# INFORMED CONSENT IN SOCIO-LEGAL RESEARCH ON PEOPLE LIVING WITH HIV: ETHICAL CHALLENGES AND BEST PRACTICES

***Dr. Aderonke E. Adegbite* and Esther- Mary Olufunke Umeano*****

**Abstract**

Informed consent is a foundational ethical principle that ensures participants voluntarily engage in research with full awareness of its implications. Obtaining informed consent is very crucial because it is the bedrock of any research especially when it comes to a vulnerable population such as this. In Nigeria, in particular, mainly because of its many heterogenous communities, obtaining meaningful consent from PLWHA poses unique challenges such as stigma, discrimination and cultural and religious taboos. Also included among the challenges are low literacy levels, and mistrust of researchers. This study shall be examining the key elements involved in the process of obtaining informed consent in a research while also examining how the elements intersect with legal, social, and cultural dynamics to impact the quality of informed consent and how cultural and religious norms in our heterogenous communities have contributed to stigma and discrimination, thereby raising disclosure and confidentiality concerns which are a major impact on the consent process. A cursory look at the adequacy of current legal protections and ethical guidelines in safeguarding the autonomy and dignity of PLWHA shall be done. The study therefore calls for the development of culturally appropriate communication, community engagement, and the strengthening of health and legal safeguards. Using a qualitative methodology involving already documented and reported interviews with researchers and PLWHA participants, the study highlights key gaps in the implementation of ethical guidelines. It also identifies major hindrances to ethical research practices. Despite these challenges, the study outlines best practices that can enhance ethical compliance. These include community engagement, use of culturally sensitive consent procedures, simplification of consent forms, and capacity-building for researchers in order to protect the rights and dignity of PLWHA in socio-legal research.

Keywords: Informed consent, People Living with HIV/AIDS (PLWHA), Socio-legal research,

Nigeria, Vulnerable populations

## 1. INTRODUCTION

The human immunodeficiency virus (HIV) is a virus that is highly contagious and it is believed to have originated from the simian immunodeficiency virus (SIV) which is a virus that infects monkeys and apes predominantly in Africa.[1]It was then spread to humans, by human hunting and handling of the infected animals.[2] Blood transmission and sexual contacts with already infected humans have played a major role in the contribution to the spread of the disease.[3] Untreated HIV infections is what degenerates into the Acquired Immune Deficiency Syndrome (AIDS) which is the final stage of the infection.[4] The World Health Organisation (WHO) began international surveillance of the disease in 1983 and later declared HIV/AIDS a pandemic in 1987.[5] So far, the HIV/ AIDS pandemic has killed over 30 million people worldwide and has been described as "the king of all plagues".[6]

In Nigeria and in general, transmission of HIV/AIDS has been through sexual transmission (heterosexuality, homosexualism, anal sex and oral sex), Mother-to-Child Transmission and blood transfusion/blood products, the use of contaminated sharp objects, female genital mutilation, circumcision, medical procedures like injections, surgical operations, obstetric procedures, dental procedures and intravenous drug use (IDU) and the like.

---

*

**

[1] Sharp P.M and Hahn B.H "Origin of HIV and the AIDS Pandemic" (2011) Cold Spring Harbor, Perspectives in Medicine Journal. perspectivesinmedicine.cshlp.org Assessed on 25/03/25

[2] ibid

[3] "How is HIV Transmitted". hiv.gov/hiv-basic dated February, 2023. Assessed on 27/03/25

[4] Balogun A.S "HIV/AIDS Epidemic in the History of Nigeria, 1986-2007" Journal of the Historical Society of Nigeria (2010) vol 19. p 167

[5] WHO: AIDS. Report on the Meeting on AIDS, Geneva,28-30 November 1983. See also Sepkowitz K.A(2006). The First 20 Years of AIDS. Clinical Infectious Diseases, 43(11),1424-1427. doi:10.1086/508544

[6]Tukura D.W "HIV/AIDS and African Development: The Social and Economic Root of an Epidemic" (2007): Bolabay Publications, Lagos, p vii

At the initial stage, it was thought that "scare tactics" could be used to curb the spread of HIV/AIDS and as such it was presented to the public as a disease to be 'greatly feared' because a cure had not been found for it and that people who had contacted the disease do not have long to live.[7] There were also the use of terminologies like AIDS victims, AIDS patients, AIDS orphans that increased stigmatization and discrimination in the country. Today, it is proven that the scare tactics method has not been able to raise a positive resistance to its spread but has only increased stigmatization and discrimination. Therefore, a more proactive method of creating awareness and prevention of the spread through the development of AIDS education and enlightenment programmes has been adopted by the Nigerian Health sector. Its agenda was to promote "Safe Sex" through the ABC model. The A stands for Abstinence, B stands for Be faithful to one partner while the C stands for Condom use if you must have sex. Another thing put forward was a change of language in that AIDS patients/victims were now called "people living with HIV/AIDS" (PLWHA).

Also, it must be noted that, stigmatization and discrimination of the PLWHA, has caused many people to be afraid of undergoing tests, disclosing their status or even undergoing treatment.[8] The HIV/AIDS is one of the most prominent health challenges in Nigeria and globally, most especially because of the stigma and discrimination associated with the condition. Once infected, it is for life and does not go away but has to be managed for the rest one's life.

Also, due to the vulnerable nature of the PLWHA, it became necessary to protect any form of research done on them and as a result, in the year 2001, the federal government of Nigeria through NACA, established a National Ethics Board. This board was responsible for the

[7] ibid

[8] People are afraid to go for tests even when they have not engaged in anything that is likely to expose them to the disease. The researcher from experience, discovered that medical laboratories, hospitals, clinics and the like, do take tests on all patients that come in for one blood test or the other without the knowledge and consent of the patient.

formulation and publication of the National Ethics and Operational Guidelines for Research on Human Subjects in Nigeria. The board is a regulatory framework that ensures that research is conducted in an ethical, legally compliant, and culturally sensitive manner. Part of its responsibility is to ensure that the required informed consent is obtained from vulnerable groups such as the PLWHA by setting additional ethical safeguards**.**

Informed consent is one of the fundamental ethical requirements in research involving human participants. It ensures that individuals voluntarily agree to participate in a study after understanding its purpose, risks, benefits, and their rights.[9] Stigma, discrimination and a whole lot of other challenges have made obtaining informed consent from PLWHA in Nigeria a delicate and uneasy task. The ethical guidelines emphasize that consent must not be obtained by force, undue influence, or pressure. Also, that any form of incentives accompanying participation in the research should be carefully structured to avoid manipulation due to the economic vulnerability of many PLWHA.[10] Participants must also be assured that refusing to participate will not affect them in any way, especially their access to medical care and social services.

This study explores the key elements, challenges, and possible recommendations for obtaining informed consent from PLWHA in Nigeria while ensuring ethical compliance and protection participants' rights.

[9] World Medical Association [WMA], (2013). WMA first adopted the Declaration of Helsinki in 1964 and amended it several times with its latest revision in 2013. It entails a set of ethical principles that guide the medical research on human participants. The most crucial principle being that of obtaining informed consent from research participants. See sections 4,7,9.10,17,26 of the Declaration. http://aix-scientifics.net/en/_helsinki 13.html (QR/DM code) (vCard)(SSL)

[10] ibid

### 1.2 Problem Statement

The PWLHA often face severe social, economic, and psychological challenges due to societal stigmatization and discrimination, which continue to make it an uphill task for researchers to obtain voluntary informed consent from PLWHA.

### 1.3 Objectives of the Study

a. To examine the ethical challenges involving obtaining informed consent from PLWHA.

b. To identify the best practices in obtaining informed consent from PLWHA that is in compliance with ethical standards.

## 2. LITERATURE REVIEW

### 2.1 PLWHA as a Vulnerable Population

PLWHA do often experience and suffer from stigma, discrimination, and potential legal and social consequences of disclosure because of the fact that the disease has no cure and is highly infectious if care is not taken. This is why PLWHA is classified as a vulnerable group.[11] Researchers are therefore encouraged to approach informed consent with heightened sensitivity to privacy and autonomy, in order to avoid breaches of confidentiality that can cause social ostracization/exclusion or even loss of employment.[12] It must be noted however

[11] Adebajo S.B et al., (2014), "Prevalence of HIV and associated factors among men who have sex with men in Nigeria. The Lancet Global Health, 2(8), e348–e357. https://doi.org/10.1016/S2214-109X(14)70228-3

[12] Umeora O.U.J et al., (2011) "Ethical and legal issues in the management of HIV/AIDS in Nigeria. Nigerian Journal of Medicine", 20(3), p.225.

that researchers face a lot of ethical dilemmas especially when dealing with traditional communities where privacy is difficult to guarantee.[13]

### 2.2 The Concept of Informed Consent

Informed consent is an ethical requirement for any research done on human participants requiring that adequate information about the research prior to participation must be released to them. [14] It must be noted that the concept of informed consent is based on three essential elements which are namely; information disclosure, comprehension and voluntariness on the part of the research subject or participant.[15]

#### 2.2.1 Key Elements of Informed Consent

**2.2.1.1** Disclosure of information is to include:

i. The purpose and objectives of the research,
ii. The methods or procedure to be adopted in the participation,
iii. The potential risks and benefits.
iv. Measures to be taken by the researcher to protect confidentiality.
v. The voluntary nature of participation and the right to a withdrawal at any time.

#### 2.2.1.2 Comprehension by Participant

It must be given in a manner that is comprehensible enough for the research participant to understand. Therefore, the researcher in Nigeria must take into cognisance Nigeria's linguistic diversity and ensure that PWLHA fully understands what the research is all about by translating information into local languages where it is necessary for better

[13] Akinsete I. (2017). "Ethical dilemmas in HIV/AIDS legal research in sub-Saharan Africa. African Journal of Legal Studies" 10(2), 134–153.
[14] Adegbite A.E "Fundamentals on Legal Research and Methods in Nigeria" College Press, Leads City University, Ibadan. 2022. P 50 -51. See also World Medical Association [WMA], 2013)
[15] According to the Belmont Report and Nigeria's National Health Research Ethics Code, informed consent is to include all the stated above. See also the National Health Research Ethics Committee (NHREC) ,2016

comprehension.[16] In order to enhance comprehension, researchers may need to use visual aids, story telling techniques or oral explanations to pass on information.[17]

### 2.2.1.3 Voluntariness

Informed consent must show voluntariness on the part of the participant. There must be no display of any form of duress, coercion or undue influence.[18] They must also be allowed the opportunity to ask questions if they so choose to and also be informed that they have a right to withdraw at any given moment they choose to.[19] Due to the possibility of PLWHA being economically disadvantaged, researchers are not to capitalize on this, while structuring the benefits or incentives to be distributed, in order to avoid exploitation and manipulation.[20]

The basic information that is to be included in the Consent Form to be approved by participants before research begins are as follows:[21]

i. The reasons, benefits, expected duration and procedures for the research.
ii. Potential risks, inconveniences, setbacks or adverse effects of the research.
iii. Participants' rights to refuse to participate and their liberty to withdraw when they wish and that there is no negative consequences for refusal to participate entirely or withdraw during the process.
iv. The extent of information to be retrieved
v. Interactions and the researcher's plan on confidentiality.

---

[16] Afolabi M.O. (2014) "Multimedia Informed Consent Tool for a Law Literacy African Research Population: Development and Pilot- Testing". Journal of Clinical Research and Bioethics. (5) 3. doi.10.4172/2155-9627.1000178. In this research, an informed consent document was developed into a multimedia tool integrating video, animations and audio narratives into three Gambian languages and it was reported to be successful because it was clear and easy to understand by the low literacy level research participants.
[17] ibid
[18] Adegbite A.E "Fundamentals on Legal Research and Methods in Nigeria" College Press, Leads City University, Ibadan. 2022. P 50 -51. See also Deborah S. "Five Principles on Research Ethics" (Monitor Vol.34. No.1, 2003) at www.apa.org on 23/12/22.
[19] Beauchamp T. L and Childress J.F (2019) "Principles of Biomedical Ethics" (8th ed). Oxford University Press
[20] Wolemonwu, V. C. (2023). Incentivization and the Moral Problem of Involuntary Consent in Medical Research. History and Philosophy of Medicine, 5(1), 6. https://doi.org/10.53388/HPM2023006Academia
[21] Adegbite A.E Supra. See also Deborah S. Supra

vi. Incentives for participation and plans for feedbacks and follow ups.

### 2.3 The Context of Culture and Consent

Nigeria embraces a system of respect for communal values and hierarchical structures whereby decisions are often made by family or community leaders and this often contradicts Western notions of individual autonomy.[22] Therefore it may be said that PLWHA participants who give their informed consent to research are doing that out of deference to their communal authority or because of the benefits/ incentives that may come to them, instead of offering genuine voluntariness to participation in the research.[23] Moreover, low levels of educational and health literacy coupled with acute poverty go a long way in influencing participants' understanding of research processes, sometimes believing that research participation is help them receive medical treatment which is a therapeutic misconception.[24]

### 2.4 Legal Consciousness and Rights Awareness[25]

A major gap in socio-legal research is that more often than not, PLWHA are unaware of their legal rights such as the right to decline participation or to withdraw consent from participation.[26] The level of legal knowledge or consciousness of knowing that one has rights that ought to be protected and even enforced is very low, especially in rural areas where traditional justice systems operate unquestioned. This limits the effectiveness of informed consent, as participants may not feel empowered to make independent decisions or question authority.

---

[22] Ezeome, E. R and Marshall, P. A. (2009). Informed consent practices in Nigeria. Developing World Bioethics, 9(3), 138–148. https://doi.org/10.1111/j.1471-8847.2009.00257.x

[23] Osuji, P. I. (2014**).** Introduction: Informed Consent in a Communal Culture. In African Traditional Medicine: Autonomy and Informed Consent. https://link.springer.com/chapter/10.1007/978-3-319-05891-7_1

[24] Ezeome, E. R and Marshall, P. A. (2009) Supra

[25] Folayan, M. O.et al (2014). "Debating Ethics in HIV Research: Gaps Between Policy and Practice in Nigeria. Developing World Bioethics*", 15*(3), 214–225. https://doi.org/10.1111/dewb.12064

[26] Ezeome, E. R and Marshall, P. A. Supra

The literature highlights that informed consent in socio-legal research involving PLWHA in Nigeria is bedevilled with ethical, legal, and cultural challenges. Despite the presence of legal framework, the application of informed consent in field research is weak, and PLWHA suffer stigmatization from disclosure which is often escalated by socio-cultural and legal complexities. Researchers must therefore endeavour to lay more emphasis on a combination of confidentiality, PLWHA participant education, and continuous consent processes in order to bridge the gap.

### 2.5 Legal Framework

Nigeria is guided by both national and international regulations and guidelines relating to PWLHA, as regards their well-being and their participation in researches. These are as follows;

#### 2.5.1 National Health Research Ethics Code

The National Code of Health Research Ethics, is the highest policy document on research ethics in Nigeria and it was approved by the National Council on Health in its 50th Annual Meeting in January 2007.[27] The code outlines the duties and standards a researcher must adhere to in order to ensure the protection of the research participants, and in particular, as in this case, the PWLHA which belong to a vulnerable class population, the researcher must take meticulous measures in obtaining informed consent from them.[28] With specific regards to PWLHA the duties outlined in the code are inter alia;

i. Protection of the PLWHA: Researchers must ensure that they prioritize the welfare, safety and rights of the PLWHA.

[27] Federal Ministry of Health (FMoH); Proceedings of the 50th National Council on Health Meeting, Sheraton Hotels and Towers, Abuja, Nigeria.2006

[28] It must be noted that when conducting research on PLWHA in Nigeria, obtaining informed consent is particularly critical due to the sensitivity of the subject, the stigma associated with HIV/AIDS, and the legal and cultural complexities surrounding the disease. See also Adepoju A. (2020) "Cultural Barriers to Informed Consent in HIV/AIDS Research in Nigeria". African Journal of Ethics, 12(3), 112-126.

ii. Informed Consent: Researchers must ensure that PLWHA is fully aware of and understand the research nature, risks and benefits must obtain voluntary and informed consent from PLWHA before conducting research on their condition.

iii. Confidentiality: Researchers must maintain mandatory confidentiality of PLWHA with strict guidelines on data security and privacy.

iv. Risk Minimization: Researchers are to adopt measures that will lead to the minimization of any potential risks and discomfort likely to be suffered by the PLWHA.[29]

### 2.2.2 National Agency for the Control of Aids (NACA)

NACA was established in February, 2000 to coordinate Nigeria's response to the HIV/AIDS pandemic in the country. In relation to our study, some of the mandates of NACA are;

i. To support HIV/AIDS research in the country.

ii. Facilitate the engagement of all tiers of government and all sectors of HIV/AIDS prevention, care and support.

iii. Formulate policies and guidelines on HIV/AIDS.

iv. Co-operate with persons and institutions undertaking research in Nigeria and in other countries.[30]

### 2.2.3 National Health Act of 2014

This is a comprehensive legislation that regulates Nigeria's national health system without exactly focusing on PLWHA but however provides a framework that affects their healthcare experience. In line with this study and other legal frameworks, the Act does emphasize the importance of maintaining patient confidentiality and privacy which is crucial to PLWHA

[29] Federal Ministry of Health (n.d.) National Health Research Ethics Committee. Retrieved from https://www.health.gov.ng/Source/74/National-Health-Research-Ethics-Committee

[30] History of NACA. naca.gov.ng/history

who are prone to facing discrimination and stigma.[31] The Act also outlines the responsibilities of healthcare providers to provide care without discrimination.[32]

### 2.2.4 HIV/AIDS Anti- Discriminatory Act 2014

This Act equally aims at protecting the PLWHA from discrimination in employment, education, healthcare and other areas. It also protects the privacy and confidentiality oof PLWHA.

### 2.2.5 Declaration of Helsinki

This is an International Guideline that sets ethical principles for medical research involving human participants. It was first adopted by the World Medical Association (WMA) in 1964 but went through several revisions, the latest revision being the 2013 version.[33] One of the reasons for the declaration was the protection of the rights and dignity of human participants in medical research. [34]In achieving this purpose, the Declaration was to maintain respect for the autonomy of its human participants by ensuring that informed consent is obtained from them before conducting research.[35] No doubt the Declaration has promoted ethical research practices by creating and raising awareness as to the necessity of protecting PLWHA in medical research.[36]

### 2.2.6 Belmont Report

[31] Akpoghome T, (2018) "Examining the Protection of Access to and Delivery of Healthcare by the National Health Act 2014". Advances in Social Sciences Research Journal. DOI:10.14738/assrj.56.4802. At www.researchgate.net
[32] ibid
[33] World Medical Association (2013). "Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects". Journal on the American Medical Association, 310(20). 2191-2194.doi:10.1001/jama.2013.281053
[34] ibid
[35] ibid
[36] World Health Organization (WHO) (2017). Research Ethics Review Committee training manual.

The Belmont report was published in 1979 by the National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research.[37] Just like Declaration of Helsinki, it also outlines the basic ethical principles for conducting research involving human participants. The major one being the principle of autonomy which tantamount to respecting the decision made by the human participant.

## 3. METHODOLOGY

### 3.1 Research Design

This study is purely doctrinal and shall therefore be using a qualitative approach to the study. Already documented case studies and interviews shall be used for analysis. This is because of the limited time the researcher has to do and submit the work and also due to financial constraints.

### 3.2 Case Studies[38]

It is important at this juncture to refer to some cases where researchers had obtained informed consent from PLWHA. For instance, in the study below, all PLWHA comprised of persons 18 years of age or older, who had been diagnosed with HIV within the last 5 years and who had enrolled in the HIV clinic at Lagos University Teaching Hospital, Nigeria.[39] They were ascertained to speak English, Yoruba or Pidgin-English and had given their informed consent.[40] A total of 200 respondents were recruited using a purposive sampling technique and an interview was conducted among 26 PLWHA at the anti-retroviral therapy clinic of the

[37] National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research (1979). The Belmont Report: Ethical principles and guidelines for the protection of human subjects of research. Federal Register, 44(76), 23192-23197

[38] Emmanuel O. Et al "Stigmatization, Medication Adherence and Resilience Recently Diagnosed People Living with HIV/AIDS(PLWHA): A Mixed Method Study" February,2025. Wiley Online Library https://doi.org/10.1002/puh2.70036. Assessed on 30/03/25

Lagos University Teaching Hospital, Lagos, Nigeria.[41] One of the objectives was to determine the level of their stigma through their experiences.

The participants recounted their experiences at the point of being diagnosed with HIV and treatment. Their experiences are elucidated in detail within the subsequent subthemes below;

### 3.2.1 Disclosure of HIV Status[42]

There was a mixed response regarding the disclosure of their HIV status. Many of the respondents recounted how difficult it was for them to disclose their HIV status to even their family members. Some eventually disclosed to selected family or friends, but many did not. These are some of the actual responses;

- No, I didn't disclose my status to my family because they have soft minds, and I don't want them to start feeling bad and scared because of my health or feeling that I am going to die. It is only one of my friends who has the same status that knows about my condition and her family members… (P10, Female, 26 years, Student)

### 3.2.2 Impact of Diagnosis on Their Physical and Mental Health[43]

Participants articulated how they felt around the time of their diagnosis and treatment, unveiling the consequential effects of this experience on their physical and mental well-being. Some of them stated that they were depressed and felt they were already dead when they broke the news of their diagnosis. Some had eczema, consistent headaches, general body weakness and coughing. The actual responses were;

[41] ibid
[42] ibid
[43] ibid

- *They sent me a message a few years ago, that I should come and do an HIV test when I had Eczema, and they could not find a treatment…they just broke the news. I became very worried and depressed not just about the test result… if it were to be a pregnancy issue, abortion would be done and the problem solved, but this cannot be solved that way. (P15, Female, 57 years, Civil servant)*

### 3.2.3 Socioeconomic Impact of Diagnosis[44]

PLWHA described how being diagnosed with HIV has impacted their socioeconomic status. Many could not continue their jobs, whereas others could no longer get their dream jobs. Some were indecisive about what job they could do given their current condition. Participants highlighted the impact of an HIV diagnosis on their marital relationships, with single individuals expressing apprehension about entering marital commitments, whereas married participants feared potential abandonment by their spouse or significant changes in the dynamics of their relationship. The real responses were;

- *It has not been easy… I don't know which job I will be able to do. Yes, it affected me, like I have people that want to marry me, but I cannot accept them. Because as a human being, I don't want anything that will cause problems. I don't know how to tell them… (P8, Female, 22 years, Trader)*

### 3.2.4 Stigma and Its Impact[45]

Participants narrated their ordeals regarding the stigma effect of being diagnosed and treated for HIV. Some expressed the shame they felt when others recognized their status which altered how they interacted with them. Conversely, some participants highlighted how their

[44] ibid
[45] ibid

family members have assisted in concealing their HIV status aiming to mitigate the potential shifts in behaviours resulting from knowledge of their condition. The real responses were;

- *Even the time I told my bosom friend, and he went around telling people and when I came back, I noticed the way they were doing, how we used to shake hands before, some of them keeping their hands, so when I noticed, I had to call him and he didn't deny, so no problem. (P19, Male, 27 years, Student)*

Some articulated the circumstances around them that influenced their attitude. These include the fear of stigmatization especially if people see them taking their medications, lack of funds and the exhaustive effect of taking the medications repeatedly. The actual responses were;

- *Ah, initially I took it as normal, I thought the drugs they were giving me would give me another thing, it was not like…you know. I am just tired of taking the drugs. It's not easy, sometimes I forget to take it, so I had to put it where I can see it., you know I'm old. (P11, Female, 87 years, Trader but no longer trading)*

Here also, are some individuals in Nigeria who have openly shared their HIV-positive status to challenge stigma and support others by sharing their experiences.

a. Aisha Bello:[46]

Diagnosed with HIV in 2000. She faced significant adversity, including the dissolution of her marriage and societal ostracization. Despite these challenges, she became the first Muslim woman in Kaduna State to publicly reveal her status. Aisha now dedicates her life to

[46] Daily Trust. (2023). Despite living with HIV/AIDS, I overcame adversity and found courage – Aisha Bello. Daily Trust. Retrieved from https://dailytrust.com/despite-living-with-hiv-aids-i-overcame-adversity-found-courage-aisha-bello

supporting other women living with HIV/AIDS, providing transportation to medical appointments and offering counsel to those in similar situations.

5. Ogechi Stella Njoku:[47]

After enduring multiple traumatic experiences, including being raped twice, Ogechi Stella Njoku was diagnosed with HIV. Rather than succumbing to despair, she pursued higher education, became an Oracle Database Certified Expert, and established her own company. Ogechi emphasizes that HIV is a manageable condition and advocates against the stigma and discrimination that often accompany the diagnosis.

## 4.0 Socio-Legal Challenges in Obtaining Informed Consent from PLWHA

Informed consent is a crucial ethical and legal requirement in socio-legal research involving PLWHA in Nigeria. However, challenges such as stigma, legal uncertainties, and cultural complexities make the process difficult. To uphold ethical standards, researchers must prioritize confidentiality, use culturally appropriate consent procedures, engage communities, and ensure compliance with legal protections. By addressing these challenges, socio-legal research can contribute meaningfully to understanding and improving the rights and well-being of PLWHA in Nigeria.

### 4.1 Fear of Disclosure/Stigma

A major barrier to obtaining informed consent for research is the fear of disclosure. PLWHA fear that their status might be revealed, leading to discrimination and social stigma in

[47] The Guardian Nigeria. (2023). The Ogechi Stella Njoku story: Raped twice, living with HIV, and standing tall against all odds. The Guardian Nigeria. Retrieved from https://guardian.ng/guardian-woman/the-ogechi-stella-njoku-story-raped-twice-living-with-hiv-and-standing-tall-against-all-odds. See also UNICEF. (2023). My face, my voice: Living positively with HIV in Nigeria. UNICEF Nigeria. Retrieved from https://www.unicef.org/nigeria/stories/my-face-my-voice

employment, healthcare, from the general public and even from families.[48] Hence, they are reluctant to disclose their status through voluntary participation in any form of research. Cultural misconceptions and religious beliefs that associate HIV/AIDS with immorality and promiscuity mostly directed towards females also tend to pose a challenge to getting informed consent from female PWLHA.[49] The fear of stigma through disclosure of status before marriage and employment can also affect the informed consent of PLWHA.[50]

Researchers must therefore take extra steps to ensure that consent processes uphold the principles of beneficence[51] and non-maleficence[52] and in protecting the confidentiality and autonomy of PLWHA.

It must be noted that the use of anonymous data collection and secure storage of information would better ensure stricter confidentiality measures to mitigate the fears of disclosure.

### 4.2. Poor Comprehension and Low Levels of Literacy

Informed consent documents in Nigeria are often written in English and as such many illiterate PLWHA rural dwellers are less likely to be familiar with medical and legal terminologies, due to low literacy levels.[53] Researchers on the other hand too, may not be able to effectively translate legal and ethical terms into local languages or culturally appropriate expressions. Even oral explanations may be misinterpreted due to lack of shared

[48] Moalusi, K. P. (2018). "Employees' experiences of the stigma of HIV in a retail organisation: Secrecy, privacy or trust?" African Journal of AIDS Research, 17(4), 313–322. doi: 10.2989/16085906.2018.1536671.
[49] Akinbebije C. O. et al (2020) "Cultural Factors and Sexual Practices of Women Living with HIV/AIDS in South West, Nigeria" Kampala International University, https://hdl.handle.net/20.500.12493/14645.
[50] Folayan, M. O.et al (2014). Supra

[51] This means maximizing benefits while minimizing harm
[52] This means avoiding harm
[53] Ezeome, E. R and Marshall, P. A. (2009) Supra

vocabulary around rights, ethics, or research processes. .[54] Hence, the ability of PLWHA to fully understand the consent process may not be there. There is therefore, the need for the researcher to adopt culturally appropriate and accessible means of communication, such as using local languages to explain difficult terminologies with the help of visual aids.

### 4.3. Risks of Undue Influence

It is important for the researcher to remember that it is unethical to exploit the vulnerability of PLWHA in obtaining consent through the provisions of incentives. PLWHA may suffer from the pressure of undue influence where financial incentives are promised and if they feel that the re searcher has an aura of authority over them. In such cases it could be said that PLWHA have given consent due to external pressures and not out of free will.[55] Also, in Nigeria where a large percentage of the population already live below the poverty line, the combination of suffering from HIV/AIDS more often than not multiply the struggles to get basic necessities such that informed consent may be unduly influenced because of incentives promised.[56]

### 4.4 Cultural and Religious Challenges

Due to Nigeria's heterogenous societies, there is the presence of cultural and religious influences. PLWHA in almost all families especially when it comes to major decision-making, heads of families, religious leaders, or even community elders are likely to influence PLWHA choices to participate in research as result of traditional beliefs and religious

[54] Afolabi M.O. (2014) "Multimedia Informed Consent Tool for a Law Literacy African Research Population: Development and Pilot- Testing". Supra
[55] Ezeome, E. R and Marshall, P. A. (2009). Informed consent practices in Nigeria. Supra
[56] ibid

doctrines that they hold.[57] Some PLWHA may feel compelled to participate based on the advice or pressure from community authorities. Also, in certain traditional or religious settings, females lack autonomy in decision-making.[58] This cultural dynamic raises ethical concerns about autonomy and the extent to which consent is truly voluntary.[59]. "Consent may be formally obtained, but culturally it is not freely given." [60]

It is therefore necessary for researchers to discreetly channel these cultural and religious norms in a way that will still ensure that consent remains voluntary and informed.

### 4.5 Ethical Dilemmas and Legal Requirements

Although Nigeria has, the legal requirement of mandatory disclosure of HIV status under the Nigerian HIV/AIDS anti-discrimination laws most especially before marriage can be conducted and also before employment is given and also the reciprocal protection from discrimination through its emphasis on confidentiality.[61] In reality the government seems to pay lip service in its weak implementation. There is often no clear legal recourse if a participant's rights are violated.[62] Also, legal protections for data privacy and participant welfare in non-medical (i.e., socio-legal) research are still evolving.

This has created ethical dilemmas for researchers because it causes PLWHA to fear legal repercussions and also suffer from breach of confidentiality, making them to deny the researcher their informed consent.[63] This fear may make them reluctant to participate or give consent under pressure. Even when confidentiality is promised, mistrust in the system and

---

[57] Ezejimofor M.C and Nwabueze R.N (2021) Supra and see also Ezeome, E. R and Marshall, P. A. (2009). supra

[58] Ezejimofor, M. C and Nwabueze, R. N. (2021). Consent, culture and autonomy in African settings: Rethinking the paradigms in HIV research. Bioethics in Africa, 12(1), 55–70.

[59] ibid

[60] ibid

[61] Adebayo S. (2019) HIV/AIDS and the Law in Nigeria: A Critical Analysis of Legal Protections and Gaps. Nigerian Law Journal of Human Rights, 7(2), 45-63

[62] NHREC. (2014). National Code of Health Research Ethics. National Health Research Ethics Committee of Nigeria.

[63] Adebayo S. (2019) HIV/AIDS and the Law in Nigeria. Supra

researchers can persist. [64]"Fear of being 'outed' keeps many away from even fully understanding what they're consenting to." [65]

Researchers must navigate these legal challenges while ensuring that participants' rights are upheld.

### 4.6 Mistrust and Past Negative Experiences

PLWHA may view researchers with suspicion, especially if the research is associated with government or foreign institutions.[66] This is due to negative past experiences with researchers or organizations. Negative experiences like unkept confidentiality, unfulfilled promises of benefits and incentives, or exploitative practices can erode trust.[67]

### 4.7 Researcher's Personal Bias and Ethical Troubles[68]

It is not unlikely that researchers of PLWHA themselves may underestimate the complexity of the true nature of obtaining pure voluntary consent in socio-legal contexts. This makes them to begin to rush the consent process due to deadlines or funding pressures.

### 4.8 NGO and Healthcare Interventions[69]

In many cases, researchers go through HIV-focused NGOs, support groups, or healthcare providers to access PLWHA. These intermediaries often do not give chance for pure

[64] Adebajo, S. B et al (2014). Prevalence of HIV and associated factors among men who have sex with men in Nigeria. The Lancet Global Health, 2(8), e348–e357. https://doi.org/10.1016/S2214-109X(14)70228-3
[65] ibid
[66] Marshall A. and Batten S.D (2004), "Researching Across Cultures: Issues of Ethics and Power Forum" qualitative Social Research 5(3) Article 39
[67] Oluwafemi D (2019) "Enforcement of Research Ethics in Nigeria: Challenges and Prospects, Nigeria Health Law Review" 7(2) 102-115.
[68] Tindana, P. et al. (2012). "The informed consent process in a rural African setting: A case study of the Kassena-Nankana District of northern Ghana". IRB: Ethics & Human Research, 34(1), 1–6.
[69] CIOMS. (2016). International Ethical Guidelines for Health-related Research Involving Humans. Council for International Organizations of Medical Sciences.

voluntary consent because they may try to filter or influence PLWHA participants, or even pressure them to take part. This is against the principles of ethical considerations.

### 4.9 Difficulty in Sustaining Ongoing Consent[70]

Socio-legal research on PLWHA is definitely not a quick or fast process, and may involve long term studies, repeated interviews, or follow-ups. Participants are therefore likely to forget or misunderstand the evolving nature of the research or may be unavailable for next appointments. Researchers too, may on their part, assume that a one-time consent suffices and therefore neglect to reaffirm consent over time.

## 5.0 CONCLUSION

It is quite clear that PLWHA in Nigeria face numerous challenges. The number one challenge being stigma and discrimination. Despite legal protections, many PLWHA continue to experience discrimination and social stigma and this has become the root cause of all other challenges. These challenges we have seen, range from economic hardships, limited healthcare access, low levels of literacy, legal barriers, and mental health issues. These socio-cultural, legal, and practical challenges affect informed consent among PLWHA. Researchers must therefore adopt skilful tactics in their ability to combine adhering to ethical standards on issues of confidentiality, trust, and voluntariness with cultural sensitivity through community engagement.

Therefore, with concerted efforts from the government, civil society, and international organizations on developing a stronger legal enforcement on protections, improved healthcare access, economic empowerment programs, and mental health support in communities for PLWHA because of their vulnerability, Nigeria would be able to create a

[70] Tindana, P. et al. (2012). supra

more inclusive and supportive environment for them, improving their quality of life and overall health outcomes.

Above all, it is prudent to view informed consent in socio-legal research on PLWHA as a procedural requirement and more importantly as an ethical commitment to respect, protect, and empower participants.

This study therefore, calls for continuous ethical considerations, enhanced researcher training, and community engagement as necessary steps towards achieving truly informed and meaningful consent in research on PLWHA participants in Nigeria.

## 6.0 Recommendations for Best Practices for Ethical Research

### 6.1 Legal Safeguards and Advocacy

Nigeria's HIV/AIDS Anti-Discriminatory Act of 2014 aims to protect PLWHA in their workplace and from healthcare discrimination, yet there are hardly any violations that are being reported yet alone prosecuted. Therefore, there is need for the government to strengthen the enforcement of the Act by increasing public awareness, encouraging report of violations and stigma and prosecuting those violations. Hence, the need for government to step up to a greater collaboration between legal professionals, health workers, and communities. Where this is done, it becomes much easier for PLWHA come out boldly and give their informed consent to researchers. Researchers too, should not only be familiar with Nigeria's legal framework on HIV/AIDS but also ensure they themselves comply with all the laws and ethical (local and international) guidelines such as the NHREC and also advocate for policies that enhance the protection of PLWHA research participants.[71]

[71] ibid

Also, researchers need to know that seeking approval from ethics review boards to safeguard PLWHA rights and well-being in conjunction with legal experts and human rights organizations can help to handle any legal issues related to informed consent.

### 6.2 Community Engagement for Nigeria's Heterogenous Societies

As earlier stated in this study, Nigeria is a country full of diverse languages, cultures, traditions and religious beliefs and low literacy levels. Community engagement can be used to address cultural concerns and misconceptions about research on PLWHA. Hence, to help those with low literacy levels there is the need for culturally sensitive consent processes such as translating informed consent documents into local languages via audio or video mechanisms as consent options. The use of visual aids and culturally relevant storytelling methods would also be of help to understanding the participants giving consent and in cases where oral consent is more appropriate instead of depending solely on written forms, researchers should document the process while respecting PLWHA preferences.[72]

Secondly, in order to gain trust and confidence, the researcher needs to employ culturally appropriate engagement strategies by engaging heads of families, local leaders in the communities about the intended research work to be done in the community. Even though involvement of community leaders can improve credibility, it is still very necessary to ensure that PLWHA participation in research is voluntary and that their rights are not compromised by social expectations.[73]

Thirdly, it must be noted that public education campaigns can also help reduce stigma and discrimination, thereby promoting a more inclusive and supportive society for PLWHA.

---

[72] Adepoju A. (2020). Cultural Barriers to Informed Consent in HIV/AIDS Research in Nigeria. African Journal of Ethics, 12(3), 112-126

[73] Ezejimofor M.C and Nwabueze R.N (2021) Supra

Fourthly, legal and social programs should support female PLWHA in vulnerable situations to prevent gender-based violence, by ensuring they have access to protection and justice in their communities. This is why it is necessary to have community engagement so that rural areas in particular could be educated as to how females are at the helm of discrimination and need joint effort in their protection.[74]

### 6.3 Amendment of Consent Forms to be PLWHA Centred

In furtherance to the above, apart from the fact that consent forms should be written in a way that participants can understand, PLWHA should be given ample time to give consent due to their particular vulnerability. Also, consent should be an on -going thing instead of a one-time agreement, however the fact that one of the ethical principles are that participants have a right to withdraw at any time of the research may suffice instead.

### 6.4 Qualitative Ethics Training for Researchers

Ethical review boards must ensure that research protocols adequately address confidentiality risks. The NHREC must improve on the training of researchers most especially when it concerns PLWHA. These group of people are worst hit when it comes to stigma and social discrimination. So, researchers are to properly guided in treating PLWHA data with utmost confidentiality Researchers should adopt stringent confidentiality protocols, such as using pseudonyms instead of using real names, storing data securely, and limiting access to identifiable information.[75] Also, researchers should be able to conduct consent procedures in private and safe locations so as to prevent unintended disclosure.

### 6.5 Improving on Healthcare and Mental Services

[74] UNIADS (2021). See also Adepoju A. (2020) supra
[75] National Health Research Ethics Committee of Nigeria [NHREC], (2016)

More investment in healthcare infrastructure, especially in rural areas, is needed to ensure PLWHA receive consistent and affordable treatment. It would be good if researchers can collaborate with government to put forward policies that are implementable so that PLWHA through the genuine provision of incentives at the end of the research would be provided essential support in the medications of anti-retroviral drugs that can improve their quality of life and response to research efforts.

Also, a lot of PLWHA suffer from depression, anxiety, suicidal thoughts due to the stigma and discrimination from the society at large.[76] Hence, the need to upgrade our health care facilities to include mental health care services in the form of offering psychological support to be integrated into HIV treatment programs to help PLWHA cope with emotional and mental health challenges.

### 6.6 Researcher Responsibility and Ethical Reflexivity

Researchers must endeavour to build trust, engage community gatekeepers, and employ culturally sensitive communication strategies. Some scholars are even advocating for ongoing consent, where participants are regularly reminded of their rights and the nature of the research.[77]

When all the above is done, researchers are rest assured that PLWHA will consent more easily and voluntarily to research work.

[76] Ezejimofor M.C and Nwabueze (2021) supra

[77] Tindana P. et al., (2012). "The informed consent process in a rural African setting: A case study of the Kassena- Nankana District of northern Ghana". IRB: Ethics & Human Research, 34(1), 1–6.