

## Respecting Autonomy in African Communities: Traditional Beliefs and Challenges for Informed Consent in South Africa

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### Abstract

The Western notion of libertarian, rights-based autonomy, emphasizing individual rights, can conflict with African cultural values that prioritize communal well-being. In African communitarian ethics, collective interests often take precedence over individual choice, which can influence decision-making processes and challenge the application of standard informed consent procedures in biomedical research. This study examined the perspectives of African biomedical researchers regarding the practice of informed consent and potential limitations of the principle of respect for autonomy within African communities. We conducted a qualitative study using in-depth, semi-structured interviews with 12 biomedical researchers (five women and seven men) aged 34–74 years, all affiliated with an African university. Each interview lasted between 35 and 40 minutes, allowing participants to share their perceptions and experiences regarding autonomy and informed consent in African contexts. Interviews were audio-recorded, transcribed, and analyzed using thematic content analysis. This empirical data was interpreted alongside a review of relevant literature on African communitarian ethics, consistent with the empirical bioethics approach. Findings indicate that informed consent, rooted in Western conceptions of individual autonomy, faces challenges in African settings. Participants highlighted the difficulty of applying standard consent procedures due to the predominance of communalism, customary beliefs, spirituality, and relational approaches to autonomy, as reflected in African moral philosophies such as Ubuntu/Botho and Ukama. Additional barriers included language differences, educational disparities, poverty, and entrenched cultural norms, all of which complicate obtaining fully informed consent. The principle of individual autonomy and conventional informed consent models have limitations when applied in African communities, particularly in biomedical research. We recommend adopting a relational ethical framework, such as Ross's *prima facie* duties, to better align consent practices with communal and cultural values in these contexts.

**Keywords:** Biomedical research, Africa, Empirical bioethics, Informed consent, Communitarianism, Indigenous knowledge systems, Ubuntu/Botho, Ukama, Respect for autonomy

### Background

Beyond general human development, further reductions in mortality depend on advances in medical technologies, pharmaceuticals, and vaccines. Achieving these innovations requires biomedical research conducted in

human populations to evaluate safety, efficacy, and cost-effectiveness. Such research relies on human participants, including randomized controlled trials and other study designs. Ensuring proper informed consent is essential for maintaining ethical standards in these studies. This paper examines the application and comprehensibility of informed consent within African populations, highlighting a tension between the Western emphasis on individual autonomy and the communal values prevalent in Southern African societies, such as Ubuntu. For instance, the Khoisan people of South Africa recently established a code of ethics in response to historical research conducted in San communities

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without appropriate consent from community leaders [1, 2].

Western-European notions of autonomy, which prioritize individual rights [3, 4], often contrast with African cultural norms [5–9]. African ethical frameworks emphasize relational wholeness, where personhood is defined through connections with others in the community [6, 7, 9, 10]. Central to this worldview is the idea that one's existence is intertwined with others: "We exist because of others, and they exist because we do" [5, 9, 11]. African communitarian ethics therefore prioritize collective interests—usually of the family or community—over individual choice, meaning that collective decision-making often supersedes individual consent. Importantly, the notion of community here extends beyond the Western sense, encompassing a collective humanity in which the individual's identity is understood through the perspective of others. As Menkiti notes:

*"A crucial distinction exists between the African conception of man and the Western view: in African thought, it is the community that defines the person as a person, rather than an isolated quality of reason, will, or memory"* [12].

These cultural perspectives suggest that applying Western biomedical ethics in Africa may encounter ethical dilemmas stemming from traditional values, practices, rituals, and taboos that continue to shape social behavior [13]. Moral dilemmas in this context may challenge conventional Western ethical reasoning, often presenting multiple, seemingly valid yet mutually exclusive solutions, or issues that appear irresolvable [14]. Addressing such dilemmas requires recognizing the problem and deliberating within a framework of accepted rules, principles, and ethically relevant factors. Differences in cultural and moral norms highlight the potential need for alternative, context-sensitive approaches to ethical decision-making [15]. This study thus explores and proposes possible adaptations to the informed consent process in African communities, drawing on moral pluralism and empirical data.

In clinical and research settings, consent is generally viewed as a process of shared decision-making that integrates both respect for autonomy and beneficence within the doctor-patient relationship [16–18]. A legal illustration is found in the American case *Grimes v. Kennedy Krieger Institute (2001)* [16, 19], in which the Maryland Court of Appeals recognized that consent in non-therapeutic research could create a legally

enforceable contract if provisions such as mutual assent, offer, acceptance, and consideration were present. This underscores that informed consent functions not only as an ethical obligation but also as a social and legal mechanism in research and healthcare institutions [16, 20, 21]. Ideally, the consent process involves a dialogue initiated by the healthcare professional or researcher with the patient or participant, emphasizing transparency, active engagement, and ongoing communication. Evidence of consent, such as a signed form, is often required, and participants retain the right to withdraw at any time. Consent may also be invalidated if circumstances change without appropriate communication or agreement with the participant [16, 20–22].

### *The African concept of personhood*

Menkiti [12:172] asserts that in the African worldview, the community holds ontological primacy, meaning that the individual's existence is secondary and dependent on the communal context. He explains that, for Africans, "the reality of the communal world takes precedence over the reality of individual life histories, whatever these may be" [12]. While African cultures are diverse, many share common values, beliefs, and practices [9, 23–27] that reflect this communitarian perspective [5, 9, 23–27]. Central to this worldview is the ethos of communal living, particularly captured in the principle of Ubuntu, as highlighted by Munyaka and Motlhabi [23, 28]. This study explores Ubuntu and other African moral values to address the ethical tensions that arise when Western bioethics, focused on individual autonomy, is applied in African biomedical research.

The dynamics between healthcare providers and patients—or researchers and participants—often encounter challenges in African contexts [29]. These challenges stem from the application of Western biomedical ethical principles, which prioritize individual autonomy [3, 4, 18, 30]. In contrast, African philosophies such as Ubuntu [31] and Ukama [10] emphasize relationality and connectedness within society [12, 30, 32]. Communitarianism in Africa holds that personal identity and social character are fundamentally shaped by one's relationships, with the individual considered within the broader collective [9–12, 23, 30–32]. Thus, the African notion of personhood is inherently relational. While other ethical frameworks, such as care ethics and feminist ethics, also recognize relational dimensions

[30], this study employs Ross's model of moral pluralism (prima facie duties) because it emphasizes responsibilities to others in ethical decision-making.

#### *Ross's model of moral pluralism*

Ross's approach centers on prima facie duties, which are initially binding moral obligations accepted as valid unless overridden by stronger duties in particular circumstances [33]. These differ from absolute duties, which apply universally, and conditional duties, which depend on specific conditions [3]. Ross explains that prima facie duties reflect the objective moral significance of a situation, even if initial impressions may later prove incomplete or misleading [34]. For instance, if one must choose between keeping a promise or preventing a serious accident, two prima facie duties arise: fidelity and the obligation to relieve harm. In a given context, the duty to prevent harm may take precedence over fidelity, illustrating how prima facie duties guide moral decision-making [33, 34].

Ross identifies seven prima facie duties: fidelity, reparation, gratitude, justice, self-improvement, beneficence, and non-maleficence. This model aligns with African moral philosophy because it emphasizes relational responsibilities, resonating with Ubuntu's focus on just and ethical relationships [23, 35, 36]. For example, fidelity and reparation correspond to obligations arising from one's own actions, while gratitude reflects obligations toward others. Duties related to justice, beneficence, self-improvement, and non-maleficence further reinforce obligations toward society. Importantly, Ross's framework extends beyond individual interactions to broader social, legal, and policy contexts, supporting concepts like restorative and distributive justice [23, 36–38].

In this study, Ross's model provides a conceptual foundation for exploring potential alternatives to the conventional informed consent process in African communities, integrating moral pluralism with empirical evidence.

## **Methods**

### *Study rationale*

This research examined the contrast between informed consent, rooted in the principle of respect for individual autonomy, and African traditional values and belief systems. Specifically, the study analyzed how informed

consent is applied in biomedical research within Southern Africa, with the goal of assisting researchers and scholars in understanding the influence of culture on ethical research practices. The study rests on the premise that the norms and rules guiding informed consent in bioethics predominantly emerge from Western-European intellectual and moral traditions, which prioritize the individual over the collective.

### *Aims and objectives*

The primary aim of this study was to investigate the perspectives of biomedical researchers at an African university regarding the comprehension and practical application of informed consent among African populations. This inquiry stems from the tension between Western notions of individual autonomy and Southern African concepts, such as Ubuntu and Ukama, which emphasize communal relationships [10, 23, 28, 31, 35, 36]. For instance, the San communities in Southern Africa recently established their own code of ethics [1], motivated by historical instances in which researchers conducted studies without proper consent from community leaders or elders [2]. Accordingly, this study explored the dynamics of informed consent in doctor-patient and researcher-participant interactions, situating these practices within African traditional values. African communitarian and other cultural systems—encompassing family structures, language, spiritual beliefs, ancestral reverence, and customs—may at times conflict with Western-derived bioethical principles [5, 29, 39, 40, 41].

### *Conceptual framework*

The study considered whether a top-down (deductive) or bottom-up (inductive) ethical approach was most appropriate. According to Beauchamp and Childress and other scholars, moral judgments can be framed through two lenses: top-down reasoning, which justifies specific actions by applying established moral principles and theories, and bottom-up reasoning, which derives general moral principles from concrete instances of right and wrong behavior [3, 42–45]. Traditional ethical theory aims to guide human conduct by defining what constitutes moral action, including concepts of good and evil, virtue and vice, and justice and wrongdoing. Principles and theories are outlined to direct ethical decision-making.

Top-down approaches, however, are often characterized as monistic and reductionist, attempting to ground all moral reasoning in a single overarching principle. Beauchamp and Childress argue that such reductionism oversimplifies morality, ignoring the complexity of human decision-making and the influence of non-moral factors [3, 44, 45]. These approaches provide limited guidance on selecting the appropriate course of action in context-specific situations and struggle to reconcile universal principles with particular circumstances. As a result, top-down models may inadequately address practical ethical dilemmas in biomedical research, leaving unresolved tensions between general ethical rules and local cultural realities [3, 45].

## Methods

### *Rationale for approach*

Considering critiques by Beauchamp, Childress, and others regarding the limitations of the traditional top-down ethical model [3, 45], this study adopted a bottom-up approach [43, 44]. Conventional moral theories often appeal to an abstract, universal notion of personhood, which may inadvertently impose Western intellectual and cultural norms, potentially amounting to a form of cultural imperialism. Bioethics—defined broadly as the application of ethics to all life [46–48]—concerns real individuals in specific contexts, and its principles are necessarily rooted in culture. Excluding cultural perspectives risks rendering bioethics non-representative and globally inapplicable [6–8, 13, 16, 39, 48, 49].

While Beauchamp and Childress proposed four universally recognized principles—respect for autonomy, beneficence, non-maleficence, and distributive justice [3]—these principles reflect a Western-European worldview that may not align with African cultural norms [4, 5, 9, 23–27]. Therefore, bioethics cannot function effectively without consideration of local cultural frameworks. For this reason, a case study approach was employed, enabling the analysis of historically and culturally situated examples to draw contextually relevant insights about informed consent in African communities [50].

Additionally, the study favored a pluralistic ethical framework over a monistic one, recognizing the compatibility of moral pluralism with multiculturalism [49, 51]. As argued by Kevin and Wildes, morality is deeply interwoven with culture, which justifies a

pluralistic approach that respects diverse ethical practices embedded in cultural norms [50]. Bioethics, in this light, seeks to examine moral systems as they operate within specific cultural contexts, advocating for both multicultural and morally pluralistic approaches [16, 49–51].

### *Research question*

This study aimed to address the following question: Can the principle of informed consent be implemented in African bioethics without compromising traditional values and belief systems?

### *Research design*

A qualitative methodology was selected, utilizing semi-structured, in-depth interviews with relevant stakeholders. Qualitative approaches are particularly suited for exploring phenomena in contexts where variables cannot be controlled [52, 53], allowing researchers to investigate not only what occurs, but also how and why events unfold. This method facilitated a nuanced understanding of informed consent and its implications within African contexts. The study integrated empirical data with an extensive literature review [54], in line with empirical bioethics standards that combine normative analysis with real-world data [55, 56].

### *Sample and data collection*

Participants were purposefully selected biomedical researchers and practitioners at the University of KwaZulu-Natal (UKZN) to explore the application of bioethical principles to African communities and potential cultural conflicts. The target sample size of 12 participants was determined based on literature and biostatistical guidance [52–54]. Semi-structured interviews, guided by a pre-prepared question set (Additional file 1), allowed participants to share detailed perceptions, attitudes, and experiences regarding informed consent in Southern Africa.

Interviews lasted 30–40 minutes and were conducted by the principal investigator (FA-I) at participants' workplaces. Audio recordings were transcribed for thematic analysis and triangulated with findings from the literature [54]. Three potential participants could not be included due to time constraints, but their exclusion did not affect the study, as data saturation was achieved by

the twelfth interview, with no new themes emerging [57].

**Table 1** provides an overview of participant characteristics.

**Table 1.** Demographic characteristics of the study participants

	Age (years)	Race	Gender	Field
Participant 1	64	White	Female	Clinical Research Laboratory
Participant 2	38	Indian	Female	Clinical Trials
Participant 3	72	Indian	Female	Pediatric Nephrology
Participant 4	53	African	Female	Chair BREC
Participant 5	46	African	Female	Medical Technologist in Clinical Pathology
Participant 6	39	African	Male	Gynaecologist
Participant 7	57	White	Male	Medical Researcher
Participant 8	56	African	Male	Medical ethics, informed consent, and Traditional Medicine
Participant 9	37	African	Male	General Practitioner
Participant 10	65	White	Male	Bioethics Committee
Participant 11	34	Colored	Male	Medical Law
Participant 12	74	White	Male	Medical Law

<sup>a</sup> The term 'Colored/s' is a non-derogatory term used to describe a multiracial ethnic group native to Southern Africa, with ancestry from more than one of the various populations inhabiting the region, including Khoisan, Bantu, White, Austronesian, East Asian, or South Asian. <https://en.wikipedia.org/wiki/Coloureds> [58]

### *Sampling methodology*

The study initially attempted to use random sampling to select participants. However, this approach proved impractical due to the demanding schedules of researchers, lecturers, and healthcare professionals (HCPs). Consequently, the study adopted a snowball sampling strategy, in which one participant refers the researcher to another potential participant, creating a chain of contacts [53]. Snowball sampling falls within a broader category of link-tracing methods [53, 54], which leverage the social networks of identified participants to generate an expanding pool of respondents [52–54]. This approach relies on the assumption that connections exist between the initial participants and others in the same target population. For this study, the participants were biomedical researchers at the University of KwaZulu-Natal (UKZN) in South Africa with experience implementing the informed consent process in African contexts.

### *Data analysis*

Thematic content analysis was employed to evaluate the qualitative data and draw inferences. This method is

suitable for descriptive presentation of qualitative findings [52, 53], allowing for the identification, examination, and reporting of patterns or themes within the dataset [59]. The principal investigator (PI) conducted a manual, iterative coding process, extracting key terms and assigning codes to the data. This iterative method facilitated refinement of the coding framework and helped determine the point of data saturation.

The analysis process began with a comprehensive reading of each transcript to gain an overall understanding. Subsequently, the text was summarized using codes to generate a code report. Coded data with similar meanings and context were grouped into categories, and these categories were further analyzed to identify patterns and relationships, ultimately forming overarching themes [60]. Findings were summarized descriptively, with verbatim quotations included to illustrate key points. The PI conducted the primary analysis, which was cross-checked by a research supervisor, with no disagreements regarding coding or theme identification [54]. To reduce bias, the PI maintained neutrality during data collection and analysis and was largely unknown to participants. Reporting adhered to the Consolidated Criteria for Reporting



Qualitative Research (COREQ) [61] (see Additional file 2).

### *Ethical approvals*

The Humanities Research Ethics Committee (HREC) at UKZN approved this study. All participants provided written informed consent following full disclosure of study details (Additional file 3). Confidentiality was ensured through secure data storage, and findings were reported anonymously. Portions of this article are derived from research conducted as part of the PI's Master of Population Studies degree, completed in 2017 [54].

## Results

### *Participant characteristics*

The study sample (n=12) included five females and seven males, aged 34–74 years. Participants comprised four professors, six academic doctors, and two practicing clinicians. Detailed demographic characteristics are provided in **Table 1**.

### *Thematic analysis findings*

Five major themes, along with several subthemes, emerged from the interviews: (i) participants' perceptions of informed consent, (ii) perceptions of informed consent in the African context, (iii) views on applying the principles of respect for autonomy and informed consent, (iv) the influence of education on the informed consent process, and (v) the impact of poverty on informed consent in Africa. The themes and subthemes are summarized in **Table 2**.

Below is a paraphrased version of **Table 2** and **Table 3**, maintaining the structure and meaning of the original content while rephrasing the text:

**Table 2.** Key Themes and Subthemes Identified from Thematic Analysis

Main Themes	Subthemes
Understanding of Informed Consent	General views of participants on informed consent, the procedure for consenting to research or treatment, South African regulations governing informed consent
Informed Consent in African Contexts	Implementation of informed consent in African communities, obstacles to effectively applying informed consent in these settings

Views on Applying the Principle of Respect for Autonomy	Current practices in upholding autonomy, difficulties in implementing this principle, tensions between individual and collective decision-making
Influence of Education on the Informed Consent Process	Lack of access to Western-style education, ability to understand the informed consent process, capacity to make informed choices
Impact of Poverty on the Informed Consent Process	Limited financial resources to access Western education, heightened vulnerability, misconceptions about therapeutic benefits

**Table 3.** Coding System for Research Participants

Codes	Interpretation
F	Female participant
M	Male participant
R	Respondent
Number	Age of the respondent
<i>Example:</i> RM74 refers to a male respondent aged 74 years	

### *Respondents' understanding of informed consent*

Participants described informed consent as a process in which research participants or patients voluntarily agree to take part in biomedical research or medical treatment. They emphasized that consent must be given without coercion or undue influence and that participants should fully understand the information provided. RM56 highlighted the key components required for valid informed consent, noting that it is more than signing a document. It requires comprehensive disclosure of all relevant information, assurance that the participant comprehends this information, and freedom to make an unpressured decision. Participants should not feel compelled by fear or incentivized in ways that could compromise their voluntariness. RM56 also stressed the principle of justice, emphasizing that participants should be fairly compensated for their time and effort, particularly if they withdraw from a study. Privacy and confidentiality were further highlighted as essential elements, alongside transparency about potential risks, benefits, and the duration of participation. Proper informed consent, therefore, relies on detailed documentation and ethics committee-approved protocols.

Similarly, RM74 highlighted that South African common law stipulates that informed consent requires

understanding of the proposed procedure and its consequences, and must be freely and voluntarily given without undue inducements. In line with this, RF46 referred to the criteria set out in the South African National Health Act, underscoring that participants must be informed of all available options and potential consequences of participation. RF46 also emphasized that information must be communicated in a language and level of complexity appropriate for the participant to ensure comprehension. For clinical trials, particularly those involving novel drugs, RF46 noted that participants should also be informed about post-trial arrangements, including the continuation of treatment, reflecting evolving ethical committee requirements. Overall, participants highlighted that informed consent is a cornerstone of ethical research, although applying it in African contexts presents specific challenges.

#### *Perceptions of informed consent in African contexts*

Participants consistently reported that applying informed consent in African communities can be challenging due to its Western origins emphasizing individual rights, which may conflict with African communal values. RM56 observed that the Western notion of libertarian rights does not align seamlessly with African cultural norms such as Ubuntu. RM37 added that the concept of individual autonomy is largely foreign to African traditions, noting that historically, communities have functioned collectively without prioritizing personal autonomy.

RM56 further explained that African communitarian philosophies, including Ubuntu and related beliefs in ancestors, relational autonomy, and spiritual practices, often place the community's interests above those of the individual. In some African societies, gaining the community's endorsement is crucial, and community interests may supersede individual preferences. This presents a clear contrast with Western-informed consent practices, where individual rights typically take precedence. Participants also noted additional barriers, including limited Western-style education and vulnerabilities among participants, which may complicate the direct application of standard informed consent processes in African settings.

#### *Participants' perceptions of applying the principle of respect for autonomy*

The study revealed that applying the principle of respect for autonomy in African settings has met only partial success, primarily due to the strong emphasis on communitarianism in African cultural values and belief systems. Concepts of individual autonomy that underpin Western-informed consent procedures often conflict with African social norms, where decision-making tends to be collective rather than individual. Consequently, a research participant or patient's autonomous choice may be constrained by the expectations and authority of family or community members.

RF53, who conducted biomedical research in a rural community in Northern KwaZulu-Natal, highlighted the challenges in implementing autonomy and privacy. She explained that in her experience, even decisions regarding a mother or child required approval from other family members, such as the father or grandmother. She stated that the individual's ability to make independent decisions was limited: "For me to talk to the mother and the child, the granny and the father must give me permission. It means now, they are the ones who are allowing that person, so that person is not, there is no autonomy in her because she is not allowed to decide whether she wants it or not. She must first get consent from these two other people or the mother-in-law, must say yes or no or even father-in-law." This demonstrates that in many African communities, participants often perceive themselves as part of a group, and the interests of the collective can take precedence over individual choice.

RM56 emphasized that the fundamental obstacle in translating Western-informed consent practices to African settings is the conceptual difference in understanding autonomy: "The primary obstacle in translating informed consent as it is in the Western construct to the African construct is that the people will not even understand the concept of autonomy because they don't think as individuals." This perspective reflects the deeply relational nature of personhood in many African societies, where selfhood is understood in terms of relationships with others rather than as an independent entity.

RM57 added that this communal approach presents challenges in medical practice as well. Patients frequently come to healthcare facilities accompanied by their extended families, and even when they arrive alone, family consultation remains critical. He observed, "In African settings, people come as families. They are brought in by families, and even if they do not come with

families, whatever you do to them it affects their families, and in terms of medical intervention, it creates a bit of a challenge.” Even mature adults may defer decisions to family members, reflecting the strong influence of relational autonomy and the ethics of care in African communities.

RM37 shared a similar experience while working in a community hospital treating a patient with multidrug-resistant tuberculosis. He explained that the patient’s decisions were embedded in the communal structure of the society, where he acted not only as an individual but as a member of his family and community. He stated, “I worked in a remote area where the culture is still intact; you are not an individual; you are part of the community. When I see you, I see you as the representative of the community or even the family. Like in this instance, this man has spoken to me about the fact that he is married, and he also has to speak to his mother before he can leave, and that also meant to us that whatever we do with him, it means they might also be affected.” In such cases, researchers and healthcare professionals must navigate decisions carefully, recognizing that interventions affecting one individual can have wider social repercussions.

Several participants pointed out that for autonomy to be meaningful in African contexts, it must address the legacy of paternalism in healthcare systems. RM37 reflected, “From my experience, I will say that except we are talking about the autonomy against paternalism, that I will advocate for. However, in most cases the person is the person with their community... The autonomy that needs to be entrenched is the one that fights paternalism.” He argued that historically, healthcare practitioners often made decisions on behalf of patients, a legacy that complicates attempts to implement individualistic autonomy. Similarly, RF72 observed, “Applying autonomy was very, very difficult; at a point, we even had to break the rules so we could get the work done and make sure that the community was cared for. We couldn’t worry about the individual; we had to worry about the community.” This highlights the tension between prioritizing individual rights versus the well-being of the collective.

The influence of communal structures was further illustrated in RF53’s doctoral research. Before interacting with her target participants, she had to seek permission from the head of the homestead. In cases involving young mothers, she also had to obtain consent from their elders. RF53 described, “Firstly, as we enter

each homestead there is the head of the homestead; you must ask permission from that head... It’s not just me and you, everybody comes here to listen to me, and implementing privacy, that is difficult.” Her experience demonstrates that privacy and individual decision-making are inherently challenging in communal settings, where multiple family members are involved in observing and participating in research interactions. Language barriers were another recurring challenge; without understanding local dialects, communication and comprehension during the consent process would have been significantly hindered.

#### *Participants’ perspective on the impact of education on the informed consent process*

Several participants highlighted that limited education among potential research participants poses challenges to obtaining proper informed consent. Education plays a key role in helping participants understand the research process and their rights. As RM34 stated:

“Among the rich Africans, there is a level of comprehensibility in terms of informed consent because they are more educated in the Western educational system, and they have a reasonable form of income, they know the consumer rights, and they can ask questions because they have been educated.”

However, the widespread lack of education and poverty in rural areas creates vulnerability. RM56 noted: “The African people that are consenting; the majority of them are not educated, and this is a vulnerability because it makes them vulnerable.”

This situation often results in participants agreeing to take part in research without fully understanding it, sometimes influenced by the appearance of the researcher or perceived benefits, rather than informed judgment. Poverty frequently exacerbates this issue, which is discussed below.

#### *Participants’ perspectives on the impact of poverty on the informed consent process*

Poverty is closely tied to educational limitations, as many Africans lack access to formal schooling due to financial constraints. RM56 shared findings from a study in South Africa:

“We conducted a study in South Africa, and we found out that almost 65% of the general population of South Africans that were going to public hospitals have no jobs nor a form of income, including grants.”



This high level of economic hardship leaves many participants vulnerable to consenting to research without fully understanding the risks, often motivated by incentives. RM56 explained:

“Poverty makes them vulnerable, especially in the context of research [where] any offer, whether it’s medication, taxi fare, money, are liable to induce them to agree because they are already in a very, very desperate situation.”

He further elaborated on the concept of therapeutic misconception:

“Anything that the researcher offers to them—even if it is treatment, which is not good enough motivation to get them to accept—they will accept because there is no alternative.”

Young people, in particular, are often drawn into research due to financial incentives:

“There is a lot of evidence of young people enrolling in research in Africa just because there is money that induces them to participate, and it has to do with the fact that most Africans are generally poor.”

Participants emphasized the need to implement African values and ethical frameworks to protect research participants, suggesting that a relational consent process—one that accounts for community structures and collective decision-making—is essential to prevent exploitation and ensure that consent is genuinely informed.

## Discussion

### *Informed consent and its constraints*

This study examined how the ethical principle of respect for autonomy [3, 21] is implemented in biomedical research and clinical practice through the framework of informed consent [16, 21, 22, 62]. The focus was on assessing whether this principle could be effectively applied in African contexts, where community-centered values and relational understandings of autonomy prevail. To explore this, we adopted an empirical bioethics approach, combining ethical theory with data gathered from real-world research situations, allowing insights that purely theoretical approaches might miss [16, 55, 56, 62]. As Mertz and colleagues define it, empirical ethics involves research that is “normatively oriented” while directly incorporating empirical evidence [56]. In practice, this approach merges observation and ethical analysis to generate knowledge unattainable

through either method alone [16, 55, 56, 62]. Our study used qualitative interviews with biomedical researchers operating in Africa, alongside a review of literature on principlism and respect for autonomy [3], Ross’s prima facie duties [33, 34], and African communitarian philosophies like Ubuntu and Ukama [10, 23, 28, 31, 36–39], to explore how informed consent is carried out in South African biomedical research.

Our findings confirm that informed consent is still considered a core element of ethical biomedical research globally, including in African settings. This is consistent with the assertion by Manson and O’Neil [63] that informed consent remains a defining concept in contemporary bioethics. Researchers widely regard it as essential for ensuring ethical interactions with human subjects [22, 29].

In South Africa, the participants emphasized that informed consent requires participants to be fully informed about the research and its implications, and to voluntarily decide whether to participate. This includes explaining the study thoroughly, ensuring comprehension, and avoiding any form of coercion, undue influence, or intimidation [16, 22, 62]. The principle of justice also plays a critical role: participants should receive fair compensation for their time and effort, even if they withdraw from the study, and using their time without agreement would constitute exploitation. Researchers are responsible for outlining potential benefits, minimizing risks, and safeguarding the privacy of participants [16, 22, 62, 64]. These standards are embedded in South African law, including the Constitution [65], common law, the National Health Act 2003 [66], and international codes like the Declaration of Helsinki [67].

International guidelines, such as those from CIOMS [68], the Nuffield Council on Bioethics [69], and the National Bioethics Advisory Commission [70], reinforce the idea that ethical standards should be consistent across cultural and economic contexts [29, 67–71]. These guidelines stress that voluntary, individual consent is required for all research participants, and that studies not permissible in developed countries should generally not take place in developing nations [70, 71]. Their aim is to prevent exploitation, especially among vulnerable populations [71].

Despite these global expectations, our participants reported that aligning universal ethical norms with local practices can be difficult. In African communities, traditional customs sometimes clash with international

guidelines, creating practical challenges for researchers. This was evident in South African settings and mirrors experiences in other rural African areas [72, 73]. Respondents also highlighted that relational autonomy and ethics of care—concepts emphasizing family and community involvement in decision-making—can shape how autonomy and informed consent function in African contexts, a finding consistent with previous research [30].

#### *Language, education, and cultural context in informed consent*

Several respondents in this study emphasized that both language and educational background significantly influence participants' comprehension of informed consent in African biomedical research. Limited literacy and unfamiliarity with technical or medical terminology can hinder understanding, as has been documented in previous South African studies [16, 62, 74]. In recognition of this, the South African National Health Act [63] mandates that healthcare professionals (HCPs) take participants' language skills and educational levels into account when obtaining informed consent [16, 62, 64, 74–76].

Africa faces widespread poverty and a disproportionate burden of disease, compounded by limited healthcare infrastructure. These conditions exacerbate the challenge of reconciling universal ethical principles with local cultural norms and behavioral expectations [5, 24, 25, 39, 40, 41, 48]. Applying globally standardized ethical guidelines in research without understanding the local cultural context is especially difficult. Since informed consent is central to ethical research conduct, it cannot simply be globalized; its application is inherently culture-dependent. Kuper (1999) notes that “Anthropologists have described culture as a symbolic system representing ideas, values, cosmology, morality, and aesthetics, shared by individuals and groups” [77]. This perspective highlights the challenge of imposing universal ethical principles, as cultural norms are specific to each community, meaning consent procedures must remain adaptable to local contexts.

Nevertheless, most mainstream ethical frameworks are rooted in Western-European traditions that emphasize individual autonomy and privacy. Applying these frameworks without modification in traditional African societies is likely to be ineffective, a conclusion supported by other studies on informed consent in Africa

[11]. Yet, it is important to recognize that African culture is not monolithic. Despite its diversity, there exists a shared sense of “Africanness,” as argued by Peter Kasenene [78]. Many indigenous African communities share common beliefs, including reverence for ancestors, a communal conception of the individual, and relational worldviews [5, 23–27, 79]. These shared cultural features could form the foundation of an African-centered bioethical framework [39].

Akin Makinde further argues that African medical theories and practices are deeply intertwined with cultural norms. Concepts such as illness, diagnosis, treatment, life, and death are inseparable from the social and cultural contexts in which they occur [80]. This viewpoint is echoed by Sindiga, Nyaigotti-Chacha, and Kanunah, who observe that each cultural group approaches health and illness in ways shaped by their traditions, values, and accumulated knowledge, including distinct etiologies, classifications, medical practitioners, and pharmacopeias [81]. Their analysis underscores that medical ethics and healthcare practices cannot be assumed to produce universal truths applicable across all cultural contexts.

This cultural divergence manifests in differing conceptions of disease: Western medicine often focuses on the physiological functioning of the body, whereas African perspectives may link illness to interactions between the “visible” and “invisible” worlds [81]. Gloria Waite has described this as a “medico-religious” understanding of disease, contrasting with the biotechnical orientation of Western medicine [82]. Similarly, Shutte argues that healthcare approaches based solely on scientific principles risk neglecting the spiritual aspects of illness [83]. Within African contexts, a purely technical approach to medicine can be seen as dehumanizing. African bioethics emphasizes the holistic dignity of the human person, suggesting that treatments focusing only on repairing bodily organs fail to address the broader causes and experience of illness. From this perspective, Janzen notes that the African holistic view of healing motivates many individuals to complement Western medical treatments with traditional African medicine [84].

#### *Complementing Western medicine and informed consent challenges*

It can be suggested that combining Western medical practices with African traditional medicine could

potentially allow for the application of Western-based processes, including informed consent. However, none of the participants in this study fully endorsed this perspective. Some argued that exposure to Western-style education might encourage more individualistic thinking, creating conditions conducive to understanding informed consent from a personal perspective [75]. Yet, as African educational systems increasingly incorporate traditional values alongside modern curricula, education alone may not fully resolve the tension between Western-informed consent practices and conventional African cultural norms and behaviors [24, 26, 27, 75]. This persistent ethical tension has, in some cases, prompted indigenous communities to develop their own ethical frameworks, such as those observed among the San people of Southern Africa [1, 2, 85, 86].

#### *Toward an alternative ethical approach*

The findings of this study indicate the necessity of rethinking informed consent practices in Southern Africa. By integrating empirical research insights with normative ethical analysis, we propose introducing ethical pluralism as a framework for bioethical decision-making in African contexts. Contemporary bioethical decision-making often relies on a bottom-up approach to moral reasoning [42, 43]. Traditional monistic ethical theories—such as consequentialism, utilitarianism, and deontology—tend to assume a universal concept of personhood, which may risk imposing Western intellectual and cultural norms on non-Western societies [51, 87, 88].

However, bioethics deals with actual individuals in specific social and cultural contexts. Ethical principles are inseparable from culture because the existence of bioethics itself presupposes cultural practices and ways of life [13, 39, 48–51]. The four globally recognized principles of biomedical ethics—autonomy, beneficence, non-maleficence, and justice—articulated by Beauchamp and Childress since 1989 [3], reflect a Western-European moral perspective. These principles, while widely applied, cannot be assumed to be culturally neutral, and they may conflict with African worldviews [3–9, 24–29]. This study favors a pluralistic ethical approach over a monistic one, given its alignment with multiculturalism. As Kevin and Wildes argue, culture and morality are closely intertwined [50]. A pluralistic moral framework recognizes diverse value systems, reflecting the embeddedness of moral practice in cultural life [4–9, 49–

51]. Given the ethical tensions revealed in this research, including conflicts between traditional African norms and Western-informed consent, it is essential to adopt a principled alternative approach.

Ross's model of moral reasoning provides such a framework. By employing *prima facie* duties [33, 34], which are relational and context-sensitive, rather than absolute or conditional duties as proposed by Beauchamp and Childress [3], Ross's approach aligns with the relational nature of African personhood. This resonates with the Ubuntu/Botho philosophy, which emphasizes mutual responsibility, justice in relationships, and the dignity of all humans [31, 37, 38].

The South African Constitutional Court's ruling in *Dikoko v Mokhatla* (2006) exemplifies this approach in practice. In this defamation case, Justice Mokgoro highlighted that Ubuntu emphasizes restorative rather than retributive justice, focusing on healing relationships rather than imposing punitive monetary awards. She argued that remedies should restore the plaintiff's dignity and promote reconciliation between parties, reflecting the relational values central to African ethics. According to her judgment:

"In our constitutional democracy the basic constitutional value of human dignity relates closely to Ubuntu or Botho, an idea based on deep respect for the humanity of another [...] A remedy based on the idea of Ubuntu or Botho could go much further in restoring human dignity than an imposed monetary award in which the size of the victory is measured by the quantum ordered and the parties are further estranged rather than brought together by the legal process [...]. The goal should be to knit together shattered relationships in the community and encourage across-the-board respect for the basic norms of human and social interdependence" (*Dikoko v Mokhatla* 2006, paras 68–69) [38].

This judgment underscores that ethical practices in Africa must account for relational, restorative, and context-sensitive values—principles that could also inform culturally appropriate models of informed consent.

It is important to recognize that Ross's model extends beyond individual or micro-level interactions, as it also addresses broader issues such as reparations. This capacity aligns with restorative justice practices at societal, legal, and policy levels, paralleling the principles of Ubuntu, as highlighted by other scholars [23, 37].

Based on these considerations, Ross's framework appears particularly well-suited for the African context. Its focus on interpersonal relationships and restorative justice resonates with the African philosophical tradition of Ubuntu. Accordingly, it may be necessary for political and legal systems in Africa to adopt reforms that allow the implementation of informed consent and respect for autonomy in ways that reflect local socio-cultural realities. This could include the involvement of family or community members in the consent process during biomedical research [72, 73], or the application of Ubuntu/Botho values, which prioritize dignity and harmony in human relationships [31, 35–38].

Consistent with previous research [16, 62, 74–76], this study also found that low levels of education in African communities can hinder understanding of the informed consent process, particularly when the information is not provided in a language participants comprehend. Therefore, African bioethics and biomedical research should consider group consent processes that are culturally sensitive, accommodate participants' literacy levels, and respect communal decision-making structures.

#### *Limitations of the study*

This study would have benefited from direct empirical data highlighting the practical challenges and conflicts encountered when applying the principle of autonomy and informed consent among specific population groups in Southern Africa. Nevertheless, findings from other African studies [30–32], including research conducted in Ghana [72] and Kenya [73], corroborate the observations presented here. Additionally, this study did not include perspectives from individuals receiving consent or their family members, who may be considered integral participants in relational autonomy. Despite the absence of such direct experimental data, the qualitative evidence collected and the analysis of published literature provide sufficient grounds to support the study's conclusions. Future research could further validate these findings and address limitations related to scope, time, and location.

#### **Conclusions**

Analysis of empirical and normative ethical data in this study highlights a clear tension between Western and African interpretations of informed consent and respect for autonomy within South African biomedical research

contexts. Western models of informed consent, rooted in individualistic libertarian rights, may not be fully applicable in Africa. However, this does not imply that informed consent is irrelevant; rather, it must be adapted to local socio-cultural contexts. Researchers need to consider participants' socio-economic status, literacy, environment, spirituality, and cultural norms. This approach echoes the ethical perspectives advocated by the San peoples of Southern Africa, who emphasize respect, honesty, truthfulness, and the understanding that individuals exist as part of a community. In this worldview, an individual's experiences and actions have direct implications for the broader community.

Drawing on Ross's framework, researchers working in Africa should recognize that Western practices of informed consent cannot simply be transplanted into African contexts. Effective implementation requires sensitivity to traditional values, collective decision-making, and the communitarian worldview, where group survival and communal interests may take precedence over individual rights. In this way, informed consent in Africa can be meaningful and ethically appropriate, provided it is designed with a clear understanding of local cultural and philosophical principles.

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#### **References**

1. South African San Institute. San code of research ethics. 2017. <http://trust-project.eu/wp-content/uploads/2017/03/San-Code-of-Research-Ethics-Booklet-final.pdf>. Accessed 3 April 2017.
2. Daley J. San people of South Africa issue code of ethics for researchers. 2017. <https://www.smithsonianmag.com/smart-news/san-people-south-africa-issue-code-ethics-researchers-180962615/>. Accessed 14 March 2021.
3. Beauchamp TL, Childress JF. Principle of biomedical ethics. Oxford: Oxford University Press; 2013.

4. Gobel MS, Benet-Martinez V, Mesquita B, Uskul AK. Europe's culture(s): Negotiating cultural meanings, values, and identities in the European Context. *J Cross-Cultural Psychol.* 2018;49(6):858–67. <https://doi.org/10.1177/0022022118779144>.
5. Chima SC. Religion politics and ethics: Moral and ethical dilemmas facing faith-based organizations and Africa in the 21st century-implications for Nigeria in a season of anomie. *Niger J Clin Pract.* 2015. <https://doi.org/10.4103/1119-3077.170832>.
6. Schwartz SH. Beyond individualism/collectivism: new cultural dimensions of values. In: Kim U, Triandis HC, Kagitcibasi C, Choi S-C, Yoon G, editors. *Individualism and collectivism: theory, method, and applications.* Thousand Oaks, CA: Sage; 1994. p. 85–119.
7. Schwartz SH. A theory of cultural value orientations: explication and applications. In: Esmer Y, Pettersson T, editors. *Measuring and mapping cultures: 25 years of comparative value surveys.* Leiden: Brill; 2007. p. 33–78.
8. Schwartz SH. Cultural value differences: some implications for work. *Appl Psychol.* 1999;48:23–47.
9. Mbiti J. *African religions and philosophy.* London: Heinemann; 1969.
10. Murove MF. The Shona concept of Ukama and the process philosophical concept of relatedness, with special reference to the ethical implications of contemporary neo-liberal economic practices. MA dissertation. University of Natal, Pietermaritzburg; 1999.
11. Frimpong-Mansoh A. Culture and voluntary informed consent in African health care systems. *Dev World Bioeth.* 2008;2:104–14.
12. Menkiti IA. Person and community in African traditional thought. In: Richard A, Wright RA, editors. *African philosophy: An introduction.* 3rd ed. New York: University Press of America; 1984. p. 171–81.
13. Chukwuneke F, Umeora O, Maduabuchi J, Egbunike N. Global bioethics and culture in a pluralistic world: how does culture influence bioethics in Africa? *Ann Med Health Sci Res.* 2014;4(5):672–5.
14. Connolly P. *Ethics in action: a case-based approach.* Oxford: Wiley-Blackwell; 2009.
15. Brody B. *Taking issue: pluralism and casuistry in bioethics.* Washington, DC: Georgetown University Press; 2003.
16. Chima SC. An investigation of informed consent in clinical practice in South Africa. LLD Thesis. University of South Africa; 2018; [uir.unisa.ac.za/handle/thesis\\_chima\\_s](http://uir.unisa.ac.za/handle/thesis_chima_s). [https://www.researchgate.net/publication/328459054\\_An\\_Investigation\\_of\\_Informed\\_Consent\\_in\\_Clinical\\_Practice\\_in\\_South\\_Africa](https://www.researchgate.net/publication/328459054_An_Investigation_of_Informed_Consent_in_Clinical_Practice_in_South_Africa). Accessed 11 Oct 2020.
17. Grubb K, Liang B, McHale J. *Principles of medical law.* 3rd ed. Oxford: Oxford University Press; 2009.
18. Gillon R. Autonomy and the principle of respect for autonomy. *Br Med J Clin Res Ed.* 1985;290(6484):1806–8. <https://doi.org/10.1136/bmj.290.6484.1806>.
19. Mastroianni AC, Kahn JP. Risk and responsibility: ethics, Grimes v Kennedy Krieger, and public health research involving children. *Am J Publ Health.* 2002;92:1073–6.
20. McCormick TR. Informed consent, its basis, problems, uncertainties. University of Washington School of Medicine. 1998, <http://depts.washington.edu/bioethx/>. Accessed 12 Aug 2017.
21. Chima SC. Respect for autonomy as a prima facie right: overriding patients' autonomy in medical practice. *Transactions.* 2009;53:38–44.
22. Chima SC. Consent and patients rights in human biomedical research. LLM dissertation. Northumbria University, Newcastle-upon-Tyne, England; 2006.
23. Nzimakwe TI. Practising Ubuntu and leadership for good governance The South African and continental dialogue. *Afr J Publ Aff.* 2014;7(4):30–41.
24. Juma JO. African Worldviews—their impact on psychopathology and psychological counselling. MA dissertation. University of South Africa, Pretoria; 2011. p. 42–6.
25. Chalk JP. Genesis 1–11 and the African worldview: conflict or conformity? Doctor of Literature and Philosophy thesis. University of South Africa, Pretoria; 2006.
26. Thabede D. The African worldview as the basis of practice in the helping professions. *Soc Work/Maatskaplike Werk.* 2008;44(3):233–45. <https://doi.org/10.15270/44-3-237>.
27. Graham MJ. The African-centered worldview: toward a paradigm for social work. *J Black Stud.* 1999;30(1):103–22.
28. Munyaka M, Motlhabi M. Ubuntu and its socio-moral significance. In: Murove MF, editor. *African ethics: an*



- anthology for comparative and applied ethics. Pietermaritzburg: University of Kwazulu-Natal Press; 2009. p. 63–84.
29. Chima SC. Regulation of biomedical research in Africa. *BMJ*. 2006;332:848–51.
  30. Osuji PI. African traditional medicine: Autonomy and informed consent. *Advancing global bioethics* 3. Cham: Springer International Publishing; 2014.
  31. Metz T, Gaie JB. The African ethic of Ubuntu/Botho: implications for research on morality. *J Moral Educ*. 2010;39:273–90.
  32. Sogolo G. Foundations of African philosophy: A definitive analysis of conceptual issues in African thought. Ibadan: Ibadan University Press; 1993.
  33. Skelton A, Ross WD. The Stanford encyclopedia of philosophy (summer 2012 edition), Zalta EN, editor. <https://plato.stanford.edu/archives/sum2012/entries/william-david-ross/>. Accessed 20 Feb 2021.
  34. Ross WD. The right and the good. New York: Oxford University Press; 2002.
  35. Broodryk J. Ubuntuism as a worldview to order society. Pretoria: University of South Africa; 1997.
  36. Mfenyana B. Ubuntu, abantu abelungu. *Black Sash Mag*. 1986;28(4):18–9.
  37. Maqutu TM. African philosophy and ubuntu: Concepts lost in translation. Master of Law dissertation. University of Pretoria, 2018.
  38. Dikoko v Mokhatla 2006 (6) SA 235 (CC).
  39. Mbugua K. Respect for cultural diversity and the empirical turn in bioethics: a plea for caution. *J Med Ethics Hist Med*. 2012;5:1.
  40. Acquah F. The impact of African traditional religious beliefs and cultural values on Christian-Muslim relations in Ghana from 1920 through the present: A case study of Nkusukum-Ekumfi-Enyan area of the central region. Ph.D. thesis. University of Exeter; 2011.
  41. Agbiji OM, Swart I. Religion and social transformation in Africa: a critical and appreciative perspective. *Scriptura*. 2015;114(1):1–20.
  42. Wallach W, Allen C, Smit I. Machine morality: Bottom-up and top-down approaches for modelling human moral faculties. *AI & Soc*. 2008;22:565–82. <https://doi.org/10.1007/s00146-007-0099-0>.
  43. Meslin EM. The value of using top-down and bottom-up approaches for building trust and transparency in biobanking. *Publ Health Genom*. 2010;13(4):207–14. <https://doi.org/10.1159/000279622>.
  44. Flynn J. Theory and bioethics. The Stanford encyclopedia of philosophy (spring 2021 edition), Zalta N editor. <https://plato.stanford.edu/archives/spr2021/entries/theory-bioethics/>. Accessed 3 Feb 2021.
  45. Hedgecoe AM. Critical bioethics: Beyond the social science critique of applied ethics. *Bioethics*. 2004;18:120–43. <https://doi.org/10.1111/j.1467-8519.2004.00385.x>.
  46. Potter VR. Bioethics, the science of survival. *Persp Biol Med*. 1970. <https://doi.org/10.1353/pbm.1970.0015>.
  47. ten Have HA. Potter's notion of bioethics. *Kennedy Inst Ethics J*. 2012. <https://doi.org/10.1353/ken.2012.0003>.
  48. Chima SC, Mduluzi T, Kipkemboi J. Viewpoint discrimination and contestation of ideas on its merits, leadership and organizational ethics: expanding the African bioethics agenda. *BMC Med Ethics*. 2013;14(Suppl 1):S1. <https://doi.org/10.1186/1472-6939-14-S1-S1>.
  49. Gordon E. Multiculturalism in medical decision-making: the notion of informed waiver. *Fordham Urb Law J*. 1997;4:1321–62.
  50. Kevin WM, Wildes SJ. Ethics and deep moral ambiguity. In: Cherry MJ, Smith Iltis A, editors. *Pluralistic casuistry—balancing moral arguments, economic realities and political theory*. Heidelberg: Springer; 2007. p. 37–48.
  51. Penna DR, Campbell PJ. Human rights and culture: beyond universality and relativism. *Third World Quart*. 1998;19(1):7–27.
  52. Henning E, Van Rensburg W, Smit B. Finding your way in qualitative research. Pretoria: Van Schaik; 2004.
  53. Vogt WP, Gardner DC, Haeffele LM. When to use what research design. New York: Guilford Press; 2012.
  54. Akpa-Inyang FF. Southern African traditional values and belief systems and the informed consent process in biomedical research: perceptions of the San's code of ethics. M Pop dissertation, University of KwaZulu-Natal, 2017. <https://researchspace.ukzn.ac.za/handle/10413/16425>. Accessed 2 Aug 2021.
  55. Ives J, Dunn M, Molewijk B, et al. Standards of practice in empirical bioethics research: towards a consensus. *BMC Med Ethics*. 2018;19:68. <https://doi.org/10.1186/s12910-018-0304-3>.

56. Mertz M, Inthorn J, Renz G, et al. Research across the disciplines: a road map for quality criteria in empirical ethics research. *BMC Med Ethics*. 2014;15:17. <https://doi.org/10.1186/1472-6939-15-17>.
57. Fusch PI, Ness LR. Are we there yet? Data saturation in qualitative research. *Qual Rep*. 2015;20(9):1408–16.
58. Posel D. What's in a name? Racial categorisations under apartheid and their afterlife. *Transformation*. 2000;47:50–74.
59. Anderson J. Content and text analysis. In: Keeves JP, editor. *Educational research, methodology and measurement: an international handbook*. 2nd ed. New York: Pergamon; 1997. p. 340–3.
60. Saldaña J. *The coding manual for qualitative researchers*. London, England: Sage; 2016.
61. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349–57.
62. Chima SC. Evaluating the quality of informed consent and contemporary clinical practices by medical doctors in South Africa: an empirical study. *BMC Med Ethics*. 2013;14(Suppl):S3. <https://doi.org/10.1186/1472-6939-14-S1-S3>.
63. Manson NC, O'Neill O. *Rethinking informed consent in bioethics*. Cambridge: Cambridge University Press; 2007.
64. Aderibigbe KS, Chima SC. Knowledge and practice of informed consent by physiotherapists and therapy assistants in KwaZulu-Natal Province, South Africa. *S Afr J Physiother*. 2019;75(1): a1330. <https://doi.org/10.4102/sajp.v75i1.1330>.
65. Republic of South Africa. *Constitution of the Republic of South Africa 1996*. Pretoria: Government Printer; 1996.
66. Republic of South Africa. *National Health Act No. 61 of 2003*. Pretoria: Government Printer; 2003.
67. World Medical Association (WMA). *Declaration of Helsinki-Ethical principles for medical research involving human subjects*. Fortaleza, Brazil: WMA; 2013.
68. Council for International Organizations of Medical Sciences (CIOMS). *International ethical guidelines for biomedical research involving human subjects*. Geneva: CIOMS-WHO; 2002. <https://cioms.ch/wp-content/uploa>
69. Nuffield Council on Bioethics. *The Ethics of Research Related to Health- care in Developing Countries*. London: Nuffield Foundation; 2002. <https://www.nuffieldbioethics.org/assets/pdfs/Ethics-of-research-related-to-healthcare-in-developing-countries.pdf>. Accessed 5 June 2017.
70. National Bioethics Advisory Commission (NBAC), USA. *Ethical and Policy Issues in International Research: Clinical Trials in Developing Countries*. Bethesda: MD; NBAC. <https://bioethicsarchive.georgetown.edu/nbac/pubs.html>. 2001. Accessed 5 June 2017.
71. Chima SC. Contemporary ethical issues and regulation of biomedical research in African communities. In: Mduluzi T, editor. *A gateway to biomedical research in Africa*. New York: Nova Science Publishers; 2007. p. 19–38.
72. Tindana PO, Kass N, Akweongo P. The informed consent process in a rural African setting: a case study of the Kassena-Nankana District of Northern Ghana. *IRB*. 2006;28:1–6.
73. Molyneux CS, Wassenaar DR, Peshu N, Marsh K. “Even if they ask you to stand by a tree all day, you will have to do it (laughter)...!”: Community voices on the notion and practice of informed consent for biomedical research in developing countries. *Soc Sci Med*. 2005;61(2):443–54. <https://doi.org/10.1016/j.socscimed.2004.12.003>.
74. Chima SC. Language as a barrier to informed consent and patient communications in South African hospitals—a working paper, in *The Asian Conference on Ethics, Religion & Philosophy 2018*, 18–22 March, Official Conference Proceedings, Kobe, Japan: The International Academic Forum (IAFOR). p. 67–83. [http://papers.iafor.org/wp-content/uploads/conference-proceedings/ACERP/ACERP2018\\_proceedings.pdf](http://papers.iafor.org/wp-content/uploads/conference-proceedings/ACERP/ACERP2018_proceedings.pdf). Accessed 12 Aug 2018.
75. Chima SC. “Because I want to be informed, to be part of the decision- making”: patients’ insights on informed consent practices by healthcare professionals in South Africa. *Niger J Clin Pract*. 2015;18:S46–56.
76. Chima SC. Informed consent in South Africa: a legal, ethical, and cross-cultural perspective. In: Vanswevelt T, Glover-Thomas N, editors. *ds/2017/01/WEB-CIOMS-EthicalGuidelines.pdf*. Accessed 5 June 2017.

- Informed consent and health: a global analysis. Cheltenham: Edward Elgar Publishing; 2020. p. 183–214.
77. Kuper A. Culture, The Anthropologists' Account. Cambridge: Harvard University Press; 1999.
  78. Kasenene P. African medical ethics: African ethical theory and the four principles. In: Veatch RM, editor. Cross-cultural perspectives in medical ethics. 2nd ed. Sudbury, MA: Jones and Bartlett Publishers; 2000. p. 347–57.
  79. Murove MF. African ethics: an anthology of comparative and applied ethics. Pietermaritzburg: University of Kwazulu-Natal Press; 2009. p. 63–84.
  80. Makinde MA. African philosophy, culture, and traditional medicine. Athens: Ohio University Press; 1988.
  81. Sindiga I, Nyaigotti-Chacha C, Kanunah MP. Traditional medicine in Africa. Nairobi: East African Publishers; 1995.
  82. Waite G. Public health in precolonial East-Central Africa. The social basis of health and healing in Africa. Soc Sci Med. 1987. [https://doi.org/10.1016/0277-9536\(87\)90047-5](https://doi.org/10.1016/0277-9536(87)90047-5).
  83. Shutte A. Ubuntu: an ethic for a new South Africa. Pietermaritzburg: Cluster Publications; 2001.
  84. Janzen JM. Medicalization in comparative perspective, and drums anonymous: towards an understanding of structures of therapeutic maintenance. In: de Vries M, Berg RL, Lipkin M, editors. The use and abuse of medicine. New York: Praeger; 1982. p. 154–66.
  85. Lwango-Lunyiigo S, Vansina J. The Bantu-speaking peoples and their expansion. In: Hrbek I, editor. UNESCO General History of Africa. Africa from the Seventh to the Eleventh Century, vol. 111. Paris: UNESCO; 1992. p. 75–85.
  86. Chima SC, Ryschkewitsch CF, Stoner GL. Molecular epidemiology of human polyomavirus JC in the Biaka Pygmies and Bantu of Central Africa. Mem Inst Oswaldo Cruz. 1997;93:615–23.
  87. Cobbah JAM. African values and the human rights debate: an African perspective. Human Rights Quart. 1987;9(3):309–31.
  88. Queiroz R. Individual liberty and the importance of the concept of the people. Palgrave Commun. 2018;4:99. <https://doi.org/10.1057/s41599-018-0151-3>.