 2017). However, the ideology and practice intrinsic to "informed consent" remains a contested space.

To understand and know the world, researchers position themselves in different research traditions favouring specific theoretical frames, tools and products (Roux and De Beer 2016). Perpetually, however, social science researchers are expressing discontent about a perceived experience of losing this liberty (Parsell et al. 2014; Tolich 2010). This experience of loss is particularly prevalent among those committed to address the social problems of communities through participatory and community engaged research approaches (Hammersley and Traianou 2011; Stacey and Stacey 2012).

Lamentations about the consequences of accepting a research ethics ideology prescribed by universities that lean towards biomedical and quantitative paradigms are rife (Keane 2008). These requirements tend to be culturally and disciplinary biased in favour of the use of biomedical standards for obtaining informed consent, thus casting a shadow on the process of obtaining informed consent in social sciences research, in particular in rural communities in Africa (Keane 2008; Kruger et al. 2014). Whilst individual informed consent, based on the notion of individual autonomy, is acknowledged in Africa, this practice has mainly been informed by the biomedical principlist doctrines from outside Africa (Kruger et al. 2014). Subsequently, the processes of obtaining individual informed consent from research participants in rural communities, might neglect the beliefs and ideologies of those communities (Bull et al. 2012) (see Chap. 3). In a contribution on paternalism in

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research ethics, Miller and Wertheimer (2007, p. 30) argue that “the criteria for valid consent vary greatly from context to context”.

Our own experiences as members of research ethics review committees (RERCs) resonate with the abovementioned reservations against the application of universal principles to the process of obtaining informed consent, uncritically and unmodified, to community settings in Africa. We argue that a one-size-fits-all notion of informed consent to all fields of research, as well as to all types of research populations postulated in principlism, have not only proved to be difficult in practice, but is inherently flawed from an Afro-communitarian perspective, as supported by the arguments by Schoeman in Chap. 1. Informed consent in these communities imply an extension of individual autonomy to include consideration for collective autonomy (Bhutta 2004). In the absence of internationally known guidelines specific to the process of obtaining informed consent in a community setting researchers have developed certain principles and frameworks that are more suited to these situations (Dickert and Sugarman 2005). However, the authentic realisation of the communitarian notions inherent to these frameworks remains inhibited in a research ethics regulatory system that is still more skewed towards individual participant autonomy. In this chapter, we position informed consent as a social construct, firmly entrenched in the socio-, cultural and historical contexts of potential research participants (Miller and Wertheimer 2007).

We advocate for an integrated stance founded on the argument that the process of obtaining free, prior informed consent in the African context is deeply entrenched in cultural values from an Afro-communitarianism stance. Most of the studies referred to in this chapter relate to sub-Saharan Africa, with the majority relating to Southern Africa, although the principles could be transferred to other parts of Africa. The focus is on rural communities to demonstrate some of the stark differences between the theoretical informed consent guidelines developed from the notion of principlism and the practical application in communities with different value orientations.

The first section sets the scene for the rest of the chapter. We provide an overview of some salient challenges inherent to social science researchers’ endeavours to obtain informed consent in rural African communities. We acknowledge that the debate about improved consent practices, in particular in community engaged research is not new (IJsselmuiden and Faden 1992). Consequently, the aim of this chapter is to extend the debate by offering a comparative analysis of the concepts “individual autonomy” and “collective autonomy”, followed by an application of these concepts to the notion of a participant’s right to free, prior informed consent. Finally, we recommend a series of research best practices, founded on Afro-communitarianism, to harmonise the unique autonomy requirements in these settings.

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12.2 Ethical Challenges Faced by Social Researchers Regarding Informed Consent in Rural African Communities

As already alluded to in the introduction, the fiercest critique against informed consent in social sciences research is its inherent universalism, namely the "Western notion of autonomy and the primacy of the individual", as well as its firm roots in biomedical research (Israel 2015, p. 79). Consequently, social science researchers (henceforth referred to as researchers) conducting research in rural communities in Africa are faced by challenges in negotiating the balance between individual and collective autonomy. This creates a need for obtaining both individual and community consent for certain types of research. In the absence of specific published guidelines on the interpretation and application of principlist doctrines on obtaining informed consent within the African context, researchers are often unprepared to integrate the customs and values of participants in the informed consent process.

Subsequently, Ryen (2016) has identified three main problem areas with the application of Western ethical guidelines for social science research in the African context, namely consent, trust and confidentiality. Based on her ethnographic research experience in East Africa, she has identified the importance of honest interaction with all the relevant parties in the interlinked areas of consent, securing trust and confidentiality. However, Ryen warned researchers against unilaterally including other parties in the research process, as it could taint the trust relationship with the research participant (Ryen 2016).

Another noteworthy study for the purpose of this chapter, is the one by Jeko et al. (2012) on *Obtaining informed consent in non-Western contexts*. In their reflections on fieldwork experiences in Zimbabwe, the researchers report that they were often confronted by language barriers between themselves and the community. For example, the low literacy levels of members of the research population impeded communication, while the translated consent documents did not adequately convey some central concepts (Jeko et al. 2012). A similar problem was experienced by MacJessie-Mbewe (2004) in a study conducted in Malawi. MacJessie-Mbewe (2004) reports that the documentation to obtain informed consent from a Malawian community differ from the guidelines established outside of Africa, as obtaining oral consent proved to be more effective in rural communities. Furthermore, participants have shown not to trust researchers' insistence on documented consent (Jeko et al. 2012). What can be concluded from the aforementioned is that ongoing communication is crucial for sustaining a relationship of trust between researchers and rural communities.

Similarly, within cross-cultural or multicultural research settings, obtaining informed consent from participating communities has shown to be an ongoing process (Marshall and Batten 2004). In the case where individual participants tend to engage with family, friends or colleagues prior to providing their individual consent, it could result in the researchers and research ethics committees (RECs) questioning whether individual informed consent was truly obtained in an autonomous

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manner (Jeko et al. 2012). These challenges confirm a need to explore the interplay between individual and collective autonomy when informed consent is sought in these contexts from an African perspective.

12.3 Individual and Collective Autonomy Applied to Informed Consent in Rural Communities in Africa

The concept of participant "autonomy" is central to the ideology and practice of informed consent in human participant research.[1] The root meaning of the concept autonomy refers to a *state of being independent* from any external regulations or constraints (Dictionary.Com 2019). Based on the etymology of the word, autonomy as a norm necessitates a deep respect for people's ability "to decide themselves (autos) the laws (nomos) to which they comply" (Reach 2014, p. 16). The autonomous person has the right to make rational choices, free from external influence, and taking personal interest and consequences into consideration. According to Reach (2014, p. 16) such a person "expresses the will of maintaining control over her actions and denies any other person the possibility of control except if she gives the authorization". In essence, Reach (2014) draws attention to an autonomous person's capacity to choose the achievement of one action rather than another. Autonomy as a human right implies that persons have a right to self-determination, free from undue influences from others, by virtue of their inherent dignity as human beings. The tensions and paradoxes inherent to the view of the person as "independent and self-determining" (Dworkin 1988, p. 12) find expression in the notion of collective autonomy.

Collective autonomy pertains to a social group's *interdependent state of being,* characterised by the group's ability to make collaborative decisions based on shared beliefs. In convergence with Afro-communitarianism, it pertains to the freedom of a social group or institution in regulating its own interrelations and actions in support of the well-being, not only of the collective, but also of the individual (Metz and Gaie 2010).

Individual and collective autonomy applied to informed consent in research are complex phenomena. While it is beyond the scope of this section to offer extensive moral discourse about the meaning and application of these concepts from two ethical paradigms: principlism and Afro-communitarianism, we (authors) believe that it is pivotal for researchers conducting ethical research in rural communities in Africa to question their moral obligation relating to the notion of participant autonomy.

The Belmont Report which preceded the development of principlism by Beauchamp and Childress (2009) has largely influenced informed consent procedures and practices in biomedical, as well as in social sciences research. From this

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[1] The concept of autonomy extends to the participant as well as the researcher. In this chapter, we only consider the autonomy of the participant and all such references should be construed accordingly.

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theoretical perspective, personhood is underscored by Descartes' maxim "I think, therefore I am" (Descartes 1968, p. 53). This is evident in a view that the person is a dignified human being that is able, and free, to make independent choices based on a rational assessment of a situation, or a proposed action. Principlism has originally been designed as a standard analytical framework for biomedical ethics and represents a principle-based, common morality theory. As such, principlism is based on moral principles that provide a normative structure for ethical analysis and policy design in health-related fields. Principlism advocates the consideration of four sets of moral principles that act as "norms of obligation" (Beauchamp and Childress 2009, p. 14). To this end, the moral agent ought to fulfil "prima facie" duties (Beauchamp and Childress 2009, p. 14). The four sets of principles – respect for autonomy, beneficence, non-maleficence and justice – are interdependent and require balancing and clarification (Beauchamp and Childress 2009). As "moral action guides" (Kuczewski 1998, p. 516) the principles not only serve to justify moral decisions, but also the morality of subsequent actions. Accordingly, it is often applied as a framework to inform the formulation of procedural rules or conditions viewed as essential to guide researchers' moral conduct, evident for example in the Belmont Report.

Beauchamp and Childress (2009) argue that autonomy as a norm allows a person to make up her own mind about the merits of a proposed action or intervention based on the assumption that the person possesses the necessary information and has the capacity to act intentionally, without controlling influences that would hinder freedom of choice and action.

In research ethics the principle of respect for persons is a good example of how autonomy as a "norm of obligation" is used as a moral yardstick to assess the morality of researchers' actions, first by explicitly stating the moral convictions associated with it, and secondly by providing conditions that flow directly from the principle. The concept of individual autonomy in obtaining informed consent from this perspective rests on three notions. First, the person must be able to reason; in other words, be able to make rational choices relating to research participation throughout the life cycle of a research study by weighing the potential benefits and risks or harms of the activity. This clearly requires having adequate information about the study. Secondly, the person has to be free, independent and not exposed to undue influences in making decisions and acting on it. Thirdly, the participant needs to take responsibility for the consequences of her/his choice based on the assumption of a mutually respectful researcher-participant relationship. As such, researchers have a moral obligation to treat research participants as "autonomous" individuals, and to protect those with compromised autonomy, thus necessitating the process of obtaining free, prior informed consent from competent persons (or their designated proxies) (Amdur and Bankert 2011).

Furthermore, social science researchers that conduct ethical research is required to act in line with the procedural obligations that ensued from the translation of these principles in governable procedures, thus diminishing the autonomy of the researcher to respond to a different set of moral obligations that relates to the context of doing social science research. Beauchamp and Childress (2009) claim that

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most ethical tensions or dilemmas can be resolved in health-related practice areas by using these four principles as a normative decision-making framework. Paradoxically, however, principlism, due to its prescriptive nature and individualistic values, limits deep ethical reflection on informed consent practices in social and cultural spaces where the meaning of autonomy diverges from its Western conception (Jegede 2009).

In contrast, Afro-communitarianism as an ethical paradigm has the potential to challenge dominant thought on informed consent. Callahan (2003, p. 288) describes communitarianism as "a way of thinking about ethical problems, not to provide any formulas or rigid criteria for dealing with them". Communitarianism assumes that human beings are deeply connected by means of shared social, political and cultural institutions and practices. In addition, "what counts as private will be a societal decision, not something inherent in the human condition" (Callahan 2003, p. 288).

Originating from communitarian thought, "Afro-communitarianism" represents "a major strain of sub-Saharan moral thought" (Metz and Gaie 2010, p. 274). The latter authors argue that the implications of this moral conception differ from influential Western moral theories, such as Kantianism where researchers have a duty to obtain informed consent from a "principlism" approach. They also lament the unjust neglect of sub-Saharan morality in global debates. Eze (2008) is explicit in his view that Afro-communitarianism does not imply primacy of the community over the individual.

A central tenet of sub-Saharan morality is entrenched in the Ubuntu notion of personhood, "A person is a person through other persons" (Metz and Gaie 2010, p. 274). This clearly denotes the relational orientation of Afro-communitarianism. In this context personhood is a state of continuous self-realisation that takes place in community with others. The notion of interdependence is eloquently described by Metz and Gaie (2010, p. 275) as "One becomes a person solely 'through other persons', which means that one cannot realise one's true self in opposition to others or even in isolation from them". Thus, quoting John Mbiti's statement, "I am because we are, and since we are, I am" (Frimpong-Mansoh 2008, p. 107). Respect for persons is not founded on a narrow view of individual autonomy grounded in Western traditions. Rather, one should seek to live in harmony with others, not necessarily adhering to social norms, but in accordance with the majority view about what has the most value (Metz and Gaie 2010). Consequently, collective autonomy moves away from preferences on rational personal choice, liberty and independence. Rather, one has the moral obligation to consider the common good and to act in solidarity with others and identifying with them (Metz and Gaie 2010). The community "does not act as a self-generating end but furnishes those values that will enhance human identity" (Eze 2008, p. 387).

To this end, collective autonomy, as we construe the term, characterises a cooperative process of engagement between persons in a community, tied by kinship and shared values, to decide collaboratively on a course of action that is believed to serve the "common good" of all affected parties. This is based on the notion that "common good" can only be established in a communal space where people have a strong sense of oneness. The concept of "oneness" used here should not be confused

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with universality. In “Love poem for my country”, Zandile Dikene (Pillay 2004, p. 111), expresses this sense of oneness, so central to Afro-communitarianism, marked by deep historical, socio-political and culture embeddedness:

My country
is for unity
feel the millions
see their passion
their hands are joined together
there is hope in their eyes

Jegede (2009) confirms the need for informed consent practices to be grounded in communitarianism, since the community acts as the voice of the individuals and encourages their interests. How should we then make sense of the idea of free, prior informed consent from a position of oneness in social science research? As we indicated earlier, the normative implications of Afro-communitarianism relating to informed consent ideology resists prescriptive guidelines and procedures. Rather, informed consent is viewed as an inclusive, dialogical and relational process resting on the notion of interdependence and harmony between the person and the community. On the notion of informed consent being given “freely”, it is important to note that informed consent from an Afro-communitarianism perspective does not imply that community interest supersedes individual interest, or that community consent nullifies individual consent (MacJessie-Mbewe 2004; Wassenaar 2006).

If the “relationship between the individual and community is co-substantive by virtue of [a] dialogical creative dialogical process” (Eze 2008, p. 395), then the practice of *once-off*, “prior” consent is inappropriate. The process of relationship building, critical for ongoing trust, still commences prior to the study’s onset of data collection. However, it is characterised by continuous engagement with those representing community interests (Jeko et al. 2012). These parties may include a range of community gatekeepers according to local customs, such as community leaders, queen mothers, clan and family heads (Frimpong-Mansoh 2008). Similarly, being “informed” is now characterised by the communal and individual needs to make sense of how research participation can contribute to the “common good”. Henceforth, the researcher’s obligation to “inform” translates into practices that open spaces for community dialogue, consultation and engagement. As such, “consent” is multi-layered, often involving different parties and different means of expressing agreement in order to be closely linked with local cultural norms (Bhutta 2004, p. 774). An informed consent process that is not fixed by predetermined timelines or procedures emerges from this dialogical process. “Norms of obligation” now extends to consider the obligation that a researcher has to preserve and respect the participant and the community’s sense of “oneness” in obtaining informed consent. If this is achieved, trust and the ability to maintain harmonious relationships become more realistic outcomes.

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12.4 Researcher Practices to Harmonise the Unique Requirements for Autonomy in Rural African Communities

Guided by our reading, and our comparison of principlism vs. Afro-communitarianism and the consequential acceptance that a harmonious balance should be sought between individual and collective autonomy in studies involving rural African communities (see Table 12.1), we suggest that researchers should act as cultural-sensitive moral agents. The researcher's obligations are now informed by the principle to "respect the privacy, autonomy, diversity and dignity of individuals and communities" (Dingwall et al. 2017, p. 114). The notion of privacy is closely related to autonomy. Individual privacy is largely understood as a person's ability to control access to who knows what about her (Israel 2015). Researchers that conduct studies in rural African settings should be aware that what counts as private is often a family or community decision (Callahan 2003). Furthermore, the researcher ought to make appropriate judgements about the balance between individual and collective autonomy to protect individuals and the community from potential risks of harm. To this end, consideration ought to be given to community consultation, community consent, collective autonomy, and individual autonomy and consent, founded on a co-substantive, dialogical relational approach (Fig. 12.1).

Community consultation often involves a series of culturally relevant meetings with the community. The opening meeting is important to establish a sense of direction (Keane 2008) and "community". The purpose is to build trust and long-term commitment to work towards a shared outcome in relation to improving a problem in the community or to "transform practice" as suggested by Keane (2008, p. 1). The researcher shares information about the proposed participatory framework for the research from a position of humbleness and care, and with the intent to elicit community advice to shape the planned engagements and activities. In some community settings it might be possible that community consultation is done in conjunction with community consent, with the community consent crucial to proceed with the research. Other community settings might only involve the community consultation phase, with the community consent concept proving to be irrelevant. This would apply to a situation where a community gatekeeper such as a chief has to grant permission for members of the research team to access the area, however, the individual decides on participation in the study on behalf of himself/herself or on behalf of a child (Molyneux et al. 2005). However, care should be taken to adequately consider the role that community consent plays in the process of approaching the individual community member for research participation.

Community consultation, which is aimed at obtaining responses and inputs from the community, differs from community consent in that it provides researchers with the permission to engage with the research participants within the community as a precursor to individual consent (Dickert and Sugarman 2005). The members involved in the community consultation and consent processes could vary between different communities and different research projects. It is therefore necessary to

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Table 12.1 Comparative differences between individual and collective autonomy applied to informed consent

	Individual autonomy	Collective autonomy
Moral theory	Principlism (Beauchamp and Childress 2009), entrenched in the Westernised notion of individualism.	Afro-communitarianism (Metz and Gaie 2010, p. 274).
Assumptions	Rational ontology (view of the nature of persons) – *"I think, therefore I am"* (Descartes 1968, p. 53).	Relational ontology (view of the nature of persons) – *"I am because we are, and since we are, I am"* (Frimpong-Mansoh 2008, p. 107).
	A person is a dignified human being with individual freedom, inherent worth and self-determination.	"A person is a person through other persons" (Metz and Gaie 2010, p. 274)
	Personal choices considered independent and free from external influence founded on "personal good" as a precursor for social good	Personal choices influenced by concerns for the "common good", solidarity and seeking harmony (Metz and Gaie 2010, p. 274)
	Independence is a desired state of being	Interdependence is a desired state of being
	Universal relevance	Contextual and cultural-specific
Definition	A rational person's right to make choices, free from external influence, and taking personal preferences, interest and consequences into consideration.	A cooperative process of engagement between persons in a community, tied by kinship and shared values, to ascertain a course of action that is believed to serve the "common good".
Characteristics of informed consent	A competent participant's considered choice whether to independently take part in research free from undue influence, and taking responsibility for personal interests and the consequences of choices (The Nuremburg Code 1949; Amdur and Bankert 2011).	A community's collaborative decision to support and participate in a research study guided by consideration for the "common good", ultimately expressed through a combination of collective and individual consent.
Purpose	To respect participants' autonomy and to ensure the scientific community that researcher-obligations, with regards to informed consent, were properly maintained (Alby et al. 2014).	To preserve participants' "oneness" within the community by harmonising collective and individual autonomy throughout the life cycle of the research project.
Researcher obligation	"Prima facie" duties to respect participants' right to autonomy by treating them as autonomous human beings, and by protecting the dignity of those with compromised autonomy (Amdur and Bankert 2011, p. 20).	Duty to "respect the privacy, autonomy, diversity and dignity of individuals and communities" (Dingwall et al. 2017, p. 114).
		Duty to make ethical judgments which balance individual and collective autonomy based on context and culture (Dingwall et al. 2017, p. 115).

(continued)

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Table 12.1 (continued)

	Individual autonomy	Collective autonomy
Conditions	"Free" (decision to participate is not unduly influenced by external influences and the participant can decide to change the decision during the course of the study).	"Free" (decision to participate determined by local customs and norms, without disregard for individual autonomy).
	Obtained before a study commences ("prior"), in spite of recognition that obtaining informed consent is a process.	Negotiations to enter the setting, recruit the participants and invite them to participate, commences with community engagement – ongoing process.
	Informed (participant has sufficient information to make a considered decision).	Informed (community gatekeepers and individual participants receive information in such a way that they can determine the "common good").
	Capacity to consent based on intellectual development, legal status, context (i.e. prisoners) and educational level (Amdur and Bankert 2011).	Capacity to consent influenced by cultural authority structure, customs, norms, without disregarding personal capacity.
	Protect those with compromised autonomy (Amdur and Bankert 2011).	Protect those with diminished autonomy against risks of harm.
Common consent practice	The agreement is mostly a once-off prescriptive participant-researcher agreement expressed by physically signing a consent form.	Depending on literacy levels and contextual realities, agreement may be verbal.
	In some instances, verbal and implied consent is recognised as legitimate practices.	Flexible, ongoing agreement process that is informed by day-to-day occurrences, involving multiple gatekeepers.
Researcher-participant relationship	Egalitarian, contractual relationship between autonomous individuals with certain rights and responsibilities arising from the research (Barret and Parker 2003; Sanchez et al. 2001).	Co-substantive dialogical relationship between the researcher, community gatekeepers and the individual participants (Eze 2008).

consider each community and its relevant gatekeepers in its own right in order to respectfully address the different layers of community consent and to allow time for individuals to engage with communities and for participants to understand the implications (Jeko et al. 2012). Jeko et al. (2012) emphasise that researchers have to adapt when research is being conducted in community settings as to be sensitive to the cultural aspects by attempting to align the needs and values of the communities to established informed consent regulations.

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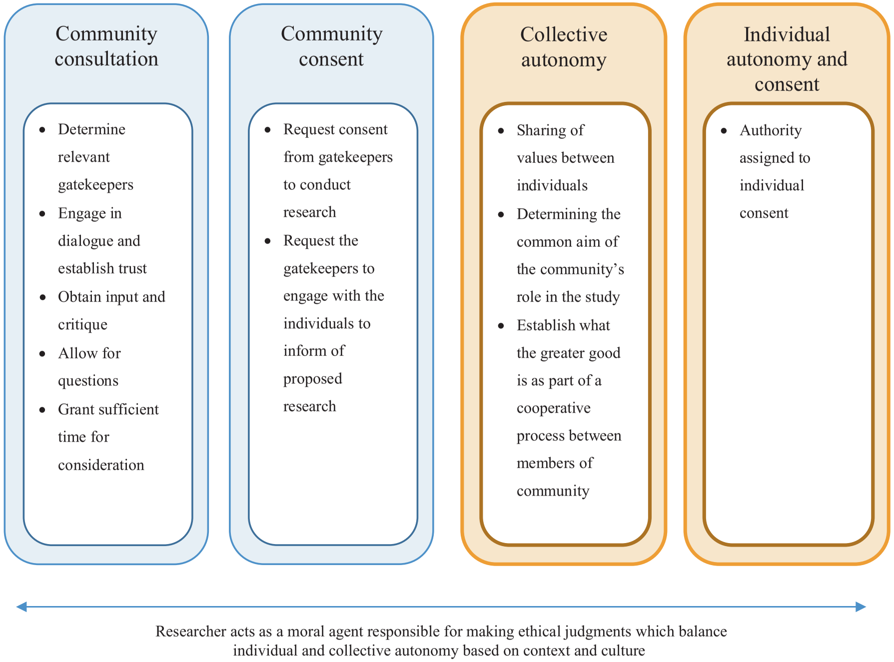

Fig. 12.1 Researcher practices relating to autonomy in rural African communities

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12.5 Conclusion

Researchers encounter various difficulties when engaging in research with rural African communities, with the guidance available to these researchers usually being grounded in the research ethics principles of the biomedical field without any significant contextualisation. The foundation of informed consent in the principlist biomedical-derived framework is not well-suited for research involving rural African communities as the rigid guidelines are not appreciative of the role that cultural and social dynamics play in these communities. We argue that the notion of Afro-communitarianism is more aptly suited for the formulation of a framework for autonomy and informed consent in these communities, since it allows for the individual to identify as part of a social community context and for the community to collectively determine their role and interests in the research agenda.

Our suggested researcher practices demonstrate an element of community consultation as part of trust building, whilst acknowledging the role that the gatekeepers play in informing the community of the study. Formal community consent from relevant gatekeepers might be required to initiate contact with the prospective research participants. These practices are underpinned by Afro-communitarianism and recognises the individual's role within the social context of the community. Individual consent is still respected and mostly required for research to commence. In this flexible and socially constructed practices, the researcher is able to adapt to the community setting and maintain harmony between all parties involved, whilst always being mindful of the moral obligation towards the community and the research participants. We hope that our reflections on individual and collective autonomy, and the practices to harmonise the unique requirements for autonomy in rural African communities, will inform researchers and members of RECs alike to carefully reflect on the notion of informed consent as a dynamic social construction.

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Chapter 13
Equity, Equality and Justice in Social Science Research in Africa

Melany L. Hendricks and Gordon M. Donnir

Abstract This chapter explores equity as a moral concern within the framework of the public good and an ethical challenge of social justice within the African context. Health equity refers to the absence of unjust and preventable differences in the health status of persons that are socially and institutionally maintained through unequal distribution of resources and the mechanisms or processes by which this occurs. Health inequity does not occur uniformly across populations but may differ between ethnic, socio-economic, cultural and gender groups within a specific country. Health inequity therefore broadly has two dimensions, inequality on the one hand, which describes how health is distributed and the processes by which it is achieved, and inequity as a pointer to social injustice on the other hand. In Africa, health inequity is all pervasive as Africa suffers from fragmentation and underinvestment in health, with a high burden of disease and a lack of resources to manage it. Social science is important in identifying and addressing the challenges caused by inequity.

The fact that health status is rarely the outcome of an autonomous choice, especially in the developing world, places it at the centre of public health ethics locally as well as globally. Health equity issues pertaining to Social Science research is a distributive justice matter, as limited public resources are directed to the majority of the population who are poor, while the bulk of the resources are more readily available to the wealthy because of their favourable economic position. This calls for both policy and ethical considerations.

The implication of the commitment to establish more equity in health has some impact on Social Science research. Some advances have been made in the

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understanding of the health inequities and its key drivers. However, in a rapidly changing world, the evidence needs to be updated to remain relevant. It is noteworthy to mention the increasing recognition of Social Sciences' approach to health services and clinical research. This brings along immense pros and offers some challenges as well.

Keywords Equity · Equality · Justice · Public good

13.1 Introduction

> *For reasons of history, geography, climate, and ecology, the people of sub-Saharan Africa ("Africa" from here on) bear the greatest burden of ill health and disease.* (Chan, M. 2014, p. 10)

Africa more than any other region in the world bears the worst health indicators. This correlates with the established fact that health outcomes are worse among the poor and Africa is burdened heavily by poverty. Health equity and the understanding thereof, have become increasingly important throughout the world (Starfield 2001), as discussed by Morrow, Worku and Mathibe-Neke in Chap. 5. O'Donnell et al. (2008) maintain that health equity remains the essential goal and other authors (Maclachlan et al. 2011; Eide et al. 2015) opined that without equity in health, the Millennium Development Goals (MDGs) would not be achieved. As health equity became a worldwide focus, so did Social Science gain significance as it offers improved insight into health equity and the regulations which informs it (Daniels et al. 2017). Daniels et al. (2017) hold that Social Science methodologies are entrenched in health systems research and it provides unique insights into the perspectives of persons who are at the centre of strategies which will enhance equity. These insights also give information about which practices enhance inequities that should be avoided.

While the concepts of health equity and health equality are used interchangeably, each contributes differently to the understanding of a complex health situation within a country and the country's relation to the world (Trinh-Shevrin et al. 2015). Health equity and health equality are closely linked to socio-economic status (Chan 2014). Both (health equity and health inequality) impact on a person's ability to contribute to society as it compounds inequalities in other areas (O'Donnell et al. 2008). In addition, health equity and health equality influence health planning and policy making (Braveman 2006), determine which resources will be allocated to certain conditions, and in this manner, it may inform the research agenda.

13.2 Health Equity

The World Health Organisation (2017) conceptualises equity as "the absence of avoidable or remediable differences among groups of people, whether those groups are defined socially, economically, demographically, or geographically". Health equity requires access to health services which is of a good standard and is provided

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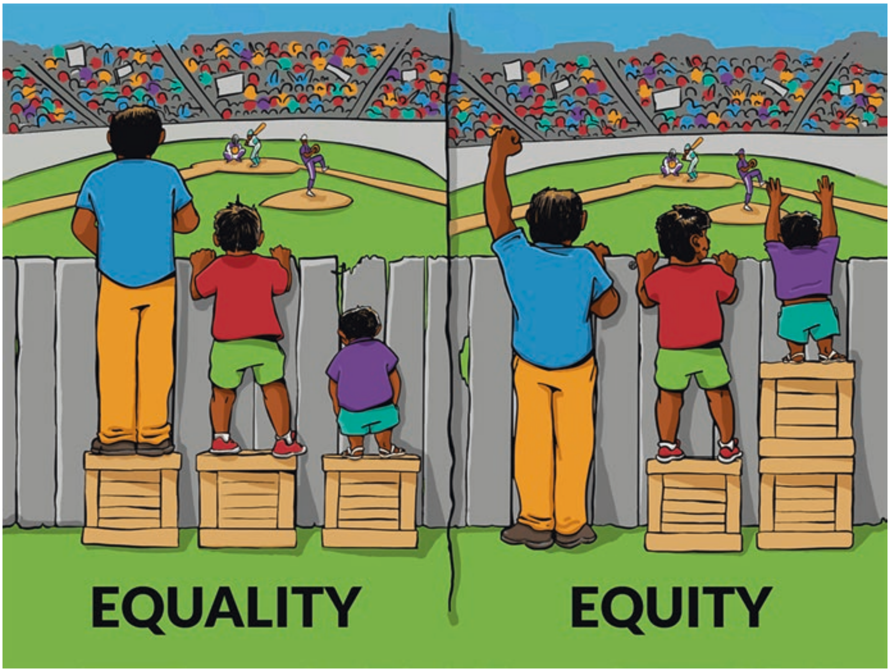
according to personal need irrespective of race, gender, disability, class or any other discriminatory factor (Maclachlan et al. 2011). Conversely, health inequity refers to the presence of preventable differences in the health status of persons that are socially and institutionally maintained through unequal distribution of resources. Health inequity does not occur uniformly across populations but may differ between ethnic, socio-economic, cultural and gender groups within a specific country. Health inequities extend/spread beyond inequality of health determinants and access to the health resources; it also involves an inability to prevent or conquer inequalities which intrude on justice and human rights standards (WHO 2017).

Health inequity is all pervasive in Africa, as Africa suffers from fragmentation and underinvestment within health as indicated by the high burden of disease and the lack of resources to manage it. Social position, grounded in a particular socio-economic, political and cultural context, is at the foundation of inequity in Africa as evidenced by the steep social gradient of health. The social gradient of health refers to the phenomenon whereby health status improves with social position. Social position determines exposure to favourable social determinants of health. These social determinants of health include the general social and economic environment impacting on health status and includes among others, level of education, employment status and environmental factors like the availability of clean drinking water. Health equity implies a duty to decrease health disparities through addressing both the social and clinical determinants of health (Braveman 2010).



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Interaction Institute for Social Change – Artist: Angus Maguire

13.2.1 Health Inequality

> *Africa is a continent of great wealth, so why is Africa's share of global malnutrition and child deaths rising so fast? The answer is that inequality is weakening the link between economic growth and improvements in wellbeing.* (Africa Progress Panel 2014)

Health inequality, sometimes called "health disparities" or "social inequalities of health", is the variation in health status between groups where the more affluent has better health than the poor (Dehlendorf et al. 2010). Not all health discrepancies between people are considered health inequalities. Differences in health status are considered health inequalities only if it is possible for these differences to be addressed through social strategies where the political will to do so is present (Braveman 2010). The concept "health inequality" thus concerns those differences in health status between those who have and those who have not, which is inextricably linked to social challenges and the experience of discrimination (Braveman 2010). Vulnerable populations such as the poor, women and children (as discussed in Chap. 15) are often at the worst end of the health continuum. Health inequality is used as a method of quantifying health equity, it (health inequality) can be avoided, and if not avoided it can be changed (Braveman 2010).

Health equity is measured through monitoring social health disparities (Braveman 2010). The primary method of measuring progress in health equity is to gauge health within a system using indicators such as infant mortality rate or chronic disease, life expectancy at birth or any indication of good health or functioning. Social stratification associated with advantage or disadvantage is the second method of measuring progress in health equity. Social stratification refers to the hierarchical grouping of people according to race, ethnicity, gender, income level, highest level of education attained or any other social yardstick which often amount to discrimination. The presence of multiple disadvantages is associated with more severe inequality. Thirdly, health indicators are compared across groups to highlight inequalities regarding the rate of difference across the various groups. Determinants of health are measured through factors impacting on health such as the socio-political environment – including housing, food availability, working environment, crime levels and health care among others.

13.3 Social Gradient of Health

This phenomenon where good health status is associated with wealth and poor health status is associated with poverty and disadvantage, is known as the social gradient of health (Braveman 2006). Social gradient, as one of the most dependable measures in public health, has implications for health inequalities. Poorer people, who have limited education and menial employment, tend to have a shorter life expectancy and a higher prevalence of disease. (Kröger et al. 2015). Kröger et al. (2015), in their systematic review of transdisciplinary literature spanning some

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20 years, established that both social causation and health selection play a significant role in generating health inequality. Social causation posits that people with better economic means live healthier lives than people in lower socio-economic positions. The social gradient in health therefore develops as a consequence of variations in resources, support, knowledge, behaviour or other factors which are socially stratified (Kröger et al. 2015). Whereas health selection is the process by which disparities in health results in variations in social standing; those who are healthy achieve advantageous positions in society, and those who are unhealthy, have poorer opportunities and achieve low status in society (Kröger et al. 2015). The root of health inequities is multifaceted, and it includes the social determinants of health (Jull et al. 2017).

Social determinants of health contribute to health outcomes and include other elements than the direct elements of health care itself. For example, climate change and housing are significant for a person's health and health care, similar to the advancement in healthcare technology or level of training of healthcare professionals.

13.4 Healthy Life Expectancy

Gadikou et al. (1999) define a healthy lifespan as a method to quantify survival and non-life-threatening health consequences. A healthy lifespan refers to the potential number of years an individual can live (usually indicated by the longest living person within a community). A healthy lifespan is distinguished from a healthy life expectancy. Life expectancy is a statistical average of the number of years people live in a community. The average is calculated by including everybody, even those persons who died at birth. Life expectancy is thus the number of years an individual is estimated or predicted to live from birth based on a statistical average. Neither healthy lifespan nor healthy life expectancy indicate how healthy people live. Gidikou et al. (1999) therefore argue that health expectancy is a better gauge for equity as it takes into account the worth and the amount of elements of health. Health expectancy is thus an indicator of healthy life years, which indicate whether life is spent healthily or if persons spend their life suffering from illness. Advances in health expectancy are reflective of progress in social, lifestyle and economic changes. It also implies improved access to healthcare services and medical technologies (Gadikou et al. 1999).

13.5 Health Equity and Human Rights

Health has long been acknowledged as a human right throughout the world and in Africa, as explained by Mnisi and Wathuta in Chap. 14. Human rights are those inalienable rights that people have because they are humans and it includes social,

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political and environmental rights. Human rights create claims people have against the government which is enforceable through international treaties incorporated into national legislation (London 2007). The Istanbul Declaration (World Federation of Public Health Association 2009) pronounces “Health: The first human right”. Article 16 of the African Union’s Banjul Charter (1986) holds that “every individual shall have the right to enjoy the best attainable state of physical and mental health” and that the state has an obligation to protect the health of the people and ensure that they obtain medical care when they are sick. The striving toward a good standard of health was reiterated by the African Union (AU) in the fifty year development plan for Africa (The Africa we want), set to be achieved by 2063. According to London (2007), health as a human right embodies both the right to healthcare access and the right to conditions that promote health, like adequate housing conditions and sanitation. Concurring with London (2007), Braveman (2010) notes that international human right instruments (UDHR, ICCPR and the ICESCR), recognise that all human rights are interdependent and cannot be separated from one another. The right to health cannot be separated, for example, from the right to vote as one’s ability to exercise the right to free political activity may be impeded by one’s health status. The concept of human rights is therefore not only relevant but is an essential part of the health equity discourse.

Some authors (Shetty 2005; London 2007; Nnamuchi 2014) hold that a human rights focus in policy decisions regarding health is essential for the attainment of the MDGs and the improvement of vertical equity in health care. Vertical equity denotes strategies and plans aimed at averting health inequalities, equitable distribution of resources and the restoration of power imbalances which are at the foundation of these inequalities. Human rights standards can be used to measure existing government policies and to agitate for policies which could bring about equity (Braveman 2010).

13.6 Health Equity: A Matter of Social Justice

Justice as fairness promotes the idea that in the distribution of society’s goods, the most disadvantaged people must be placed in an equitable position with those who are the most advantaged (Rawls 2003). Rawls’s theory of social justice (Rawls 2003) equates social justice with distributive justice.

The fact that health status is rarely the outcome of an autonomous choice, especially in the developing world, places it at the centre of public health ethics locally as well as globally. Health equity and health inequality issues about Social Science research is a distributive justice, and human rights matter as limited public resources are directed to the majority of the population who are poor while resources are more readily available to the wealthy because of their favourable economic position. Health inequalities may develop from intentional or unintentional discrimination and may lead to further social disadvantage and weaknesses. Braveman (2010) defines equity as justice, which is firmly rooted in the notion of distributive justice.

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It (health equity) implies a moral obligation to, at the very least, decrease health inequalities and at best eradicate health inequalities. Health equity places the notion that everything should be done to ensure that everybody is placed in a position to reach their full potential at the centre of public health discourse (Braveman 2010).

The pursuit of health equity and health equality is a matter of social justice and a public good which needs to be attained for its own sake (World Federation for Public Health Associations 2009). When health inequities are viewed within the framework of social justice, community engagement is emphasised. According to Trihn-Shevrin et al. (2015) interventions which attempted to improve the structural determinants of health were limited, even though they were designed for a particular population. Health inequities as a social justice issue necessitate a life course approach concentrating on early intervention and the confrontation of the structural determinants of inequities through the development of policies focussing on improved access to health and healthy social and economic environments (Trihn-Shevrin et al. 2015; Braveman 2006).

13.7 Barriers to Achieving Equity

The barriers to achieving equity straddle both the individual patient's experience on a micro level and governance and environmental factors on a macro level, as described by Mgutshini and James in Chap. 7.

On a micro level, one study reporting on the barriers in four African countries found that the main barriers to access to health care in these countries were the unavailability of transport, inadequate services, lack of medicine or equipment, and high costs of health care (Eide et al. 2015). The perceived barriers varied reflecting the differences in socioeconomic status in these countries. The barriers which are perceived to be very serious are costly transport, negative attitudes among health personnel, lack of accommodation at the health facility, dangerous travelling conditions to the facility and accessibility to a health facility (Eide et al. 2015). Eide et al. (2015) additionally found that bad treatment and poor communication by healthcare personnel and lack of necessary documentation are among the barriers that may not be insurmountable but requires attention to rectify.

All vulnerable populations, including persons with a disability, in addition to the limitation of the condition from which they suffer, also have to contend with the barriers mentioned above (Maclachlan et al. 2011), thereby increasing the existing disparities for the vulnerable groups. (See Chap. 15 for a more in depth discussion on vulnerability).

The impact of highest level of education on apparent barriers differed across the countries studied and is only positively correlated with increased equity where improved education leads to higher socio-economic status.

On the macro level, bad governance and corruption and a shortage of healthcare professionals in Africa continue to hamper the MDG project in Africa (Nnamuchi 2014). Furthermore, most African countries seemed to agree that a primary healthcare

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focus on health care will assist in bringing about equity, but their internal policies do not reflect this commitment (Nnamuchi 2014). The New Partnerships in Africa (NEPAD) mentions weak health systems as a factor impacting on the achievement of equity, while Johnson (2011) emphasises poverty and the movement of healthcare personnel from rural to urban areas and from poorer to wealthier countries as challenges in achieving equity in Africa. Health coverage in the remote parts of the rural areas remains challenging across Africa.

13.8 Millennium Development Goals (MDGs)

The Millennium Development Goals has its origin in the attempt of world leaders to address existing inequities. The MDGs have been a driving force in Social Science since its conceptualisation in 2000. Social Sciences played an important role in arriving at an understanding of cultural and behavioural factors which influence the Millennium Development Health Goals, including health-seeking behaviour in malaria treatment (Ribeira and Huassman-Muela 2011) and understanding risk-taking behaviour in HIV/AIDS (Drainoni et al. 2009), to name a few.

The Millennium Development Goals (MDGs) derive from the Millennium Declaration which has human rights as a fundamental value. There are eight MDGs which countries had to achieve by 2015. Three of these goals pertained directly to health. The three include the decrease of child mortality, improvement of maternal health and to combat malaria, HIV and other diseases. Nnamuchi (2014) adds the eradication of poverty to the three MDGs as an additional requirement to successfully address inequities in health.

In Africa, health programmes have been guided by the (MDGs), focussing on women, children and communicable diseases (Chan 2014). The health situation in Africa is becoming increasingly complex with people living longer which adds chronic, non-communicable illnesses to the burden of disease (Chan 2014). While there were some successes, the MDGs were not attained. Africa and the rest of the world moved on to the interrelated Sustainable Development Goals (SDGs). The SDGs are 17 interrelated goals of which the third goal addresses health. These goals are to be achieved by 2030. Daniels et al. (2017) maintain that without the insights provided by Social Sciences, the sustainable development goals and universal health coverage cannot be attained. Social Science research provides rich and complex information which reflects the life narratives of key actors that are impacted by the attainment of the SDG's. With reference to health systems, Lewin and Glenton (2018) concur that Social Science research methodologies, in particular qualitative research, provide local information which assists in understanding and strengthening multi-faceted health systems contributing to the SDGs. Evidence indicates that information obtained through Social Science methodology may guide health system policies and provide a method for evaluation (Lavis et al. 2009). The challenge here is for Social Science to move beyond policy making to implementation through

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engagement with stakeholders and policy users, so as to generate evidence for capacity building and proof of practice (Lewin and Glenton 2018).

13.9 Impact of Health Equity on Social Science Research

O'Donnell et al. (2008) report a sharp increase in equity research from 1980 to 2005. These studies included mostly the analysis of survey data derived from a variety of household and other data sets. With the focus on the interplay between equity, social justice and human rights, globally the importance of Social Science research is increasing, and research in the field of equity and public health is forced into the sphere of Social Science. Molyneux et al. (2009) report a growing acknowledgement for the contribution of Social Science research to health and to the development goals, especially since it is considered essential to the achievement of the SDGs (Daniels et al. 2017). Applied Social Science research does bring on board multi-disciplinary teams and expertise, employing multi-method approaches with robust outcomes in areas that purely scientific approaches cannot elucidate. It (applied Social Science research) can facilitate more relevant and targeted interventions; or an improved understanding of health systems, including policy making, management and implementation processes. Applied Social Science research can contribute to strengthened health system functioning. There is a growing recognition that clinical approaches to health and disease need to be complemented by social analyses of the broader causes of susceptibility to ill health (Molyneux et al. 2009).

The role of Social Science research in achieving equity and universal health coverage is crucial provided that Social Science remains relevant to the socio-political context (Jull et al. 2017). According to the authors Jull et al. (2017), Social Science is equity relevant if it addresses ill health or evaluates the consequences of interventions on health or its determinants, particularly of individuals or populations where social disadvantage is a causal factor. According to Moahi (2010), the South African Human Sciences Research Council's (HSCR) website indicates that Social Science research addresses areas which require understanding, such as poverty, employment, growth (among others) in South Africa specifically but also in Africa in general.

Social Science research must aim to understand and address the inequities created by the various interdependent determinants of health. To address inequity, a well-defined research plan should be developed (Starfield 2001). This plan should define the problem clearly and use methodology which will aid in better understanding the relevant issues, its aetiology and the significant other challenges associated with it. The research plan also needs to seek the methodology which best measures these associations and which can evaluate other explanations and interventions. Equity can be studied in countries and across countries.

Social Science should prove its impact and do research which is of benefit to society in order to gain support, especially in light of funding and resource scarcities (Moahi 2010). It must, therefore, reflect the needs of the society so that there

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is a tangible association between societal needs and academic work. The political context influences the spread of health in and across nations and researchers should be mindful that the political and economic factors impact equity in health (Starfield 2001). It is therefore essential that Social Science should be politically relevant so that it can influence policies, particularly those which address inequities (Starfield 2001).

13.10 Ethical Challenges in Social Science Research in Africa

Extensive research is required in Africa to understand how to ensure equitable and universal health coverage (Chan 2014). The significance of Social Science research in creating a just and fair society cannot be underscored, particularly in Africa, so much so that Ngozi et al. (2016) opined that the lack of Social Science research is indicative of a lack of development. According to Nyaong'o (2016) Social Sciences research explores social occurrences to improve social knowledge so that these social occurrences can be better understood. Social Sciences research thus focuses on the complexities (heterogeneity) of people and their behaviour within a dynamic environment (Ngozi et al. 2016). Inherently, Social science has many challenges. The most crucial for Social Sciences is the fact that it deals with the value systems of potential participants. These value systems may cause an inability or an unwillingness to participate in research and an inability to report the social facts relevant to Social Science research (Ngozi et al. 2016), highlighting the moral obligation to respect cultural values and autonomy. The language barrier and lower level of education may give rise to issues in the informed consent process (Staunton 2015). The high levels of inequity and inequality place most persons on the African continent in the vulnerable population category. Vulnerable populations are ethnic or racial minorities, disabled people, women and children, and people who are poor, as discussed in Chap. 8. Vulnerable populations are particularly at risk to be exploited, and may even be coerced into participating in research for payment/stipends despite their cultural values.

While there is limited documented evidence for research misconduct in Africa (Kombe et al. 2014) past research indicated that research integrity in Africa was not satisfactory and therefore aggravated the above situation as vulnerable populations were exposed to predatory research and exploitation (Tetty and Puplampu 2000). In South Africa, there is evidence of scientific misconduct at all the major universities which include misconduct related to the absence of an approved protocol and completed informed consent forms, cheating and plagiarism (Kombe et al. 2014). Nigerian researchers perceive research misconduct to be common to their region, and are reportedly concerned that they do not have proper mechanisms to deal with the research misconduct (Okonta and Rossouw 2014). Concurring with the findings of Okonta and Russouw (2014), Ngozi et al. (2016) found that plagiarism continues

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to shackle Social Science research in Nigeria, in part because of the non-existence of ethical yardsticks. In Uganda, Mwakwa (2017) reports that despite the adoption of guidelines promoting responsible conduct in research (RCR), research misconduct is not decreasing. Rohwer et al. (2017) studying authorship in Low and Middle Income Countries (LMIC) concluded that guest authorship (authors who did not add to the article) and plagiarism are prevalent in LMICs. However, Africa seems to be addressing the challenges with research integrity through increasing research review capacity. Currently, there are at least 170 research ethics committees across Africa registered on the Mapping African Research Ethics Review Capacity Project (Mokgatla-Moipolai et al. 2014). Most recently, African researchers established ARIN (African Research Integrity Network) to improve research ethics integrity and awareness on the African continent (https://africanresearchintegritynetwork.wordpress.com/).

Despite its importance, basic Social Science research is decreasing in (East) Africa (Nyaong'o 2016). Social Science research centres are not well resourced as the focus remains on health research (Mouton 2010). Research Centres are disappearing, and students lack the skill to do research (Ngozi et al. 2016; Nyaong'o 2016). Funding for publications is non-existent, and where funding is available, the funders specify the area of research they are funding (Ngozi et al. 2016; Nyaong'o 2016). Mouton (2010) reported that Social Science research is often published in local academic journals and consequently the research remains invisible internationally. Researchers thus have to tailor their research interests to the funders' requirements which may mean that the research may not always be relevant to the population in which the research is done. However, as funding is a major limitation, Chan (2014) maintains that research agendas need to be carefully selected to ensure that health spending is optimal and set to achieve equitable health care for all. Research topics need to be selected so that it straddles the needs of corporates and society at large (Chan 2014).

Mouton (2010) finds that research capacity building on an individual and organisational level is important for Social Sciences in the African region. According to Swayerr (2004) research capacity encompasses skills, competencies, attitudes and values normally obtained through training. Social Science research is however hampered by a lack of government involvement and an unfavourable political environment (Ngozi et al. 2016). Reporting on a Nigerian study, Ngozi et al. (2016) comment that Social Science research suffers from a lack of quality tertiary education, human skills development and an inadequate conversion to the requirements of information and communication technologies. Ngozi et al. (2016) agree with Mouton (2010) that in addition to an overdependence on external funding, neocolonialism also allows for a brain drain – the effect of which is exacerbated by an aging academic population, resistance to change and a lack of professionalism (Tettey and Puplampu 2000). Mouton (2010) reports that science institutions in Sub-Saharan Africa suffered through international and domestic economic policies which lead to a decrease in scientific productivity, devaluing of the professional status of science and consequently increasing the brain drain.

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13.11 Equity in International Collaborative Endeavours

Knowledge production is valuable irrespective of whether the parties involved are from different countries (Tettey and Puplamu 2000). Collaborations in research are necessary and common (Schroeder et al. 2017). As there are often disparities between researchers in low- and middle-income countries (LMICs), their international counterparts and their foreign funders, the need for equitable and respectful relationships is essential (Schroeder et al. 2017). In the absence of equitable relationships, the possibility for exploitation and ethics dumping increase significantly (Schroeder et al. 2017). “Dumping”, a term derived from the field of economics, refers to predatory pricing practices whereby financial and other resources are exploited particularly within the context of import/export activities (Schroeder et al. 2017). Ethics dumping sometimes occurs intentionally when research which is barred in the high-income countries are done in the LMICs. It (ethics dumping) often transpires as a result of a lack of ethics awareness (Schroeder et al. 2017). Adherence to high ethical standards is vital, especially when the power imbalances and disparities in know-how between high-income countries and LMICs create the opportunity for exploitation of participants and resources from LMICs.

13.12 Conclusion

Africa bears one of the world’s worst health indicators and is burdened with high levels of poverty. High levels of poverty correlate with worse health outcomes among the poor. The social gradient of health phenomena indicates that the lower a person’s socio-economic status, the worse the person’s health is. Health outcome is influenced by multiple complex factors which usually fall outside of the control of the people affected by it and which is mostly preventable. This difference in health outcome as a result of factors outside of one’s control is deemed unjust and it is called health inequity. Health inequity differs between ethnic, socio-economic, cultural and gender groups within a specific country. Health inequity refers to the absence of socially maintained, unjust and preventable differences in health status of persons.

With the world increasingly focussing on equality and dignity, the achievement of health equity has become more important. The MDGs and the subsequent SDGs are attempts to eradicate poverty and improve equity. Social Science as a method of understanding the factors impacting on health equity, has likewise gained greater significance. Some authors consider Social Science essential in the achievement of a more equitable society.

Despite its prominence, Social Science seems to be struggling in Africa. The problems experienced in Africa are multifactorial. Social Science is hampered by a

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lack of funding, the brain drain as skilled researchers leave the continent, and inadequate research integrity among other factors. Furthermore, social scientists end up teaching and consulting instead of engaging with relevant research. Where funding is available, the topic funded is often not aligned with the needs of the population being studied. As funding for publication is limited, Social Science papers are published in local academic journals and as such do not gain international exposure. Where there is international collaboration between researchers from LMICs and high-income countries, in the presence of unequal relationships, the potential for exploitation increases. Such instances call for high levels of integrity and an awareness of the power imbalance which may exist in order to avoid exploitation. The lack of government involvement in Social Science research adds to the challenges experienced by Social Science researchers in Africa. On the positive side, there is an increase in research review capacity, which may improve research integrity.

13.13 Recommendations for Social Science Research in Africa

The continuation of research capacity building in Africa is important to ensure that Social Science remains relevant on the continent. Social scientists in Africa need to ensure that researchers and students are upskilled in Social Science research methodology and ethical practice, so that research projects meet ethical and scientific standards. Africa has seen an increase in the number of ethics committees to oversee the ethical conduct of research. Capacity building with reference to ethics committees and research integrity structures thus likewise need to continue. This will enhance African science's reputation and in doing so the potential for receiving funding may increase.

In light of the above, it is recommended that Social Science in Africa increase its responsiveness to the needs of society so that it can amplify its reach and influence policy in a real and practical manner. Social scientists should develop clear and coherent research plans which aim to understand the challenges experienced by the community. Social scientists should form partnerships with corporates around issues which are important for both the corporate structures and the community. In doing so, funding will be secured and the community needs will be addressed. Social scientists need to implement evidence-based interventions developed as a result of Social Science research and then engage relevant stakeholders to monitor and evaluate it (interventions) using Social Science methodology.

Social scientists in Africa need to agitate for government to become involved, not only with funding but also in setting a research agenda that can inform policy.

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Chapter 14
Human Dignity Protection in Social Science Research: Perspectives from Selected African Countries

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Abstract This chapter assesses the extent of human dignity protection in the context of social science research in Africa. The availability and content of national research ethics policies, laws and guidelines of a variety of African countries is the guiding factor in this regard. An overview of the current situation regarding social science research ethics and respect for human dignity is given. Reference is made, in this perspective, to some of the universal research ethics guidelines. Despite their merits, the inadequacies of the universal research ethics guidelines can be summarised in a single aspect: the predominance or bias towards biomedical research insofar as it focuses heavily on the quantitative method and contains traces of positivist, formal and individualist thinking (even though South Africa has a document that also focuses on qualitative research). This then necessitates bringing to the fore some useful ethical frameworks and values to shed more light on the meaning of respect for dignity while conducting research in the African context. The examination of pertinent National Research Ethics policies, laws and guidelines of the given countries in Africa revealed that these National Research Ethics policies, laws and guidelines in use in parts of Africa could make explicit provision for ethics review of Social Science research, while incorporating African values. This will make them more protective of the human dignity and wellbeing of social science research participants in Africa.

Keywords Human dignity · Social science research · Africa · Biomedical research · Ethics review · Research ethics policies · Laws · Guidelines

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14.1 Introduction

This chapter assesses the nature and extent of respect for human dignity in the context of Social Science research in Africa. Specifically, it considers the state and role of national policies, laws and guidelines utilised for research ethics considering that such review is aimed precisely at assuring such respect with regard to human participants. In addition, the chapter presents the highlights of the present dynamics vis à vis its interplay with human dignity, in view of the deepened understanding of the need for ethics review of Social Science research in particular. To understand this dynamic, we (authors) briefly outline a common understanding of human dignity and expound it to include existing research ethics guidelines that support an African worldview of ethical research. The overall aim is to respond to the question regarding respect for human dignity in national laws, policies and guidelines in Africa insofar as they pertain to research ethics. The point of focus is recognition of the nature of social science research and the relevant disciplinary and contextual features.

A description is given of the evident bias towards biomedical research as reflected in the "traditional" content of the universal research ethics guidelines, as well as current provisions of the research ethics-related laws, policies and guidelines in use in a variety of African countries. To the extent that the biomedical approach is essentially positivist, this chapter shows how it tends to constrain the nature and style of Social Science research, which is more complex than is usually understood. And insofar as the biomedical method is rooted in the West that is more individualist, its historical failure to capture the importance of community networks[1] in non-Western contexts is also demonstrated.

A brief description of two existing sources that could be resourceful in fostering greater respect of research participants' dignity in Africa follows. These are the ethical framework proposed by Onuoha (2007) and the San Code of Research Ethics (TRUST 2017). Next, the current state of national provisions with regard to the biomedical and Western predominance is traced out in the relevant and available laws, policies and/or guidelines of the following countries: Ethiopia, Kenya, Nigeria, South Africa, Tanzania, Uganda and Zimbabwe.

Recommendations regarding the application of the given ethics resources to national research ethics provisions are made with a view to enhancing the understanding and increased respect for dignity from an African viewpoint. Finally, the need for a clearer distinction between Social Science research ethics and the biomedical approach is emphasised.

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[1] Authors do not claim or suggest that quantitative biomedical research does not invest in community engagements, nor that only research study in qualitative research should. The aim is to bring to light in the individualist approach of research studies in general and the non-emphasis on community engagement as should be, more so in Africa.

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14.2 Social Science Research Ethics Versus Respect for Human Dignity: Highlights of Present-Day Dynamics

Research ethics review is fundamentally concerned with assuring that the dignity and welfare of human participants is respected (Wassenaar and Mamotte 2012). As an underlying principle of ethical frameworks, it indicates the responsibility of the researcher (and by extension the research ethics' committee) towards the research participants (Gontcharov 2013), and their communities. Any shortcomings in the review and/or research process are likely to translate into a lack of respect for human dignity, regardless of the type of research. Such shortcomings may include: research not aligned to local needs, absence of meaningful engagement with the research community, and failure to provide feedback to the research participants or to share research benefits. The discussion below focuses on the major aspects of the prevailing dynamics within social science research ethics that have a more direct bearing on respect for human dignity. First, however, it is necessary to briefly present a common understanding of human dignity both in the West and in Africa.

14.2.1 Understanding Dignity

Dignity is considered a permanent and unconditional attribute, and the basis for the prohibition of discriminatory practices, degrading treatment and the "instrumentalisation" of people. It is a universal objective quality found equally in all human beings (Andorno 2009). The meaning ascribed to dignity in the Universal Declaration of Human Rights as being inherent remains valid to date. It corresponds to the African understanding of the human person and their dignity, to the value of human life *as such*. As the African ethicist, Tangwa (2000) affirms, if there is a divergence in the understanding of the human person between the West and Africa, it is because of an error in the interpretation made or conclusion reached. He presents the African view as one of unconditional acceptance and *reverential respect* of a human being solely by virtue of being human. In a nutshell, the two perspectives are basically in harmony, even if not identical, which can be attributed to the fact that human beings are equal in dignity regardless of their sex, race and colour. Other concepts of dignity exist, but this one is foundational. Potential sources of an enriched understanding of dignity in the context of research conducted in Africa are explained later in this chapter.

14.2.2 Expanded Review of Social Science Research

It is noteworthy that the scope of ethics review has gradually grown to cover social science and humanities' research. Some institutions have research ethics committees dedicated exclusively to the review of this category of research proposals

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(Wassenaar 2006). The expanded focus is a consequence of growing recognition of the significant harms that could be caused by unethical social science research. The nature of the harm in this area comprises emotional distress, stigma and other social harms such as destabilisation of social and relational systems, and violation of privacy and confidentiality (Mutenherwa and Wassenaar 2014). This growth has nevertheless been negatively described as "ethics creep" for seemingly proceeding without evidence of its need and effectiveness, and without giving due attention to the valid practices of ethical governance in social sciences (Gontcharov 2013; Haggerty 2004), as described in Chap. 3.

14.2.3 Failure to Distinguish Biomedical and Social Science Research Ethics Review

The historical Western dominance of a biomedical approach to review presents some difficulties regarding Social Science ethics review. This is partly attributed to the heavy bias towards biomedical research ethics review when the existing guidelines are used for Social Science research ethics review. Added to this is the failure by some REC members, as per Schoeman's argument in Chap. 1, to be sensitive to the particular risks and methodologies of the Social Sciences owing in part to research ethics training that is not specifically adapted to address social science ethical issues (Mutenherwa and Wassenaar 2014). The perceived assumption that biomedical research principles apply universally has been discussed by Redwood and Todres (2006). The automatic application of ethical guidelines from one context to another may undermine human dignity, where for example, respect for persons and their beliefs in the given setting, is not upheld. This approach has consequences that are particularly important, as discussed below.

14.2.4 Social Science Methods Against the "Ideals" of Biomedical Research

The restriction of ethical Social Science methods, insofar as they do not fit into the positivist biomedical research model and its "prescribed ideals" is one of the undesirable consequences. Some of the ideals are *confidentiality* and *consent* (Van den Hoonard 2011 cited in Gontcharov 2013). The biomedical model, for example, gives a lot of weight to the signed informed consent form, yet it is not always appropriate and could be deemed coercive, obtrusive and a breach of the existing bonds between the researcher and the research participant (Van den Hoonaard 2001). Such formality can engender mistrust. The curtailment of ethical Social Science research may lead to failure to accord the dignity of the research participant its due regard. On the other hand, suitable provisions can reinforce respect for human dignity, as will be illustrated later in this chapter.

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14.2.5 Individual Versus Community Rights in Context

Predominant Western focus on the individual research participant, that is, the emphasis on individual rights and freedoms that occurs at the expense of the community is another disadvantage (Van den Hoonaard 2001). This may harm dignity particularly in the contexts that pay similar – or even greater – attention to the good of the community as compared to the good of the individual. Commendably, the New Brunswick Declaration signed in Canada in 2013 (Gontcharov 2013) challenges this individualistic approach by advocating for a shift of focus from individuals exclusively, to individuals and communities, while encouraging a socially embedded contextual ethics education.

This position is further supported by the World Health Organisation (2011) recommendation that researchers actively engage with communities in decision making about the design and conduct of the research, while being sensitive to respecting the communities' cultural, traditional and religious practice. It was captured earlier in the Universal Declaration on Bioethics and Human Rights (2005), which although aimed at promoting responsible biomedical research and clinical practice, nonetheless recognises the need to promote the welfare not only of individuals, but also of families, groups or communities and the whole of mankind, as well as respect for cultural diversity and pluralism. Such a provision ought to be captured in national research ethics policies and guidelines. The Belmont Report (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1979), a milestone document in the development of bioethics, on the other hand, is negatively positioned in this regard, a point which is supported by Rakotsoane and Nicolaides in Chap. 2. Accusations of Western cultural imperialism have been levelled against it, arguing that certain contextual factors are not taken into account. It is considered discriminatory of qualitative research and a promoter of procedural ethics while disregarding ethics in practice (Tolich 2016). This issue is discussed in the section that follows directly below. Molyneux and Geissler (2008) similarly consider the Belmont Principles too difficult to apply due to context, history and culture. Mutenherwa and Wassenaar (2014), additionally, describe the blanket application of universal and so-called Western ethical principles to all communities as "inappropriate, unfair, imperialistic and insufficient to address ethical issues in Africa and … other non-Western countries".

14.2.6 Ethical Codes Precedence Over Moral Reflexivity

Another latent shortcoming in the review of Social Science research proposals is the apparent disconnect between procedural (formal, positivist) ethics and ethical practice as if the latter cannot occur outside the scope of the review process (Gillumen and Gillam, cited in Tolich 2016). It is further argued that the typical prospective review is only a snapshot of the entire research process and that the manner in which this process normally unfolds does not facilitate the researcher's recourse to the REC

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for further consultation when unpredictable ethical dilemmas arise during fieldwork. Some ethical issues have to be resolved situationally or even spontaneously. As long as the procedural approach that is inspired in universal guidelines is adhered to unconditionally, it will potentially lead to disrespect of human dignity insofar as human interaction tends to generate unforeseen circumstances (Tolich 2016).

14.2.7 Understanding the Complexity of Social Science Research

Overall, there is a limited understanding among ethics reviewers of the complex and nuanced nature of qualitative research, characteristic of social science research (Tolich 2016). This can lead to discrimination against this type of research and all parties involved. The scarcity of appropriate provisions does not help to address this challenge. A positivist approach moreover fails to pay heed to the dynamics found in the real world of social science research. This, as earlier stated, heightens the likelihood of not respecting the dignity of research participants. Unless the individuals and communities are protected from all types of harm, any research conducted potentially undermines their inherent dignity and intrinsic worth. Where necessary, national research ethics guidelines and policies in the given African countries would need to be adapted to ensure they accord every research participant the respect due to them. This would entail addressing the shortcomings primarily rooted in the overemphasis on biomedical ethics over Social Science research ethics. One way to do this is to draw from the already existing instruments that propose a specific ethical framework or values to guide research in Africa and similar contexts. The section below has more details.

14.3 Enhancing the African View of Dignity in Ethics Review of Social Science Research

In addition to addressing the abovementioned drawbacks related to Social Science research and respect for human dignity, two notable sources can help to provide a deeper view of what the dignity of social science research participants in the African context consists of. These are: the proposed ethical framework by Onuoha (2007) and the San Code of Research Ethics (TRUST 2017).

Onuoha's (2007) framework for ethical thinking contains values, which as he argues, express the main features of African life. They are: *humanity, community,* and *morality. Humanity* is subject to respect and is the basis of the other values. It is the foundation for respect of human dignity. He states that his community's notion of dignity[2] is similar to the German *Menschenwürde*, meaning that dignity pertains

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[2] The Igbo (Nigeria).

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to all human beings. This affirmation supports Tangwa's point above. *Community* emphasises the *interdependent nature* of human beings, which has important repercussions when it comes to contextualising research ethics principles such as those of Belmont. *Morality,* he says, refers to how the dignity of life is protected in the web of interactions. He concludes that, "a framework that emphasizes these elements would be a coherent approach that resonates with the African worldview, cultures and value systems" (p. 263). Despite its valuable insights, Onuoha's proposal is yet to be operationalised (Mutenherwa and Wassenaar 2014).

A complementary resource, as discussed in Chap. 2, is the San Code of Research Ethics (TRUST 2017) by the South African San Institute (SASI) that is part of the TRUST Project. It was co-developed with the San Community, a vulnerable South African population. It calls for respect,[3] honesty, justice and fairness, care and process, in the course of conducting research within this community. Its content is drawn from the experience of unethical and undignified behaviour in their regard and can be generalised to a great extent. The World Health Organisation, which promotes global universality and solidarity in REC operations and functions, similarly recommends that researchers actively engage with communities in decision making about the design and conduct of the research, while being sensitive to respecting their cultural, traditional and religious practice (WHO 2011).

These two instruments can contribute greatly to adapting the universal ethical principles to a non-Western context. They can help, for example, to elaborate the communitarian and moral significance of the Belmont principles in the given setting. The section below consists of an overview of selected REC policies and guidelines, with a view to determining how their provisions foster respect for the dignity of research participants, understood as being inherent, inclusive of Social Science research, and further enhanced with African values like those indicated above.

14.4 An Overview of National Provisions for Research Ethics Review in Selected African Countries

"Research oversight capacity is critical for the protection of human research participants, as well as to prevent exploitation of African populations, communities, institutions, and countries. RECs, which are one part of the research oversight system, have an obligation to safeguard the welfare of research participants" (Ndebele, Mwaluko, Kruger, Oukem-Boyer and Zimba cited in Kruger et al. 2014). Since the first cases of ethical review of health research in Africa were documented,[4] an oversight system has evolved in various countries over the years. Individual countries have implemented laws, policies and guidelines on how RECs should be formed, registered and run.

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[3] Inter alia for community and culture.

[4] 1967 in South Africa.

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This section aims to review the national research ethics provisions of the seven African countries listed below (Table 14.1).

The material was sourced from the internet through Google search, by inserting the individual African country's name and keywords, for example "Kenya REC guidelines" or "Kenya's REC policies" or "national policies" or "guidelines".[5] The abovementioned countries and institutions yielded tangible results. The policies and guidelines are in part drawn from international codes such as the Declaration of Helsinki, the International Ethical Guidelines for Biomedical Research involving Human Subjects by CIOMS, Nuremberg Code, Belmont Report, International Conference on Humanisation of Good Clinical Practice (ICH GCP), as well as various individual national legislations and professional guidelines. All the policies and guidelines are in accordance with the WHO Standard and Operational Guidance for Ethics Review of Health-Related Research with Human Participants of 2011.

Almost all the national documents listed are intended for research governance of health research. Even the one by the Human Sciences Research Council of South Africa, despite being a Social Sciences research institute, makes no specific reference to unique Social Science research needs.

Across the board, the seven countries have moreover established various research legislative and ethical oversights to protect research participants' dignity. South Africa (SA), for instance, has prescribed legislative measures including obligatory reviews based on national guidelines (Kruger and Horn 2014) and policies. These policies and guidelines also stipulate that REC members be from various professional backgrounds. Some also require that an expert in both qualitative and quantitative research methodology be included. Missing in the directives on REC membership is the need for qualified persons in Social Sciences and ethics per se, to give specialised input in the review process. Such an omission may result in the violation of the dignity and rights of Social Science research participants. It is necessary to have members with the necessary qualifications to review all types of studies, or else to form RECs or sub-committees that focus on Social Science studies (Mamotte and Wassenaar 2009). Failure to do so may lead to overlooking the likely harms caused by social science research.

That notwithstanding, the SA National Policy (Department of Health 2015) stipulates that best practices, standards and expectations that may exist in the different disciplines be considered because the moral standards by which RECs judge the ethical acceptability of planned research do not differ simply because a different methodology is to be used. Even though researchers may refer to discipline (or paradigm-specific) norms and frameworks, adherence to national research ethics guidance is still required. Like in quantitative research,[6] RECs must consider competently, fairly and without prejudice any ethical tensions arising from the specific

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[5] For more information of other African countries that are not mentioned please see: https://www.hhs.gov/ohrp/international/compilation-human-research-standards/index.html

[6] Qualitative approach or research refers to "methodological approaches to qualitative research include research but are not limited to ethnography participatory action research, oral history, phenomenology, narrative inquiry, grounded theory and discourse analysis".

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Table 14.1 Overview of the national research ethics provisions of seven African countries

Country	Title of document	Responsible organisation/regulatory body
Ethiopia	National Health Research Review Guidelines, Fifth Edition of 2014	FDRE Ministry of Science and Technology
	National Health Research Ethics Review Guidelines. Fourth Edition. Chapter 9 of 2005	
	Drug Administration and Control Proclamation No. 176/1999. Article 21	Food, Medicine, and Health Administration and Control Authority
Kenya	National Ethical Review Committee: Guidelines and Standard Operating Procedure (SOPs) of 2004	Kenya Medical Research Institute (KEMRI)
	Guidelines for Ethical Conduct of Biomedical Research Involving Human Subjects in Kenya of 2004	National Council for Science and Technology (NCST)
	Science, Technology & Innovation Act of 2013 and Guidelines for Accreditation of Institutional Ethics Review Committees in Kenya	National Commission for Science, Technology & Innovation (NACOSTI)
	HIV and AIDS Prevention and Control Act, Chapter 14 of 2006	
	Pharmacy and Poisons Act	Pharmacy and Poisons Board
	Kenya National Guidelines for Research and Development of HIV/AIDS of 2005	
	Guidelines for Applications to Conduct Clinical Trials in Kenya of 2014	
	Kenya National Guidelines for Research and Development of HIV/AIDS Vaccine of 2005	Ministry of Health (MOH)
Nigeria	National Code of Health Research Ethics of 2007	National Health Research Ethics Committee of Nigeria
	National Health Act of 2014	
	Decree No. 15 of 1993	National Agency for Food, Drug Administration and Control (NAFDAC)
	Good Clinical Practice Guidelines of 2016	
	Frequently Asked Questions	National Health Research Ethics Committee of Nigeria
	Policy Statement on Storage of Human Samples in Biobanks and Biorepositories in Nigeria	

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Table 14.1 (continued)

Country	Title of document	Responsible organisation/regulatory body
South Africa	National Health Act No. 61 of 2003	Department of Health of the Republic of South Africa
	Protection of Personal Information (POPI) Act of 2013	
	Ethics in Health Research: Principle Process and Structure	National Health Research Ethics Council (NHREC)
	South African Good Clinical Practice Guidelines, Second Edition of 2006	
	SAMRC Standard Operation Procedures (SOP) of 2010	South African Medical Research Council (SAMRC) Ethics Committee
	General Ethical Guidelines for Health Researchers of 2008	Health Professional Council of South Africa
	Code of Research Ethics	Human Sciences Research Council (HSRC)
	Medicine and Related Substance Control Act, 101 of 1965	Department of Health (DoH) and Medicine Control Council
	General Regulations Made in Terms of Medicine and Related Substance Act, 1965 (2003)	
	Guidelines for Good Practice in the Conduct of Clinical Trials in Human Participants in South Africa of 2006	
	FAQs	South African National Clinical Trials Register
	Regulations Relating to the Use of Human Biological Material, 2 March 2012	Department of Health (DoH)
	Regulations Regarding General Control of Human Bodies, Tissues, Blood Products and Gametes, 2 March 2012	
	Regulations Relating to Blood and Blood Products, 2 March 2012	
	Regulations Relating to Artificial Insemination of Persons, 2 March 2012	
	Regulations Relating to Stem Cell Banks, 2 March 2012	Medical Research Council of South Africa (MRC)
	Guidelines on Ethics in Reproductive Biology and Genetic Research of 2002	
	Guidelines on Ethics in Reproductive Biology and Genetic Research	
Tanzania	Guidelines of Ethics For Health Research in Tanzania	National Health Research Ethics Committee of Tanzania
	National Institution for Medical Research Act of Parliament No 23 of 1979	Ministry of Health (MOH)

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Table 14.1 (continued)

Country	Title of document	Responsible organisation/regulatory body
	Tanzania Commission for Science and Technology No. 7 of 1986	National Institute for Medical Research (NIMR), National Health Research Ethics Committee
	Amendment of NIMR Act 1997, Tanzania Government Gazette, No. 675	Tanzania Commission for Science and Technology (COSTECH)
	Coordination of Health Research in Tanzania	Ministry of Health (MOH)
	Coordination of Formation of Institutional Health Research Committee to Formally Approve for Local Health Research	National Institute for Medical Research (NIMR), National Health Research Ethics Committee
	Coordination of Research in Tanzania	Tanzania Commission for Science and Technology (COSTECH)
	Brochure for Health Research in Tanzania of 2006	Ministry of Health (MOH)
	Guidelines on Ethics for Health Research in Tanzania of 2009	National Institute for Medical Research (NIMR), National Health Research Ethics Committee
	COSTECH Guidelines on Research Permits and Clearance of 2006	Tanzania Commission for Science and Technology (COSTECH)
	Tanzania Food, Drug, and Cosmetic Act of 2003	Tanzania Food and Drug Authority
	Medical Device Act of 1988	
Uganda	National Guidelines for Research involving Humans as Research Participants of 2014	Uganda National Council for Science and Technology
	Uganda National Council for Science and Technology Act (CAP 209)	
	National Drug Policy and Authority Act (CAP 206)	National Drug Authority
Zimbabwe	Guidelines for Research and Ethics Reviews of Committees in Zimbabwe of 2004	Medical Research Council of Zimbabwe
	Medical Research Government Notice Act of 1974	
	Research Act of 2001	Research Council of Zimbabwe
	Medicine and Allied Substances Control Act of 1997	Medicine Control Authority of Zimbabwe
	Statutory Instrument 150 of 1991	
	Guidelines for Good Clinical Practice of 2012	
	Pharmacy Guidelines for Investigational Drug of 2016	
	Medicine and Allied Substances Control (Condom) Regulations of 2005	
	National Biotechnology Authority Act of 2006	National Biotechnology Authority of Zimbabwe

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methodological and analytical approaches. Proposals should explain the intended process of the research, its predictability or lack thereof, and how foreseeable ethical issues will be managed. This information must appear in the information sheet given to potential participants. As this SA policy clearly provides, Social Science studies should be reviewed in a manner that does not violate participants' rights and dignity.

In addition, these National REC policies and guidelines have made provision for consulting with Community Research Members (CRM) to further safeguard and protect participants and communities' dignity. This is a further step towards ensuring that research is sensitive to communities' values and norms and is a noteworthy recognition of the communal nature of the African research participant. Researchers, funders and RECs should not overlook the fact that Africa is community-based; individual interests are important, but still inseparable from those of the community. All this is important for protecting human dignity.

The ethical principles found in the seven countries' policies and guidelines include: informed consent, beneficence and non-maleficence and justice.

It is stated that for *consent*[7] to be valid, it has to be given by an individual who is mentally competent, or whose consent can be validated, if mentally incompetent. Special provision is made for specific groups of people. Notably, South Africa further includes individuals for whom English is not their first language. Provision has also been made for both verbal and non-verbal consent, information to be given to research participants and the procedure to be followed by the full research team. Moreover, provision has been made for obtaining informed consent from communities especially in cases where research involves matters affecting them. However, there is less emphasis on community consent than on the individual one, which may be problematic in the African context, as illustrated in Chap. 3. Although it is understood that informed consent seeks to protect an individual's rights, respect for the community should be equally catered for in Africa's REC policies and still regarded as protective of the individual. Protection of dignity in the African sense implies, as argued by Visagie, Beyers and Wessels in Chap. 12, that *both* individual and community consent are valid and important.

Additionally, REC policies provide for the *protection of privacy and confidentiality*. This should be interpreted and implemented in a socio-culturally relevant way, reflecting the African context and norms. A "counter-example" is the way in which privacy and confidentiality were dealt with regarding HIV/AIDS, leading to increased stigmatisation of affected individuals. The approach was unsuitable for Africans because of the restrictive understanding of privacy and confidentiality emanating from the West. Privacy and confidentiality may therefore need to be interpreted to suit the context, thus resulting in an approach that is more appealing and more protective of human dignity in Africa.

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[7] *Informed consent* is aimed at ensuring that: an individual participating in the research is protected, they have freely chosen to participate, and, this decision is based on adequate understanding of what the research entails (WHO 2011).

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Beneficence and non-maleficence refer to the risk, harm and benefits associated with research. Individual RECs across Africa have made provision for identifying and addressing potential benefits, risk or harm. Ensuring that benefits and risk ratio is well calculated fosters a sense of responsibility in the researchers. However, these are taken to refer only to the individual research participant and not extended towards the respective community. Pain or harm suffered, or risk encountered, is not the concern solely of the individual research participant, but also of the communities they belong to; it is a *shared* pain or sickness. It is therefore important that RECs in Africa review beneficence and non-maleficence not only from the angle of the individual research participants, but also with a view to how the respective communities may be jointly affected, as is supported by Amugune and Omutoko in Chap. 4. This requirement should be incorporated into the national guidelines for RECs.

According to Kruger and Horn (2014), *justice* requires that participants in the research studies are not targeted based on their racial, social and/or economic disadvantages and that equity is maintained in the selection of the research participants. This definition is widely reflected in the individual REC policies and guidelines and the types of measures that need to be taken subsequently stipulated. The definition also signifies an indirect acknowledgment of the communal nature of the prospective research participants, apart from being a subtle affirmation of their inherent dignity. The definition of justice in the policies and guidelines could be further enriched with some of the African values mentioned earlier.

In conclusion, REC policies and guidelines in use in Africa need to address more Social Science research needs as most of them are intended for quantitative research. This should be extended to all REC policies and guidelines across Africa. Additionally, the existing ethical principles need to be elaborated to better incorporate the African worldview and so become more protective of the human dignity of research participants in Africa.

The final section comprises recommendations to address some of the existing gaps.

14.5 Recommendations and Conclusion

To be correctly called universal and therefore more protective of the human dignity and well-being of research participants in Africa, research ethics guidelines need to incorporate non-Western ethical frameworks and be more sensitive to non-Western sociocultural contexts. This responsibility, as well as compliance oversight, could be governed by the African Union. Some prominent sources in this regard are the Onuoha framework and the San Code, described in a previous section of this paper. One notable feature in both of them is the value of community and solidarity, owing to the widely held view about the mutual interconnectedness of the individual (in this case the research participant) and the community. Specification and elaboration of values and principles as done by the proponents of these ethical frameworks offers a more refined understanding of dignity that can be applied when research is

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conducted on the continent. Another useful source regarding research and communities is the New Brunswick Declaration (Gontcharov 2013), developed in Canada. Such a Declaration suggests that Africa, too, needs to continue developing and/or revising its laws, policies and research guidelines pertinent for governance of all research conducted on the continent. Some terms such as "individual informed consent" and "community consent or agreement" and "justice for harmony" can be utilised to make sure that the national guidelines, at the very least, are more reflective of the context. Definition of terms such as "privacy" and "confidentiality" should also be expanded to include the African understanding of those terms. The need to consult with the CRM is a commendable step, as is the need for community consent.

Finally, all research ethics policies and guidelines should make explicit provision for ethics review of Social Science research. This will help to address the Social Science research needs, thereby safeguarding better the dignity of the research participants.

The above measures will contribute to the much needed guarantee that Social Science research conducted in Africa is genuinely respectful of human dignity, understood in context.

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Chapter 15
The Vulnerability of Children and Prisoners in Social Science Research

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Abstract The understanding of vulnerability in this chapter is informed by Ten Have's approach to the concept. We consider how children and prisoners which are seen as vulnerable groups by researchers, have "double vulnerability" in common and explore the interrelated factors which impact their external and internal conditions of vulnerability. This is followed by a pragmatic consideration of the ethical aspects of doing research with these groups. We conclude the chapter highlighting the importance of including children and prisoners in research.

Keywords Vulnerability · Ethics · Autonomy · Children · Prisoners · Participation

15.1 Introduction

We commence this chapter acknowledging some issues that one has to be sensitive to when engaging with the theme of vulnerability.

First of all the terminology being used. We are going to use the terms *children* rather than *learners,* and *prisoners* rather than *offenders.* We consider that the concepts "learners" and "offenders" primarily refer to behaviour or functions, whilst

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the concepts "children" and "prisoners" are more closely linked to the vulnerability that is inherent to each group.[1]

For the purpose of this chapter children is defined as "every human being below the age of eighteen years" (United Nations 1989, Article 1).

With regard to prisoners, it may be more ideal to refer to *incarcerated people* in order to avoid the stigmatisation which is associated with the label of "prisoner". This chapter however continues to use the concept "prisoner". Hereby we acknowledge that most aspects of a person's reality is involved in an extremely negative context. Particularly in Africa, this is further exacerbated by overcrowding, huge numbers of people awaiting trial and the inherent way in which being locked up is in conflict with traditional African values (Van Zyl Smit and Dünkel 2001).

Secondly, whilst both children and prisoners are characterised by a number of vulnerabilities which warrants the way we have integrated their inclusion in this chapter – we assert that they are significantly different groups with unique individual needs. Although the concept of vulnerability pertain to both children and offenders, there are important differences due to the different context in which these groups find themselves in. Therefore, the chapter will also at times focus on the uniqueness of children and prisoners.

In the third place we want to sensitize the reader that the chapter's focus on the research participants' risks to harm, exploitation, deception or unfair treatment, may be at the expense of acknowledging children and prisoners' strengths.

Lastly we also need to highlight that referring to Africa as an entity does not do justice to the continent's complex and ever-changing society and the vast cultural variety which can be encompassed in individual countries. This chapter does not aim to display the diverse ways in which the vulnerability of children and prisoners in social research may present from one African context to another.

The core understanding of vulnerability in this chapter is informed by Ten Have's approach to the concept (Ten Have 2016). After clarifying the concept of vulnerability, we introduce the concept of "double vulnerability". We then explore important ethical issues, not unique to the social sciences, which should be taken into consideration when undertaking research involving children and offenders in a pragmatic manner. We conclude the chapter highlighting the importance of both Research Ethics Committees (REC) and researchers' need to be aware of and familiar with the vulnerability of children and prisoners, while at the same time acknowledging the value of including them in research. The social sciences are well placed to address vulnerability, and in particular can give children and prisoners a voice.

15.2 The Concept of Vulnerability

Our search for knowledge "in the name or science" is cluttered with projects that have done harm to fellow human beings, specifically (and regretfully also deliberately) in Africa. Research ethics aim to ensure that research promotes the well-being

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[1] Note that it is a policy requirement of the South African Department of Correctional Services that research applicants have to refer to prisoners as *offenders* and to prisons as *correctional centres*.

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and protection of participants (Roos et al. 2007). The concept of vulnerability specifically plays a pivotal role in research ethics thinking when children and prisoners are involved in research (Gostin et al. 2007; Ten Have 2016). There is, however, scholarly disagreement over the appropriate meaning and application of the concept of vulnerability in research ethics. Potter and Brotherton (2013) emphasise that there is no generally accepted definition of vulnerability. Similarly, Brown (2011, p. 314) is of the opinion that "the concept of vulnerable individuals or vulnerable social groups is often easier to talk about than to 'define' and it has been called a 'vague and nebulous concept', more often used than understood by practitioners".

Traditionally the concept of vulnerability has mostly referred to diminished individual autonomy, loss of control and lack of power and self-determination (Ten Have 2016). Ten Have challenges this view as inadequate to enable a deep understanding of vulnerability. He argues that the concept must be unpacked, differentiating its: (1) dimensions (i.e. individuals, family, group and categories of persons, communities and countries); (2) types (i.e. physical, psychological, social, cultural, political, economic, environmental exposure and adjustment resources); (3) conditions (i.e. internal and external); (4) perspectives (i.e. philosophical and political); (5) universal implications (i.e. theoretical and practical); and (6) its dynamic nature (i.e. relational and changeable). Such an understanding of vulnerability enhances the complexity of factors and their reciprocal interplay within the African context.

Ten Have (2016) utilises a general systems approach to argue for a functional definition of vulnerability. According to this viewpoint, vulnerability is socially produced by the interaction between an external condition (exposure) and two internal conditions (sensitivity and the ability to adapt). He emphasises that although "vulnerability manifests itself in individuals its sources are somewhere else" (Ten Have 2016, p. 32). Unequal social, political and economic circumstances render some groups not equal, neither in the possibility of being harmed nor the access to resources in order to "mitigate, reduce, and eliminate vulnerability" (Ten Have 2016, p. 142). Thus, Social Sciences research in Africa, need to consider the impact of the specific social, political and economic contexts on the children and prisoners they are working with. Ten Have (2016) raises the urgency to address these global causes of vulnerability, rather than just compensating for vulnerability as a symptom. This would challenge Social Science researchers in Africa to have a more determined focus to demonstrate *how* they are contributing to addressing and changing vulnerability.

Ten Have's (2016) focus on the global causes of vulnerability may seem in opposition to the viewpoint that vulnerability is an inherent condition of being human. He introduces the concept "anthropological vulnerability" to integrate these two perspectives. With anthropological vulnerability he provides a more positive understanding of the concept, the notion that vulnerability is a potential strength which can develop interdependence and sense of community – that which makes us human. "The experience that we are vulnerable to others is not merely negative, something that should be prevented, but it provides an opportunity for transformation" (Ten Have 2016, p. 16). Such an approach highlights the interdependence between individuals, communities, societies, countries, Africa and the world. This interdependence, forms the essence of African ethics (in Southern Africa, this is also known as

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"Ubuntu"[2]). Thus, due to the inherent lived experience of interconnectedness, Africa may be well able to play a crucial role contributing to the processes required to "transform" global issues. The Social Sciences in Africa, with its access to various disciplines and ability to integrate different fields of knowledge, is the best place to enable, explicate and reveal this process.

Children and prisoners are usually distinguished as groups "of special vulnerability" (Ten Have 2016) based on their diminished capacity or freedom to give autonomous consent to participate in research. According to Ten Have (2016) impaired autonomy only refers to the internal condition contributing to vulnerability.

With children, an implied internal condition would be their developmental position or decision-making capacity. It should be kept in mind that biological age may only indicate a rough estimation for a child's capabilities. Lansdown (2005) is of the opinion that biological age and neurological development of children are only an approximation of the capacity of the child. Expectations, the environment to which the child is exposed too, family background, culture and experiences contribute to the development of the competencies of children. Therefore, when conducting research where children are participants, it is important to acknowledge the role of lived-experiences and cultural background in the participants' competencies.

Whilst children's inherent vulnerability is mostly associated with an internal condition, prisoners' impaired autonomy mostly refers to the external condition of the potential effect of incarceration. It is however important to acknowledge the extent to which such an external condition may also be internalised. Being in a deprived environment which minimises autonomy to an extreme would restrict individuals to understand and believe that they have autonomy.

Researchers therefore need to be sensitive that levels of compensation and types of incentive that are considered minimal or average in free society can be unduly influential for prisoners (Hanson et al. 2015).

Understanding children's and prisoners' vulnerability would require that we consider the interaction of the internal conditions with external conditions, as well as the global contexts which exacerbate these conditions (social and economic conditions). Moore and Miller (1999) promote the concept of "double vulnerability" to point out that individuals belonging to these populations often have several interchanging elements which limit their autonomy.

15.3 The Double Vulnerability of Children and Prisoners in Africa

In the African context the double vulnerability of children and prisoners is exacerbated by the interplay of multiple factors. Amongst others issues such as conflict, climate change, migration, colonialism, industrialisation and HIV/AIDS impacts

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[2] Although "Ubuntu" is strictly speaking a term used by the Nguni-speaking people (e.g. Sotho-speaking people will refer to this concept as Botho) – academic literature tends to generalise this term to represent African ethics.

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the sense of community and social cohesion, family, and access to basic resources for nutrition, health, housing, education, employment, etc. Such factors are essential for healthy development and pro-social, self-reliant, independent functioning.

Studies have shown the importance of identifying factors that are likely to affect children's normal development stages. Several studies have highlighted the benefits that accrue from interventions that are introduced at the early stages of development. The need to maximise gains during the children's formative years has taken centre stage in global discussion (Agbenyega 2013).

Similarly, South African prison studies have demonstrated that people who are incarcerated are characterised by significant childhood needs that had not been adequately addressed (Agboola 2017; Tadi and Louw 2013) These studies have found a link between female childhood trauma and subsequent levels of reoffending. Tadi and Louw (2013) have also found that the age of first arrest has a significant impact on later recidivism rates. Clear links have been drawn between factors influencing development, juvenile delinquency and adult crime (Farrington et al. 2015; Sampson and Laub 2016; Shepherd 2010) as well as between crime and the inequality of power, economic resources, lack of social cohesion and ignoring the needs of the most vulnerable in society (Mabuza and Roelofse 2013; Muntingh and Gould 2010).

Thus, African children's and prisoners' double vulnerability are not only determined by the factors that limit their autonomy, but also by their global context which can severely restrict the options and resources for addressing vulnerability. The Social Sciences are well placed to acknowledge, describe, consider and research the complex relationships between such factors. Researchers should embrace this by approaching their respective fields being mindful of interventions that potentially reduce vulnerability.

Africa's growing youthful population is a reality which need to be prioritized by our Social Sciences. As a starting point researchers require an in-depth understanding not only of the specific target group's vulnerabilities, but also the variable nature thereof, as well as the double vulnerability that may be involved. The interrelated factors which may impact the external and internal conditions of vulnerability have been loosely grouped here into four broad categories: (1) contextual; (2) physical; (3) psychological; and (4) social. The list below is not meant to be exhaustive. The simultaneous presence of these factors in both external and internal conditions, however, made the idea of "double (or multiple) vulnerability" very useful.

The **contextual factors of "being a child" or "being imprisoned"** categorise children and prisoners as a special population group. These contexts inherently imply an increased dependency and diminished autonomy, which negatively affect their ability to provide consent to participate in research. It also involves all aspects of their well-being which would impact the way, the extent and how they might participate in research, as well as their experience of and their influence on the research. This highlights the intrinsic inequality and differential power relationship with the researcher. The African context where adults as well as people with formal education are held in higher regard exacerbates such inequality. Knowledgeable gatekeepers are therefore called upon to mediate the access and the nature of the interaction with these participants (Morrow 2008). It is thus necessary for Social

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Science researchers to demonstrate their capability to correctly and dutifully involve children and prisoners in the research. This can be done by reporting valid training or experience and explicating how a specific developmental age's characteristics and implications of incarceration have informed the research approach and study design. The researcher will need to plan how the influence of their authority status on participants' responses (usually causing a leaning towards providing socially correct answers) is limited and managed.

Children's and prisoners' **physical health and well-being** are at risk in the research process as their capacity to identify, communicate and address discomfort are diminished by internal and/or external conditions. Within a research context this may be as simple as the ability to receive sufficient time breaks and identifying an appropriate physical environment to work in. It may also involve the extent to which the participants are familiar with the environment and the emotions that are elicited by that environment. The participants' safety and well-being need to be ensured during as well as after the project. Potential negative effects that may occur at a later stage, which could be caused from having participated in the study, need to be considered and addressed before a study may commence (DOH 2015).

Various **psychological factors** impacts the vulnerability of children and prisoners in the research process which would specifically be relevant to researches in the Social Sciences.

- *Developmental level* – children's developmental capabilities, observations and frameworks of reference can be expected to differ according to factors including, but not limited to, their age (Morrow 2008). Therefore their level of decision-making capacity needs to be assessed when they participate in research (DOH 2015). This would also be relevant to research being done with prisoners in juvenile centres.
- *Neuropsychological factors* – neuropsychological issues affecting cognition are significantly prevalent among offenders and children.
- Research involving children who have specific needs often involve neuropsychological difficulties for which cognitive compensations would need to be considered (Pinheiro et al. 2016; Simpson 2014).
- As a group, prisoners have higher incidences of developmental difficulties (Schilling et al. 2011; Tadi and Louw 2013), acquired brain injury (Erasmus 2013) and learning difficulties (Fazel et al. 2008) compared to the general population.
- In African countries where the societies are exposed to factors such as violence, mal-nutrition and limited health services, these neuropsychological factors can be expected to be even more prevalent and should be considered and compensated for by Social Science researchers.
- *Cognitive ability* – Social sciences researchers need to be sensitised to remain alert to the developing executive functioning abilities in children as well as the reduced executive functioning often found in prisoners (Fishbein et al. 2009). This could in particular impact participants' initiation, disinhibition and organisation in responding to their needs within the research context.

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- *Language capacity* – can be viewed as both an internal and external condition influencing vulnerability. Speech, language and communication limitations can be inherent to both children and prisoners.
- Children's language are determined by their developmental level and in turn, prisoners have been found to have significant communication difficulties (RCSLT 2012). In addition, in Africa differences in language and comprehension between the researcher and participants often exists, not only because of socio-economic disparities, but also because of the numerous languages which may be spoken in any given district. Given the importance which language usually plays in Social Sciences research, care should be taken for the adequate identification of potential language issues from initially introducing the study to the participants, to securing their informed consent and assent and the material/questionnaires being used. Researchers should ensure that communication is appropriate according to the participants' developmental phases, cultural context and translation needs. Throughout the project, participants should be enabled to effectively express themselves in terms of their personal needs as well as the research activities.
- *Metal health and emotional well-being* – All researchers should consider the emotional well-being and mental health vulnerability of children and prisoners.
- Black et al. (2016) highlights that children's test-taking skills and response abilities may be affected by their exposure to the trauma of war, domestic violence and abuse.
- Similarly, incarceration does not only impact the psychological well-being of prisoners (Crewe 2011) but also tends to prevent the adequate detection and treatment of mental health problems (Naidoo and Mkize 2012).
- *Institutionalisation* – this factor is linked to both the internal and external conditions that increase vulnerability. The school and prison environments' respective structures tend to prompt and reinforce compliant, responsive and cooperative behaviour. This may affect children and prisoners' agency and ability to make choices and imagine alternative options. Thus, during the choice and development of study designs, the ethical considerations that are relevant to these physical contexts need to be clearly taken into consideration (Gostin et al. 2007). Additionally, the participants often have internalised the institutions so that it would prescribe their responses to others, particularly figures of authority; this is a role which can be expected to be automatically projected on the researcher. The researcher can therefore not be complacent with participants' apparent contentment to readily consent and participate in a research project. Researchers will need to demonstrate their understanding of the power relations and how they will ensure maximisation of the participants' access to agency. Researchers should familiarise themselves with the terminology, language and discourses used in a school or prisons. A good starting point would be to build rapport with the participants before moving on to the data-collection process.

The following **social factors** that could impact vulnerability should also be taken into account:

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- *Stigmatisation* is directly relevant to children with special needs and prisoners and care should be taken that the very act of research is not reinforcing stigmatisation and stereotyping (Kalima and Menon 2017).

- For example, HIV research with children demonstrated the ethical dilemma of disclosing the child's HIV status. Having a comparative group with similar biographic characteristics may stress the participants with HIV who may fear being found out and possibly stigmatised. Kalima and Menon (2017) overcame such a dilemma by sampling children at a school without showing any connection with the children whom had been seen at the clinic. They could not use the snow-ball sampling procedure lest the child was identified. The recruitment of the participants was perceived to be completely random by the children in the school.
- Children and prisoners should not only be viewed as *minority groups* in themselves, but research with them may very well also involve significant portions of known minority groups of the particular society. Social science researchers should aim to consider and actively address the impact that this "double minority status" might have on the participants' self-esteem, confidence and assertiveness in the research. They should actively demonstrate how the participants' unique contexts were considered, respected and included in the research approach and research process.
- The s*ocio-economic dependence* of the participants creates an immediate vulnerability. Ten Have (2016) points out that this dependence not only influences the capacity to choose, but also impacts "the actual choices that can be made" (2016, p. 8).
- Children may be willing to participate in a study simply because they want to benefit from the snacks or tokens that are given to participants during the research.
- Due to the sparse context of prisons, providing basic refreshments or equipment (pencils, paper) may act as an incentive giving people access to resources which can also be "sold".
- Researchers should take care not to exploit such deprivation in a direct, indirect, subtle or unintentional way, to coerce people to participate. The timing of when appreciation is shown may help to clearly differentiate between giving an incentive and showing appreciation.
- *Education levels and the extent of illiteracy* is a further vulnerability which should be considered for both groups.

- With regards to children, this is not only relevant to their age and cognitive abilities, but also their access to good education and the extent to which their socio-economic background may hamper current educational endeavours.

- Prisoners in turn, generally have lower education and literacy levels compared to the general population (Agboola 2017; Johnson 2015; Tadi and Louw 2013; Johnson and Gray 2010).

- These issues would impact how comfortable people may feel to engage in a context which they could associate with school (e.g. the classroom setup, the "paper

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> and pen" evaluations often used in Social Science research). It should be considered that the participants' ability to pay attention and concentrate would be enhanced through practical activities and the exchange of ideas rather than being passive recipients of instructions. This can be addressed by first building rapport with the participants in an interactive way that is not associated with a formal 'classroom setup'. Novice researchers can find advise by making contact with people already in the field or by directly contacting people working for the Department of Education or Correctional Services (social workers/clinical psychologists, teachers, correctional officials, and/or community supervisors), parents, ex-offenders and organisations working closely with schools and prisons.

The nature of children's and prisoners' double vulnerability often result in their exclusion from research – which is arguably to their detriment (Moore and Miller 1999). When involving children or prisoners in research the main responsibility of the researcher remains to not cause harm, but to ensure that the voices of these vulnerable groups are reported. We maintain that research with vulnerable groups are essential because of, rather than despite of their vulnerability. By avoiding research involving children and prisoners, we are avoiding our moral obligation to understand and protect those that are vulnerable in a fast-changing world where the levels of inequality between people are increasing.

15.4 Research Empowerment of Children and Prisoners

Whilst special safeguards to protect the welfare and rights of the vulnerable are required, we want to emphasise that research should also do *more* than just "taking vulnerability into account" and "not causing harm". Ten Have (2016) argues for working with the very vulnerabilities instead. This would be possible through research approaches which can address the social, cultural, economic and political antecedents of vulnerability from a "bottom-up" perspective and include interventions, advocacy, problem solving and participatory action.

When children are involved in research, it contributes to constructive new insights. Their viewpoints, experiences and participation may lead to improved interventions not only for children but also for adults (Zwi and Grove 2006).

The Inside-out Outside-in South Africa Corrections Interest Group, which focusses on studies in South African correctional services, would in principle firstly consult prisoners' views. An effort is made to ensure that needs analysis are informed and that the resources that exist in the communities in which the prisoners live are recognized and appreciated (Inside-out Outside-in South African Corrections Interest Group 2018).

Thus, a balance is required so that the concern about risk and harm should not prevent the empowerment of children and prisoners to have their views and opinions heard, including their voice about their unique vulnerabilities. It is therefore important that research proposals not only acknowledge ethical issues, but also clearly state *how* these are going to be addressed and managed.

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The **disempowered status**, respect, protection and development of participants' autonomy can be addressed by following a **participatory action approach** which is fundamentally empowering.

The Children's Act 38 of 2005, chapter 2 section 10 states the following about participation and the best interest of the child: "Every child that is of such an age, maturity and stage of development as to be able to participate in any matter concerning that child has the right to participate in an appropriate way and views expressed by the child must be given due consideration" (South Africa 2005). According to the *Oxford Dictionary* the word "participation" means to become involved in or to take part in an activity. In relation to a child, participation implies creating an opportunity for a child to think and respond on their own. According to Strode et al. (2010) South African legislators recognised that children have evolving capacity and passed laws that permit children to make certain decisions independently. Age alone should not be taken into consideration but also 'sufficient maturity.'

This process of introducing the research agenda "in consultation with" as opposed to "to" the relevant community becomes essential. It communicates that the distribution of power is even rather than hierarchical. Engagement, information sharing and collaborative learning (exchange of information, ideas and concepts between the researcher and the participant) can enable vulnerable participants to increasingly exercise their autonomy. This process can be assisted by identifying a Peer Review Committee, consisting of representatives from the vulnerable population, to independently review the material and research process critically to ensure optimal participant autonomy. Also, the individual's right to participate on any level and to withdraw at any time – with no negative consequences – need to be continuously highlighted using visual, verbal and kinetic modalities and regularly repeated and reconfirmed.

In Africa, among various indigenous cultures, **respect** is fundamentally important and tied into everything that is done or said, as such, it is an obligation and not a favour. This has a direct implication for how Social Sciences research needs to be done. A starting point would be to ask how the communities in which research is done will best benefit from the Social Science research. In this regard, prisoners who participate in research generally feel that they benefit not only from the knowledge they gain but also from their subsequent ability to share this information with others, including family members and peers who are incarcerated. Therefore, outcomes need to be of such a nature that the research results should be available to the community to be utilised to their benefit. Particularly with children and prisoners, care should be taken that such results are provided in an accessible manner, ensuring the appropriate communication of the findings (Denny et al. 2015). Findings need not only be accessible but also utilisable. Participatory action approaches in Social Sciences allow for the sharing of results as an ongoing process which enables a community to monitor their benefits. However, special care should be taken with the disclosure of personal information and the use of images of the participants should be checked (DOH 2015). In this regard participants' contribution to a study need to be properly acknowledged in all publications, but again in a way that ensures their dignity, respect and autonomy.

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Children's and prisoners' **restricted autonomy** can be managed by maximising individuals' opportunities to take meaningful decisions regarding a research project. This can be done by providing frequent choices in terms of voluntary involvement, level of involvement, flexibility in involvement, the nature of the content, the process itself and how they wish to receive feedback. Participants' choice to disengage need to at all times be based on a system where they are free to opt in rather than opt out.

Systemic complexity can be managed by utilising a collaborative approach. Given the contextual risks, as well as the ethics of collaborative responsibility, all aspects of a research project should include the active participation of the target group, family, carers, staff, professionals and administrators as much as possible (Gostin et al. 2007). This can be done through partnership, dialogue and reciprocal learning. It would be essential to have good knowledge and experience of the school or prison system as well as easy access to the various stakeholders before and while a research project is being developed. Special consideration should be given to the unbalanced power of authority in these systems and potential dysfunction and abuse which may occur in schools and prisons. Where such issues come to light, they need to be addressed responsibly by the researcher putting the interests of the most vulnerable first. Regular supervision meetings are required to ensure that the non-exploitative, participatory and empowering nature of a study does not become compromised. Debriefing sessions should be held for both participants and researchers alike.

Voluntary informed consent can be ensured by making it an interactive ongoing process which ensures voluntarily participation during all stages of the research (not just the filling in of a document by either the children participants' parents or the children who needs to give assent and the participating adults). In this regard, important ethical principles that underwrite research with human participants include that it must be voluntary and informed, in order for it to be valid consent. These aspects are regarded as the foundation upon which ethical research in Social Science rests. It is accepted that voluntary consent, where an individual choose among options, relates to the principle of autonomy. This voluntary consent needs to be free from coercion (i.e. threats) or enticements (i.e. incentives). Furthermore informed consent also holds that a person must receive relevant information in a manner which is understandable (i.e. language; level of verbiage) which will allow the individual to make a decision to either enrol or not into the study. Together with the aforementioned it is important to note that the individual, from whom consent is sought, also need to have decision-making capacity and be of a legal age (Edens et al. 2011).

The South African Department of Health's Guidelines on Ethics in Health Research states that "anyone under the age of 18 years may not choose independently whether to participate in research; a parent or guardian must give permission for the minor to choose and minors should participate in research only where their participation is indispensable to the research" (DOH 2015, p. 27–28). Thus, the parent or legal guardian should understand the scope of the study and give consent for the child's participation. Although children cannot give consent, various steps to gain assent from children can be advocated for. They can be made to understand the

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context of the study and give assent to participate in the research. This must be accompanied with the parent's or the legal guardian's consent.

Similarly research with prisoners need to demonstrate that their participation is indispensable to the research. Furthermore, concrete steps need to be taken to compensate for the institutional aspects which may influence their ability to give true voluntary informed consent. This may include having an extended period of informing and educating people about the research and their rights therein. The venue may need to be chosen in such a way that it does not occur in the space where they find themselves most of the time, but where they can be free to walk to on their own account, thereby enabling real 'opting-in'.

It is important to make children and prisoners aware of the independent decisions that they are able to take and that they may decide to stop taking part at any time from the research without negative consequences. This requires continuous reminders which are provided in different modalities, considering various learning styles. Consent forms can be jointly developed with participants, and could reflect a variety of choices. Pre-study group discussions can allow people to share their understanding of concepts and to highlight questions.

Anonymity, privacy and confidentiality should be insured. Issues about privacy, confidentiality and anonymity need to be clearly stipulated, explained, discussed, regularly reminded and adjusted to different age groups. Permission from the child and their legal guardian must be solicited to the extent that the information gathered is to be shared. Utmost caution must be exercised to ensure that the benefit of sharing this information does not exceed the anonymity, privacy and confidentiality of the participants. The participants need to decide how their voices – speaking for themselves – can be represented in the data (Parker 2005). Where participants want to recognise themselves in the data (Somekh 2006), they can be involved in the de-identification steps.

Particularly with vulnerable groups, **direct benefits** need to be maximised as far as possible and should ideally address vulnerabilities. Care should however be taken with the utilisation of rewards or incentives for participation and recruitment should pay particular attention to how coercion and undue influence will be avoided (DOH 2015). In this regard, potential benefits should not compromise participants' autonomy to provide consent, for example if related to academic performance or parole release. Both children and prisoners may sometimes offer to participate only because of the apparent benefits, without understanding the possible implications of their participation. Even when their participation is voluntary, the scope of the study must be clearly explained to the potential participants. The researchers should take it upon themselves to ensure that the full extent of the participation is understood and appreciated by the vulnerable groups.

Justice and fairness require more than ensuring that research does not cause harm. The researcher also needs to keep the potential harm of the participants' everyday multi-level vulnerability in mind at all times (Gostin et al. 2007). Research needs to be done in an environment that is humane, dignified and provides reasonable access to supportive care. Appropriate venues, adequate furniture, support and access need to be provided. Sufficient time need to be given to participants to reflect

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on the challenging and rewarding aspects of their role. Provision should be made for resources to address any discomfort or individual problems which may arise.

15.5 The Role of Research Ethics Committees

Research ethics committees (RECs) play a pivotal role in ensuring that the principles of protecting vulnerable participants and preventing harm are always at the centre of the ethical review process. They guard against exploitation by ensuring that the research cannot be conducted with non-vulnerable groups, and that children and prisoners' participation is crucial to the research (DOH 2015). The participants' benefit should be at the centre of the decisions on whether or not the study should be sanctioned. The role of the REC also has to go further to ensure than the quality of research activities do justice to the participants. Children and prisoners need to be given a voice regarding their views and opinions in matters that has implications for their lives, their experiences and expectations (Boddy et al. 2010) and the members of RECs require in-depth training to understand ethical ways of doing this. We suggest for RECs to provide guidance on the protection of the vulnerable groups and at the same time provide guidance and mentorship on how best the studies could be improved to make the lives of participants better. They can thus play a special role in empowering researchers to be sensitive in not only communicating their awareness of the multiple vulnerabilities involved, but also in explicating the strategies to address these. Given the unbalanced power relationships involved within these groups, RECs need to assure that they are indeed protecting participants and not the organisations in which they function (see Chap. 6). In some instances, the REC may choose to waiver the strict adherence to consent in situations where some of the players in the lives of the vulnerable groups may be themselves perpetrators of the topic under investigation (e.g. such as abuse by a family member, teachers or prison officials). It is therefore of the utmost importance that representatives from vulnerable groups should be included in the REC decision-making process.

15.6 Conclusion

Social Science researchers need to be familiar with their respective professional guidelines concerning research with children and prisoners (e.g. in South Africa the Human Sciences Research Council's Code or Research Ethics (HSRC 2006)). They also need to ensure compliance with the legal requirements relating to working with children and prisoners according to the specific jurisdictions (DOH 2015). They particularly need to understand how their double vulnerability could impact the realisation of the ethical issues, and focus on equipping themselves to address such vulnerabilities. The human rights of children and prisoners should be respected and addressed directly from the onset of considering a theme and developing a research

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design, throughout the research process and thereafter to ensure sound scientific and ethical results which are relevant, reliable and authentic. Both RECs and researchers ought to approach research ethics with children and prisoners with more awareness of their interests, their rights, abilities and strengths as individuals and groups.

Laws and Mann (2004) is of the opinion that to involve children directly as participants in research procedures may relate to more valid data about aspects that affect the children than to rely primarily on the data of the adults. Similarly the active engagement of prisoners can inform interventions for meaningful rehabilitation (Muntingh 2009).

More Social Sciences research with vulnerable groups are needed to acquire knowledge about their unique positions and characteristics in Africa. In the light of Ten Have's reference to vulnerability as a strength, the voices of children and prisoners in Africa need to be heard, not only about their different lived experiences, but also their voice about their own vulnerability in research and how this can be addressed.

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Chapter 16
Ethics Review Framework and Guidelines for Social Science Research

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Abstract This last chapter provides an outline of the most important social research ethics principles and values that should be considered by social science researchers and research ethics committees (RECs) who review social science research projects. The principle framework of the United Nations Educational, Scientific and Cultural Organisation (UNESCO) Universal Declaration on Bioethics and Human Rights (2005) is primarily used to organise the relevant ethics principles and considerations. The following ten principles are considered: (1) Respect for human dignity; (2) Beneficence and non-maleficence; (3) Autonomy and informed consent; (4) Vulnerability; (5) Privacy, anonymity and confidentiality; (6) Equality, justice and equity; (7) Non-discrimination and non-stigmatisation; (8) Respect for cultural diversity and pluralism; (9) Social responsibility and integrity; and (10) Benefit sharing. Lastly, the most important and relevant ethics review questions for each of the principles and values that should be posed by social science RECs during ethics reviews and deliberations are indicated.

Keywords Research ethics committees · Universal Declaration on Bioethics and Human Rights · Researchers

16.1 Introduction

In recent times, research regulatory bodies, research ethics committees (RECs) and research institutions gradually came to realise that research ethics principles are not, and should not, be exclusively applicable to medical and health research, but to all fields of research, including social science research (see Chap. 1). However, social

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science researchers are currently often frustrated and/or confused by the ethics review outcomes of human RECs (Wassenaar and Slack 2016). One of the primary reasons for this is that many REC members have predominantly been trained in the positivistic research paradigm which focuses on deductive, hypothesis-testing, quantitative research. These REC members then tend to review social science research projects from a paradigm which is epistemologically not applicable and inappropriate for social science research projects instead of reviewing it in alignment with an inductive, social constructivist paradigm (Murphy and Dingwall 2007; Van den Hoonaard and Tolich 2014). A second reason is that many of the widely-used international ethics codes are used by human RECs as ethics review reference documents without always realising that these codes have been formulated with a primary focus on strictly-controlled (experimental) health research and/or clinical trial studies, as supported by the arguments of Segalo and Molobela in Chap. 3, as well as Wathuta and Mnisi in Chap. 14. As a result, social science research projects that utilise open-ended and/or unstructured contextual research instruments and researcher-participant interactions are then often deemed by these RECs as vague, non-specific and/or subjective (Miller and Boulton 2007; Van den Hoonaard and Tolich 2014).

Over the last 30 years or so research ethics codes and principles that specifically focus on social science research have been developed to inform the ethical conduct of social science researchers and RECs who review social science research proposals (HSRC 2006). In some cases social science principles, for example respect for cultural diversity and community engagement, have been added to existing ethics codes (CIOMS 2016), while in other cases new codes, declarations and/or guidelines have been specifically developed for social science research, for example the New Brunswick Declaration of Research Ethics (Van den Hoonaard and Tolich 2014), the Brussels Declaration on Ethics and Principles for Science and Society Policy-Making (AAAS 2017) and the San Code of Research Ethics (South African San Institute 2017).

The focus of this chapter is to provide an outline of the most important social research ethics principles and values to be considered by social science researchers and RECs who review social science research proposals. Due to the fact that many of the chapters in this book are specifically devoted to the discussion of the respective ethics principles and values, we merely highlight the most important aspects of each relevant principle and value in this chapter, while providing a cross-reference to the relevant focus chapter where applicable. In addition, we indicate the most important and relevant ethics review questions for each of the principles and values that should be posed by social science RECs during ethics reviews and deliberations. The principle framework of the Universal Declaration on Bioethics and Human Rights (UDBHR) (UNESCO 2005) is primarily used in this chapter to organise the relevant ethics principles and considerations. The UDBHR framework was

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selected for two reasons: (1) it provides a universal and global ethics framework of human rights principles that guide the international research community; and (2) it takes into account and respects local cultures, traditions and schools of thought (Ten Have 2016).

16.2 Principle Framework

16.2.1 Respect for Human Dignity

A respect for human dignity should pervade and be at the core of all social science research activities; dignity should be regarded as the minimum threshold of respect in social science research (see UDBHR Article 2, UNESCO 2005), which is in agreement with the work of Wathuta and Mnisi in Chap. 14. Human dignity refers to the equal, inherent, inalienable "human worth" and moral status of research participants regardless of any personal or socio-cultural characteristics, including age, sex, mental health status, social status or ethnic origin (Rivière 2011; Van den Hoonaard and Tolich 2014). Article 3 of the UDBHR further states that the interests and welfare (dignity) of research participants should have priority over the sole interest of science or society, which essentially means that research participants should not be reduced to instruments (objects or subjects) of research since research is not an end in itself but a means to serve individuals and society (UNESCO 2005). See Chap. 14 by Wathuta and Mnisi in this book for an in-depth discussion of the protection of human dignity in social science research in Africa.

Social researchers demonstrate a respect for human dignity when they recognise and appreciate the individuality, personal integrity, values, knowledge, experiences and contextual situatedness of research participants (South African San Institute 2017). It also includes an appreciation and awareness of the potential consequences of research activities and outcomes for research participants, groups and communities during all parts of the research process (Wynn et al. 2008). Specifically in community-based research it is important for social science researchers to demonstrate respect through an awareness of and practical strategies to allow the relevant community stakeholders opportunities to interrogate and co-plan research endeavours before, during and after the research project (South African San Institute 2017). This includes plans and arrangements to duly recognise the community's contribution to the research study.

Below is a list of relevant ethics review questions regarding the principle of respect for human dignity for ethics reviewers (South African San Institute 2017).

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Ethics Review Questions

1. Which promises do the researchers make to the research participants, groups and/or communities at the onset of the study? Are these promises realistic? Do the researchers indicate clear plans and procedures (including availability of funds) to ensure the feasibility and implementation of the promises?
2. In which way will data, including audio-visual data, be collected from research participants, groups and/or communities to ensure that it is sensitive of social customs and norms?
3. In which way will timely, relevant and honest feedback of the research findings be provided in an appropriate and understandable way to the research participants, groups and/or communities?
4. Is the research process free of bribes or inappropriate incentives to gain community access?

Two important moral obligations are closely linked with a respect for human dignity, namely the duty to avoid harm (non-maleficence) and the duty to do good (beneficence).

16.2.2 Beneficence and Non-maleficence

The principle of beneficence holds that direct and indirect benefits to research participants, groups and communities should be maximised while the principle of non-maleficence holds that any possible risk and harm to research participants and their communities should be minimised (see UDBHR Article 4, UNESCO 2005). Furthermore, the overall identifiable risks, harms, discomfort and inconveniences associated with research must be outweighed by the potential benefits of the research (Wassenaar and Slack 2016). The primary responsibility to maximise benefits and minimise risks and harms lie with the researcher; clear considerations and strategies to realise it already needs to be indicated in the research proposal (Wynn et al. 2008). However, the nature of social science research often makes the identification of potential risks and harms difficult due to its inherent unpredictability (Murphy and Dingwall 2007).

The considerations of benefits, harms and risks in social science research is often different in nature and degree from the benefits, harms and risks encountered in medical and health research studies. Rather than primarily involving potential biophysical harm, social science research often poses psychological harm (e.g. emotional distress), moral harm (e.g. deception), social harm (e.g. stigmatisation), legal harm (e.g. disclosure of self-incriminatory information) or economic harm (e.g. loss of income). These potential harms and risks may occur at any point during the

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research process. The challenge for social science researchers is to anticipate, identify and minimise the potential risks and harms, as well as to implement strategies that can mitigate the impact of the harm when it occurs, for example by terminating the specific research activity and/or offering appropriate support services (Murphy and Dingwall 2007; Ten Have 2016). Ultimately, the only moral sanction for the exposure of any research participant, group or community to potential risks and harms is a favourable benefit-harm ratio. In this regard the Nuremberg Code (1947) already established that research participation and/or the research study must be suspended or terminated in all cases where a favourable benefit-harm ratio cease to exist or where the research outcomes are clearly harmful to participants/communities. See Chap. 6 by Wessels and Visagie in this book for an in-depth discussion of a risk framework for social science research in Africa.

Below is a list of relevant ethics review questions regarding the principles of beneficence and non-maleficence for ethics reviewers.

Ethics Review Questions

1. Which potential direct benefits (e.g. knowledge, information, interventions, new policies) are indicated for the research participants, groups and/or communities? Are these benefits realistic, appropriate and meeting the direct needs of the research participants, groups and communities?
2. Which indirect benefits (e.g. free assessment of mental health, a sense of altruism in being a participant) are indicated for the research participants, groups and/or communities? Are these benefits realistic and appropriate?
3. Which societal benefits (e.g. new knowledge, benefit to future similar persons and groups) are indicated for the relevant society? Are these benefits realistic and addressing societal needs?
4. Which incentives, if any, are offered to the research participants, groups and/or communities to participate in the research project? If any, are the nature and/or extent of the incentives potentially undermining personal and/or collective autonomy? Can the incentives potentially persuade individuals, groups and/or communities to accept potential serious risks and harms in being excessive, inappropriate and/or improper?
5. Which potential harms/risks are indicated for the research participants, groups and/or communities? What are the realistic magnitude and likelihood of each potential harm and risk (Murphy and Dingwall 2007)?
6. Which procedures, strategies, arrangements and/or resources have been indicated by the researcher to appropriately and timely mitigate the impact of harms when it occurs during the study, including strategies to deal with unforeseen harms and risks?
7. Are the potential risks and harms to research participants, groups and/or communities reasonable and in relation to the anticipated benefits that will be gained from the research?

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16.2.3 Autonomy and Informed Consent

The principle of autonomy (self-determination) is one of the cornerstones of modern-day research ethics. It holds that individuals, and in some cases groups that value collective autonomy, can and should in general make voluntary (free of any coercion) and informed decisions, as well as take responsibility for decisions regarding their participation in research projects. It includes freedom to refuse participation in any part of the research project, as well as freedom to withdraw their participation at any stage without any negative consequences whatsoever (HSRC 2006; Murphy and Dingwall 2007; Wynn et al. 2008; Rivière 2011). Since the formulation of the Nuremberg Code (1947) autonomy has been closely linked to the widely-accepted principle of informed consent (UNESCO 2005), which in turn is based on the principle of respect for human dignity (Miller and Boulton 2007).

The concept of research participant *informed* consent requires transparency from the researcher with regards to the research aims, research activities, possible short-term and long-term outcomes, potential risks and harms and potential benefits (HSRC 2006). In short, it should include all the research-related information that might reasonably be expected by the prospective participants, groups and/or communities to exercise his/her/their autonomy with regards to research participation (HSRC 2006). However, it is not always easy to determine what should be regarded as adequate information, especially since research projects often focus on and use technical jargon and theoretical concepts that may be difficult for potential participants to fully comprehend. In addition, social science research projects often involve research designs that emerge during the research process rather than being fixed at the planning stage. The implication is that the researcher cannot provide full information about the research design and process at the start of the project. Notwithstanding this limitation, the provided information must be truthful and without any form of deception (Murphy and Dingwall 2007).

In social science research it is also important to keep in mind that individuals' and groups' ability and understanding of autonomy and consent are influenced and shaped by cultural and societal norms, values and practices, including their use of a first language that might be different than that of the researcher (Miller and Boulton 2007). In addition, social science researchers should be particularly aware of and sensitive to conditions and characteristics that render specific individuals, groups and communities (e.g. children, elderly individuals, illiterate persons) vulnerable to making truly autonomous and informed decisions about research participation. In the case of legal minors participating in research the following principles should be kept in mind (HSRC 2006):

- research that does not exclusively require the participation of legal minors should rather be done with adults;
- legal consent should be obtained from a parent, guardian or custodian together with child assent; and

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- the legal minor has the freedom to withdraw or to be withdrawn from the research at any stage without any negative consequence.

An important implication and characteristic of social science research is that informed consent is in most cases not a once-off event or action, but rather a trust-based process and relationship between the researcher and the research participants, groups and communities; consent must be negotiated and renegotiated over time as the research continues and develops (Murphy and Dingwall 2007). It also means that social science researchers must be aware that informed consent is not merely a signature-on-a-piece-of-paper action, but a deep appreciation of the participants' contextual circumstances, including the use of culturally-appropriate consent procedures (Rivière 2011; Wynn et al. 2008). In some cases oral consent may be more appropriate and/or acceptable than written consent (Miller and Boulton 2007). See Chap. 12 by Visagie, Beyers and Wessels in this book for an in-depth discussion of informed consent and individual/collective autonomy for social science research in Africa.

The contextual nature of social science research often requires the collection of observational data in public settings. Generally in these settings, consent to collect data is not required as it is accepted that public behaviour and expressions are freely and legitimately available for scrutiny and study by researchers (Murphy and Dingwall 2007; Van Niekerk 2014). However, research integrity (see Sect. 16.2.9 in this chapter) still requires that researchers treat such individuals, groups and their behaviour with respect and ethical sensitivity (Murphy and Dingwall 2007). Also, see Chap. 9 by Nortjé and Hoffmann in this book for an in-depth discussion of research integrity for social science research in Africa.

In social science research consent is not an absolute requirement. Where the interests of science require it, covert research and deception can be implemented (Miller and Boulton 2007). However, both approaches violate the principles of respect for autonomy, informed consent and privacy. Covert research is only permissible in cases where informed consent cannot be obtained; the reason being that the nature and focus of the research requires that the research participants remain unaware of the research process. In such cases it is essential that the potential societal benefits of the research significantly outweigh the potential risks and harms to the unsuspecting participants (Van Niekerk 2014). It is also important to note that covert researchers might underestimate the harm caused to the participants, especially when they become aware of the study (Murphy and Dingwall 2007). Deception involves more than withholding information from participants; they are deliberately misled about the researcher's identity and/or actual research focus (Murphy and Dingwall 2007; Van Niekerk 2014).

Below is a list of relevant ethics review questions regarding the principles of autonomy and informed consent for ethics reviewers.

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Ethics Review Questions

1. Has the following information regarding the research project been provided to the relevant potential research participants, groups and communities: Background to the study; purpose of the study; expected duration; study procedures; potential risks, harms and discomforts; circumstances under which participants' participation may be terminated by the researcher; expected benefits; the measures to ensure confidential handling and storage of the participants' data; the measures to ensure participants' anonymity and/or the de-identification of identifiable information; contact information to report researcher misconduct and the researcher's conflict of interest declaration?
2. In which ways will the research information be communicated to the relevant potential research participants, groups and communities? Are these approaches appropriate in the specific research context?
3. To what extent is the information provided to the participants adequate and truthful (i.e. without deception) in order to allow autonomous decision making by the potential participants, groups and/or communities?
4. Which strategies will the researcher implement to assess the potential participants' comprehension of the research information? To what extent is the research information presented (i.e. method and language) to ensure optimal comprehension of the research information by the relevant potential participants?
5. How will consent be obtained to ensure voluntary participation (i.e. free from any situation-specific experience of overt/subtle coercion or undue influence from external persons or conditions, including the use of excessive, inappropriate and/or improper rewards, incentives or promises to obtain participants' consent)?
6. Are the participants aware that they are free to withdraw/refuse consent without any disadvantage or negative consequence whatsoever? What practical strategies will the researcher implement in the project to ensure that participants can withdraw their consent at any time without fear, shame or undue to pressure (e.g. threat) to remain in the study?
7. Which culturally appropriate consent method/s (e.g. written, oral and/or collective consent) will be implemented in the project? Are the participants given enough time to duly consider the research information prior to be required to provide consent?
8. To what extent is the use of covert research methods and/or deception justified by the project's prospective scientific, educational or applied value? Which alternative research methods and procedures that do not require the use of covert research and/or deception have been considered? How and when will the participants be informed about the reasons for using covert methods and/or deception to collect data (HSRC 2006)?

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16.2.4 Vulnerability

Social science research projects often involve vulnerable persons, groups and communities as research participants. Vulnerability refers inter alia to individuals and groups who experience a restriction (un-freedom) rather than an inability or incapacity to exercise full autonomy. For example, in contexts characterised by power/hierarchical imbalances (i.e. student-lecturer, employee-employer, adult-child and junior-senior ranks in the armed forces) and cultural contexts (i.e. members of traditional groups ruled by leaders with inherited authority, and the inferior position of women in male-dominated communities). However, vulnerability can also refer to the susceptibility to be exploited or unjustly treated due to the social conditions (i.e. illiteracy and marginalisation), political conditions (i.e. minorities and refugees) and economic conditions (i.e. poverty and unemployment) that individuals, groups and communities find themselves in (Ten Have 2016). See Chap. 15 for an in-depth discussion of child and prisoner vulnerability in social science research in Africa.

Social science researchers should exercise an ethics of care and sensitivity when engaging with vulnerable persons, groups and communities in three ways. Firstly, awareness that vulnerable others are prone to diverse and subtle forms of harm and exploitation in the research process. Secondly, social researchers should themselves be vigilant not to exploit potential research participants' vulnerability for their own research interests. Lastly, social science researchers should actively engage in research-related empowerment attitudes and activities to reduce or, where possible, even remove the restrictions and conditions that render participants vulnerable (Wynn et al. 2008).

Below is a list of relevant ethics review questions regarding the principle of vulnerability for ethics reviewers.

Ethics Review Questions

1. Which of the potential research participants (individuals, groups and/or communities) may experience restrictions (un-freedom) in their ability to exercise full autonomy?
2. Which of the potential research participants (individuals, groups and/or communities) are susceptible to be exploited or unjustly treated due to the social conditions, political conditions and/or economic conditions that they find themselves in?
3. Can the same research project be done with participants who are not part of a vulnerable population? If not, which strategies and additional safeguards will be implemented in the project to appropriately protect and/or empower the vulnerable participants?

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16.2.5 *Privacy, Anonymity and Confidentiality*

Privacy refers to personal freedom from intrusion from others and to maintain control access to your sensitive and intimate personal information, opinions and behaviour (Osuji 2015). Social science researchers should only obtain access to private information through proper consent procedures, including formal gatekeeper permissions in cases where the private information is kept and controlled by institutions or duly authorised professional persons, which then places an obligation on researchers to treat the information with respect (HSRC 2006; Singh and Wassenaar 2016). Anonymity refers to the context in research where the research participant's identity is either never made known to the researcher or where the known identity of the research participant, group and/or community is removed or masked by the researcher in any research outputs or documents accessible to others. Confidentiality refers to the fiduciary obligation of those who possess legitimate or privileged access to private and sensitive information to duly protect it from unauthorised disclosure, access or use; this obligation is not only applicable to social science researchers per se but it also extends to other persons who have access to the research information, for example research assistants, fieldworkers, transcribers, translators and independent coders (Osuji 2015).

In principle, research participants can autonomously decide whether to be identified or to remain anonymous in any research outputs. Exceptions to this principle can occur in research outputs which report on group-based research approaches, for example focus group interviews and community-based research, where the identity of group/community members may be known to one or more of the other group/community members. Such group/community members may then still be identifiable in the research outputs despite their autonomous choice to remain anonymous. In social science research the default position is generally to not identify participants and groups, as well as not to provide identifying information (e.g. individual biographical detail) in the research outputs unless compelling reasons exist, and then only with the explicit permission of the research participants and groups, and with due consideration of the potential negative consequences (HSRC 2006). In some cases it might not be enough to merely anonymise research participants through the use of pseudonyms. For example, in the case of small and/or unique participant groups, or for reputational (personal dignity) or security reasons, it might actually be required to intentionally mask/change any identifying information details (HSRC 2006; Wynn et al. 2008).

The confidentiality of social science research records (field notes, written research data, audio-visual data, transcriptions, etc.) can be maintained by storing it in an access-secured physical location (e.g. cabinet or office) or digital location (e.g. external hard disk drive or secure online site). Researchers who conduct sensitive and/or potentially self-incriminatory research must keep in mind that their research records are not legally protected information but can be subpoenaed by a court of law, which in turn can result in dire legal consequences for the research participants, as well as their communities and other affected or implicated persons (Murphy and Dingwall 2007). In such cases, it is advisable that all research data containing iden-

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tifying information be anonymised and de-identified as soon as possible and that the original data records be replaced by the anonymised and de-identified records (Wynn et al. 2008).

Generally, confidentiality must be respected "… to the greatest extent possible …" (UDBHR Article 9, UNESCO 2005). However, this does not mean that confidentiality is equal to an absolute right to secrecy; confidentiality can be breached when a situation poses a serious or imminent danger to others or when disclosure is mandated/ordered by law (e.g. in the case of imminent and serious threats to public health or evidence of child abuse). Social science researchers should also be aware of country-specific regulations regarding confidentiality and legally required disclosure of confidential information. Mandatory reporting regulations might significantly differ between countries. Research participants should at all times be made aware of the privacy and confidentiality regulations and the project's strategies to duly protect privacy and anonymity, and to maintain research data confidentiality.

Below is a list of relevant ethics review questions regarding the principles of privacy, anonymity and confidentiality for ethics reviewers.

Ethics Review Questions

1. Which strategies and practical provisions are indicated in the project to adequately protect the privacy and anonymity of the research participants, groups, communities, institutions and/or research locations?
2. Are the participants offered the option to remain anonymous and de-identified in all the research outputs?
3. Which data management strategies and practical provisions are indicated in the project to maintain the confidentiality of the research data, including the duration of confidential storage and the strategies to discard/destroy the research data at the end of the storage period?
4. Which limitations to confidentiality are being disclosed and which relevant strategies are indicated to duly mitigate the potential risks and harms emanating from these limitations?
5. Does the proposed project involve the collecting of potentially sensitive and/or self-incriminatory information that can result in serious harm or legal repercussions to the participants if disclosed in any way, including through court orders? If YES, which strategies and practical provisions are indicated by the researcher to protect the private information of the participants to the greatest extent possible?

16.2.6 Equality, Justice and Equity

Equality refers to the equal regard and treatment of all persons in terms of dignity, rights, freedoms, benefits and responsibilities, while at the same time fully acknowledging and respecting the diversity (e.g. physical, mental, psychological, genetic

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and value differences) between individuals, groups and communities (Culyer 2015). In principle, "the fundamental equality of all human beings in dignity" must be duly respected to ensure that they are treated justly and equitably (see UDBHR Article 10, UNESCO 2005). The implication is that all social science researchers must fully recognise and acknowledge the equal dignity, inclusive of diversity, of all research participants, groups and communities (Wynn et al. 2008). Failure to do so can result in unfair discrimination and stigmatisation of specific individuals and groups, as well as disrespect for cultural diversity (see the Sect. 16.2.8 in this chapter).

Equity refers to the willingness to duly recognise each person's rights equally while treating them in appropriate unlike fashion based on their differences; for example by allocating more research resources and efforts to groups and communities who have been previously ignored or under researched, or who might significantly benefit from research endeavours focusing on specific problems and/or needs (Culyer 2015; Ten Have 2016). Inequality increases when individuals and groups who are different in appropriately and relevant respects are dealt with in like fashion (Culyer 2015; Ten Have 2016).

In general, justice refers to the ethical obligation to treat each person, group or community in accordance with what is morally right and proper. It includes a focus to find a balance between individual autonomy and the common good (Renaud and Águas 2015). Justice is not done when we treat all persons, groups and communities in an equivalent way, but by dealing with diverse persons, groups and communities in an appropriately differentiated ways (equity) to ultimately achieve equal dignity (equality) (Ten Have 2016). See Chap. 13 by Hendricks and Donnir for an in-depth discussion of equity, equality and justice in biosocial science research in Africa.

Below is a list of relevant ethics review questions regarding the principles of equality, justice and equity for ethics reviewers.

Ethics Review Questions

1. To what extent does the project focus and objectives inform the formulation of appropriate participant inclusion and exclusion selection criteria that avoid the exclusion or inclusion of participants, groups and communities on the basis of attributes unrelated to the research project? This is especially important when exclusion criteria are specifically based on attributes such as age, gender, ethnicity, language, culture, nationality and/or geographical location?
2. To what extent does the project use fair sampling strategies that (1) avoid unfair/unjustified targeting and inclusion of specific groups, or (2) avoid unfair/unjustified exclusion of specific groups?
3. To what extent does the project fairly (equitably) and equally distribute potential research risks, harms and benefits across the potential research population in order to avoid unfair exploitation (especially vulnerable

(continued)

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groups) or the accrual of unfair benefits to the target participants, groups and/or communities? It is especially important that vulnerable groups should not be recruited when most or all of the benefits will accrue to privileged (non-vulnerable) persons, groups or communities.

4. To what extent does the project outline how participants, groups and communities will be justly and fairly recompensed for research-specific sacrifices and commitments (e.g. time, transport costs and meals) required of them during the research process (HSRC 2006)?

16.2.7 Non-discrimination and Non-stigmatisation

Discrimination refers to attitudes and actions that aim to unfairly separate, exclude, marginalise, segregate and treat others differently or inferiorly. It is based on unjust personal and social categories and characteristics, as well as on the intolerance of differences. The result is often avoidable negative comparisons (*us* vs *them*), social isolation/disadvantage, dominance (i.e. to maintain inequalities), exclusion and devaluation. In short, discrimination is in essence to deny and/or remove others' dignity (Garrafa 2015). Non-discrimination then is to recognise and respect that persons, groups and communities are at the same time equal in human rights and uniquely different (see UDBHR Article 11, UNESCO 2005).

Stigmatisation refers to a discrediting process that shames a person, group or community as abnormal and inferior based on a perceived undesirable difference or trait. This in turn justifies, at least in the mind of the one who stigmatise others, any subsequent infringement of their dignity and fundamental rights to equality (Chen and Courtwright 2015). Non-stigmatisation means to duly recognise and respect the integrity, dignity and equality of all persons, groups and communities regardless of any differences (see UDBHR Article 11, UNESCO 2005).

Social science researchers must be especially mindful of potential discriminatory and stigmatising attitudes and actions when conducting research on sensitive and private topics. It is important to use fair and justified sampling criteria (inclusion and exclusion criteria) and data collection strategies in these projects that doesn't perpetuate current discriminatory and/or stigmatising personal or social categories and assumptions. Researchers should also be vigilant to not create or establish new discriminatory and/or stigmatising categories or to publish so-called "facts/evidence" that support supposedly justified negative attitudes, behaviour and ideas.

Below is a list of relevant ethics review questions regarding the principles of non-discrimination and non-stigmatisation for ethics reviewers.

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Ethics Review Questions

1. To what extent is the project's selection of participants, groups or communities based on fair and justifiable inclusion and exclusion criteria that do not expose them to unfair discrimination and/or stigmatisation?
2. To what extent does the project justify the research-specific need to collect each biographical variable from the target participants, groups and communities? Also, are the specified categories (e.g. marital status categories) within each biographical variable scientifically recognised and socially/culturally acceptable to the target participants, groups and communities?
3. Which safeguard strategies will the researcher implement when reporting the research findings to not perpetuate or establish discriminatory and/or stigmatising attitudes and actions towards the focus participants, groups and communities?
4. Which safeguard strategies will the researcher implement when reporting the research findings to not perpetuate or establish shame, embarrassment and social discord to/between the research participants, groups and communities (Wynn, Mason & Everett 2008)?

16.2.8 Respect for Cultural Diversity and Pluralism

Culture is generally defined as a set of distinctive behavioural, spiritual, material, intellectual and emotional features shared by a social group; it includes literature, history, art, texts, values, customs and traditions (Revel 2009; Rivière 2011). From an ethics perspective culture should be regarded and respected as the common heritage of humanity that enriches society through its variety and innovative ways of living (Rivière 2011; Ten Have 2016). Pluralism refers to the affirmation, acceptance and respect of cultural diversity, otherness and social cohesion; it is thus closely linked to respect for human dignity and equality (Revel 2009).

Social science researchers working in cultural contexts should be familiar with the local customs and traditions, including the relevant local history and traditional leaders. It is also important for researchers to recognise and respect the collective identity of the participating communities. In addition, such communities often have a special relationship and understanding of the biophysical environment which inter alia affects the cultural and spiritual importance they accord to specific biological life forms, objects and places. It is also often closely linked with the community's view of ownership and custodianship in their context (South African San Institute 2017).

The general attitude and actions of social science researchers should be to conduct all aspects of research projects in close collaboration and cooperation with, and not merely on, the target community (HSRC 2006; South African San Institute 2017). This should include the following: identification of the research problem/focus; development and implementation of the research design; interpretation of the research data; distribution/communication of the research findings; and research

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funding arrangements (HSRC 2006; Wynn et al. 2008; South African San Institute 2017). Social science researchers' interactions with the community should be free from any attitude of exploitation, culture "blindness", culture superiority or cultural imperialism; it should rather be guided by a deep respect for cultural diversity and pluralism (Revel 2009). As such, researchers should clearly and carefully explain to community members all the research concepts in non-academic language and in non-patronising ways (South African San Institute 2017).

Below is a list of relevant ethics review questions regarding the principles of respect for cultural diversity and pluralism for ethics reviewers.

Ethics Review Questions

1. What evidence does the project provide to indicate that the researcher is well-acquainted with and knowledgeable of the target group and community's culture, customs and norms? Which strategies are indicated in the project regarding the ways in which the researcher will respect these customs and norms?
2. Which strategies are indicated in the project to appropriately access and obtain gatekeeper permission (e.g. traditional leader/s) to the research site and community?
3. Which strategies are indicated in the project to negotiate and implement culturally-appropriate and ethically acceptable methods to recruit research participants, obtain informed consent and collect data? How are generally accepted ethics principles reinterpreted and applied within the specific cultural contexts?
4. Which strategies are indicated in the project to ensure that the dissemination and communication of the research findings are not done to the detriment and expense of the participants' personal, social and cultural values (HSRC 2006)?

16.2.9 Social Responsibility and Integrity

Social responsibility refers to the moral obligation and awareness that extends from researchers to groups and communities, as well researchers' recognition that research activities, outcomes and effects can be beneficial or detrimental to persons, groups, communities and society (Martínez-Palomo 2009; Ten Have 2016). The research focus of social science projects should ideally address areas that are of concern to local, regional or global needs, especially when it is supported by public funds. However, it is also important to duly consider and anticipate the broader socio-cultural and socio-political implications and applications, including potentially perverse applications, of research outcomes (AAAS 2017).

In social research the concept of social responsibility is closely linked to the personal integrity of researchers and the scientific integrity/merit of research proj-

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ects. Researcher integrity refers to the researcher's trustworthiness and credibility, as well as the researcher's moral accountability for his/her knowledge, skills and conduct (Van den Hoonaard and Tolich 2014). It inter alia implies that researchers must truthfully, clearly and unambiguously report research findings while also carefully considering the socio-cultural and socio-political implications of the findings (HSRC 2006; Wynn et al. 2008). Researchers must also deliver on the promises they made regarding the benefits that the community will share in as a result of participating in the research project (South African San Institute 2017). Another important aspect of researcher integrity is the full disclosure of project funding sources, research sponsors and any potential conflicts of interest, especially vested financial interests in the initiation, completion and/or communication of research findings. All these potential conflicts of interest should be duly disclosed and appropriately managed (AAAS 2017).

The ever-increasingly complex nature of ethics governance and ethics regulations has resulted in suggestions and/or requirements for social science researchers, postgraduate supervisors and students to complete formal research ethics education programmes and refresher courses prior to conducting research projects involving human participants (Murphy and Dingwall 2007). The reason for this being that research integrity and merit in the social sciences require that all research projects involving human participants must fundamentally be ethically justifiable during all the research stages (Wynn et al. 2008). See Chap. 5 by Morrow, Worku and Mathibe-Neke for an in-depth discussion of social responsibility in research in Africa, as well as Chap. 10 by Roets and Molapo for an in-depth discussion of African social science research ethics and integrity.

Below is a list of relevant ethics review questions regarding the principles of social responsibility and integrity for ethics reviewers.

Ethics Review Questions

1. Does the research project address a valid research problem/question in the target context?
2. Does the research project use a scientifically sound research design to optimally address the research problem?
3. What evidence is presented regarding the researcher and research team's knowledge, skills, experience and professional affiliations or registration to conduct the specific research project?
4. Has the researcher and other research associates duly declared and indicated appropriate strategies to duly manage all conflicts of interest? Does any of the conflicts of interest pose potential harm, bias or detriment to the interests of the research participants, groups or communities?
5. What evidence is presented regarding the research ethics education programmes and/or refresher courses completed by the researcher, research assistants, field workers and/or students involved in the research project?

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16.2.10 Benefit Sharing

Benefit sharing refers to "… the promotion of equitable access to and the sharing of benefits derived from scientific and technological progress … (because) in many contexts, the benefits of science, scientific knowledge, and technology are unevenly distributed, primarily as a result of power, economic, and structural imbalances between countries, communities, and individuals" (Hoffmann 2015, p. 1). Note that *benefit sharing* in this section is conceptually and ethically different, but not exclusively so, to *benefits* as considered under the principle of beneficence (see Sect. 16.2.2 "Beneficence and non-maleficence" in this chapter). The latter concept is more applicable to the immediate rights and obligations to individual research participants while the former concept is more applicable to the wider community and society associated with the process and outcomes/products of research endeavours.

In social science research it is important that researchers and the target persons, groups and communities proactively negotiate the benefits that they might expect to receive and share in during and after conclusion of the project in accordance with and care of their own values, priorities and interests (Wynn et al. 2008; South African San Institute 2017). Some of the potential benefits in this regard include the following: co-research opportunities for appropriately trained community members (e.g. translators and research assistants); skills and research capacity development for interested community members; co-authorship of journal articles, books and other research outputs; and benefit sharing agreements in the case of commercially valuable traditional knowledge (South African San Institute 2017).

Social science researchers need to be vigilant when conducting research that might involve the collection and reporting of indigenous knowledge systems or private intellectual knowledge of research participants, groups and communities. In such cases, the researcher has a moral, and sometimes legal, obligation to keep the knowledge confidential and to facilitate due intellectual property processes rather than exploiting the knowledge for his/her own benefit. Indigenous knowledge inter alia include the following: oral histories; poetry and songs; dance/movement rituals; musical practices; and cultural knowledge about commerce, governance, agriculture and the environment (Wynn et al. 2008). See Chap. 4 by Amugune and Omutoko for an in-depth discussion of an African perspective of benefits in social science research.

Below is a list of relevant ethics review questions regarding the principle of benefit sharing for ethics reviewers.

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Ethics Review Questions (Hoffmann 2015)

1. Which realistic benefit-sharing indications and opportunities have been identified in the research project? How will the intellectual property rights and/or indigenous knowledge systems of all relevant stakeholders be duly acknowledged and managed?
2. Who will be the recipients of the benefits (i.e. individual research participants, communities, societies and/or the international community)?
3. When will the benefits be provided to the recipients (i.e. during the research project and/or post-research)?
4. Who is responsible to provide the benefits (i.e. researchers, research institutions, funding agencies)?

16.3 Conclusion

Ethics guidelines for social science research are limited in the following ways: (1) it cannot account for or cover all the ethical complexities and nuances of social science research contexts; and (2) it cannot guarantee that social science researchers develop a moral character and act ethically in their research endeavours (Wynn et al. 2008). As such, the role and function of social science RECs are primarily to act as independent peer review bodies of the proposed ethical processes and intentions of researchers in order to safeguard the rights and freedoms of all research participants, groups and communities (see UDBHR Article 19, UNESCO 2005). It is ultimately the moral responsibility of each researcher to (1) commit to a life-long process to internalise and reflect on relevant ethics principles, (2) to make responsible and considered ethical decisions in all research contexts based on those principles, and (3) to consistently and with integrity act on those decisions.

The ethical literacy, ethical sensitivity and practical "in the field" ethical decision-making skills of all persons who are involved in social science research can be developed and enhanced through appropriate formal research ethics education programmes and refresher courses (Miller and Boulton 2007; Murphy and Dingwall 2007). See for example the free online *Human Research Ethics for the Social Sciences and Humanities* course offered by the Macquarie University, Sydney, Australia (https://www.mq.edu.au/ethics_training/index.php). Similarly, it is imperative for social science REC members to gain high-level knowledge and to develop ethics review skills that duly appreciate and recognise the unique characteristics, paradigms and ethical frameworks of social research (Miller and Boulton 2007). As such, this chapter introduced social science researchers and REC members to the most important ethics principles and ethics review questions that should be considered by both parties in their strive towards ethical research endeavours.

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