



Informed Consent as a Challenge to Social Research Execution in Nigeria

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INTRODUCTION

The drive for knowledge acquisition and exhibition is a phenomena activity or an exercise in our contemporary dynamic world. Man, by nature is an inquisitive being with a flourishing desire to be armed with the requisite knowledge of the circumstance *inter alia* surrounding his daily existential reality. The capacity for survival in such an ever-changing and growing world is traceable to positive adaptation which draws inspiration from research (Chukwu, Ebue, Obikeguna, Arionu, Agbawodikeizu & Agwu, 2016). Research is not a haphazard exercise, rather, it is systematic. It is systematic in that the process has specific pre-arranged sets of procedures and steps which are required to adopt to have accurate results. Hence, Bennett (1983) aptly defined it as a systematic, careful inquiry or examination to discover new information or relationships and to expand or verify existing knowledge for some specified purpose. The core objective of research is adding to or expanding knowledge frontiers by ensuring knowledge vacuums are filled through discoveries, enhancing theory construction, verification and testing of corpus of knowledge, enabling the identification of relationships among variables, thereby enhancing human progress.

Some of the reasons for the orderly or systematic nature of research include the ethical principles, guidelines or standards that researchers are expected to adopt to ensure their safety as researchers, as well as that of their respondents. The pertinence of ethical rules in research include the protection of participants' right and privacy, guarantee of the public's right to know, protection of the researcher from undue litigations, ensuring the doors for future generations of researchers are opened, etc. (Harrison, as cited in Aghedo, 2017, p.). Furthermore, Aldred (2008) averred that the Economic and Social Research Council (ESRC) – a major funding body for social science researches in the United Kingdom – has provided six principles to guide the relationship between researchers and their participants, viz:

1. Integrity and quality (the character of honesty and excellence)
2. Full disclosure about the research to research staff and subjects
3. Confidentiality and anonymity (the character of secrecy)
4. Voluntary participation by participants
5. Avoidance of harm to participants
6. Avoiding or disclosing conflicts of interest

Similarly, Wiles, Charles, Crow and Heath (2006) highlight the basis for core ethical decisions in social research to encompass allegiance to respondents' right (e.g. protection of privacy), promise of respect for participants, and the protection of the researcher (which includes being saved from unnecessary litigations, etc.). However, these research ethics or principles have been violated in several ways. Diener and Crandall (1978) for instance, have categorized these unethical research practices into four major interwoven areas as follow:

- i. **Deception of Respondents.** Deception in research occurs when a researcher provides incomplete information to participants with an intention to mislead the research subjects. Covert research is usually mixed with deception and condemned as an unethical practice (Spicker, 2011). Deception happens in research when researchers represent their work as something different from what it actually is. Due to the fact that researchers want to limit participants' knowledge of what the research entails, so as to ensue natural or uncompromised response to the experimental process, they tend to deceive the participants (Bryman, 2012). It is rarely feasible (if not totally impossible) to furnish participants with the unmitigated account of what a particular research is about. Lying or misrepresentation in order to gain access to data is deception
- ii. **Harm to Participants.** This involves any act that is deemed to cause physical harm, loss of self-esteem, stress, harm to participants' development and inducing subjects to perform reproofing acts. So, there is further encouragement for the protection of participants through confidentiality of records and one of the problems with the harm to participants' principle is the difficulty in identifying in all circumstances what constitutes harm (Bryman, 2012). Worthy of mention is the fact that participant involves both the researcher.
- iii. **Privacy Invasion.** The right to respondents' privacy is a basic tenet and its infringement is not condoned or treated with kid gloves. The British Sociological Association (BSA) avers that anonymity and privacy of research participants should be accorded utmost respected (Bryman, 2012).

In the discussions of privacy, the dominant element is individual's control of information concerning him or herself. Gilbert (2001) explains that in our contemporary industrial society, information is a commodity. Also, keeping information about oneself and divulging what one feels necessary and to whom one feels necessary is a key means of ones' privacy protection.

- iv. **Lack of Informed Consent.** This is a process in which a person learns key facts about a clinical trial, including potential risks and benefits, before deciding whether or not to participate in a study (Nnebue, 2010). Getting informed consent from a prospective participant becomes difficult if what he or she is consenting to and where participation begins and ends is opaque (Miller & Bell, 2002)

The shocking discoveries about the opprobrium within some countries of the world where doctors, scientists and others alike; acting on the behalf of government and organizations ignore the rights of individuals, who are subjected to different magnitudes of injuries and sometimes death in the name of research engendered this paper. For instance, today, Forced Organ harvesting has attained a sinister dimension and it occurs on a massively state sanctioned level (Palin, 2016). The total number of legal transplant in China is about ten thousand (10,000) per year, but they surpass this figure. Sixty thousand to one hundred

thousand (60,000 – 100,000) organs are transplanted every year in Chinese hospitals. The volume in excess is gotten from people without their consent (Palin, 2016). So, this paper is tailored to informed consent (one of the core ethical principle in the research process) which is obtainable in both the physical and social sciences.

MEANING AND ATTRIBUTES OF INFORMED CONSENT

Faden and Beauchamp (1986) defined informed consent in two senses: Moral and Socio-legal. Morally, they defined informed consent as an autonomous authorization of one's participation in research. But in the socio-legal sense, informed consent concerns the practices and conventions that make it socially or legally acceptable to involve a person as a research subject, and this comprises the principles, rules, cultural, and professional guidelines governing informed consent in research.

Similarly, Chima (2017) defined Informed Consent as a legal and ethical doctrine derived from the principle of respect for autonomy; while Van Oosten (1989) asserts that informed consent is a requirement for all lawful investigations as a well-established principle. Succinctly put, it is:

...the process where a participant is informed about all aspects of the trial, which are important for the participants to make a decision and after studying all aspects of the trial, the participant voluntarily confirms his or her willingness to participate in a particular clinical trial and significance of the research for advancement of medical knowledge and social welfare (Nijhawan, Janodia, Muddukrishna, Bhat, Bairy, Udupa, & Musmade, 2013, p. 134).

Informed consent has three dimensions, viz: Knowledgeability or Information – participants must have the requisite or adequate information about the research; Volition or Voluntary Participation – participation must not be via inducement, coercion or deception; and Competent Choice or Comprehension – participants must have the capacity to understand and make an informed choice (Goduka, 1990; Thorne, 1980; Aghedo, 2017). Similarly, Pedroni and Pimple (2001) highlighted the four elements of informed consent to include: Information, Understanding, Voluntariness and Decision Making Capacity. In furtherance, Tekola, Bull, Newport and Adeyemo, (2009) added 'consent' (that is, participant's agreement to involve in the proposed research) to the aforementioned elements. Nnebue (2010) further opined that informed consent is only deemed valid when the participants are competent and their involvement is voluntarily given.

To ensure that the above elements are pursued to birth compliance with ethical guidelines and embrace a continuous improvement, Miller and Bell (2002), concluded that 'consent' should be constant. That is, it should be an ongoing and a renegotiated occurrence between the researcher and the researched throughout the research period. It should not be a condition of once gotten, forever gotten.

Nevertheless, Informed consent has generated a heated debate especially in disguised or covert observation which involves covert participant observation or contrived observation which hides the researchers' true identity where the emphasis is on the 'end justifies the means'. The focus of informed consent is that prospective research participants should have as much information as possible to avail them of the capacity to make an informed decision of whether to participate or otherwise (Bryman, 2012). But covert observation negates this principle in its

entirety because participants are disallowed from making an informed decision of whether or not to participate.

In the case of harm to participants (when there is an informed consent), it is mildly received when compared with when there is none. Erikson (1967) opined that if informed consent principle is not followed and participants are harmed due to the research, the researcher is bid to be more culpable than if the participants knew the implication. To him:

If we happen to harm people who have agreed to act as subjects, we can at least argue that they knew something of the risks involved (Erikson, 1967, p. 369).

In essence, when there is harm to participants, the vilification of a researcher is higher in cases where informed consent are not sorted and gotten. This aligns with the view of Smyth and Williamson (2004) which emphasizes non-therapeutic research could not be carried out except there is informed consent of the individual (not minding the benefits to the general society).

The merits of adhering to the research ethics of informed consent are enormous. First, it educates the respondents on his or her rights. Thus, the respondent is educated on the fact that he or she has right to discontinue at any point if he or she so desires. Second, the right upon which the participant is educated gives him or herself the liberty to divulge information about him or herself which he or herself is comfortable with and deemed necessary and to whom one feels necessary. Third, it saves the researcher from unnecessary litigation when there is harm to participants. Also, Informed consent is easy and imperative to practice in literate societies. Lastly, though not the list, it helps to mollify the issue of deception in research.

In applying or justifying the principle of informed consent, Pedroni and Pimple (2001) adduced consequentialist and non-consequentialist reasons. Consequentialist reasons are based on the conviction that there are actions that ought to be taken to achieve expected implications like being able to get participants' cling to laid-down procedures, and enhance research quality, thereby fostering public confidence on the research. On the other hand, non-Consequentialist reasons for adopting informed consent are based on the indigenous or in-built qualities of persons or actions.

Informed Consent is classified into consent (adult respondents); parental consent or permission (needed by parents or guardians for their children or minors); assent (for a child between the ages of 7-17 year's affirmative agreement to participate in research); verbal (reading the elements of the research to participants verbally); and short form (used to break language barriers).

Nnebue (2010) highlights that the verbal and written information to the respondents should include the identity of the researcher, the purpose of the research, explanation of complex procedures to the participants, identity of others associated with the research, reasons why the participants have been selected, harms and benefits, privacy, anonymity and confidentiality, future use of information, time to reflect, description of any alternatives to participating in the research project, and the regulations prohibiting, waiving or appearing to waive any legal rights of participants.

THE ORIGIN OF INFORMED CONSENT

Prior to the introduction of ethical principles to guide the conduct of research in the global space, researches were done without due recourse to respect for the fundamental human rights of the participants. Research participants were treated worse than slaves. Historically, the concept of Informed consent is placed firmly in the principles of Nuremberg Code of 1947, The Declaration of Helsinki (1964), The Belmont Report of 1979, The Council for International Organizations of Medical Sciences (CIOMS) Guidelines of 1982, and International Conference on Harmonization (ICH) to set up guidelines for Good Clinical Practices (GCP) in 1996.

Informed Consent started as a reactionary movement or outrage against the globally condemned atrocious dispositions of Nazi doctors (German doctors and scientists under the Adolf Hitler's regime) during the World War II era in the concentration camp where humans were reduced to mere experimental samples. The German doctors and scientists experimented with thousands of prisoners at the concentration camp who were used as human guinea pigs with all the paraphernalia of impairment by deep and persistent injuries sometimes resulting in the death of their participants. But at the end of the war, people were severely appalled by the horrors of the human experiments and the desire for a change was birthed. A war crimes tribunal was set up and after investigations; it convicted many of the infamous Nazi Doctors and scientists. So, as a remedy to forestall future occurrence, the War Crime Tribunal prescribed ethical guidelines to officially regulate the patterns of future experiments. This innovation is what became known as the Nuremberg Code of 1947. This became the first major international guidelines on research ethics, and its emphasis was hinged on the notion that the voluntary consent of the research participants or human subject is absolutely indispensable (Nijhawan, *et. al.*, 2013; Pedroni & Pimple, 2001; Aldred, 2008; Aghedo, 2017). Whenever a researcher is conducting a research which involves human beings, their consent must be sorted and gotten. So, the written decisions which were the emphases of the Nuremberg Code are:

- i. Participants should be availed the requisite knowledge of the research.
- ii. Based on the participants' knowledge of the research, he or she must be able to agree to participate before they are made to get involved in a research expedition.
- iii. That such consent should be void of coercion (not pressured or put under duress).
- iv. That participants should be made to understand the implications or consequences (risks and benefits) of their participation.
- v. Researchers must minimize risks or harms to participants by ensuring that the risks do not outweigh the benefits.
- vi. Researchers should emphasize the guarantee of participants to withdraw if they so wish and at any time they so wish (Nijhawan, *et. al.*, 2013).

The second epochal move for research guidelines was the 1964 Declaration of Helsinki, when the World Medical Association (WMA) in Helsinki, Finland embraced or domesticated twelve principles to regulate the activities of physicians and scientists on ethical matters that concerned biomedical research. Its focus was hinged on differentiating between medical care that directly benefits the patients and research that may not provide direct care (Nijhawan, *et. al.*, 2013).

The third major development was the 1979 Belmont Report. It identified three basic ethical conducts of research which include: Respect for persons, recognizing the dignity of individuals,

and protection of those with induced or diminished autonomy such as children, persons with disabilities, the aged, etc.

On the line of continuous improvement, the next was the 1982 World Health Organization (WHO) and the Council for International Organization of Medical Sciences (CIOMS)'s creation of International Ethical Guidelines for Research involving human subjects. It was organized to implement the ethical principles of the Helsinki Declaration.

MASS ILLITERACY IN NIGERIAN SOCIETY

Mass Literacy is one of the indices of development. Increasingly, there has been awareness on the essence of education. The awareness became domesticated by Article 26 of the General Assembly of the United Nations in 1945 which adopted the Universal Declaration of Human Rights on the 10th of December. The article clearly states that: "Everyone has the right to education" (Iwe, 1978; Nwafor, Naboth, & Agi, 2013). Despite the fact that many countries have been working round the clock to achieve basic learning needs of education for all, the global capacities still remain at the lowest ebb. Acquisition of literacy still remains very low (Wagner, 2002).

Historically, before the Nigerian political independence in October 1st, 1960, the dominant formal learning facilities which were basically faith based were Quranic schools in the North and Missionary schools in the south. Later, the Islamic clerics introduced Arabic literacy to the Northern part of the country, while the Christian missionaries, who later came introduced literacy to southern Nigeria and some parts of the inland region (Aderinoye, 2002).

CHALLENGES OF INFORMED CONSENT ACQUIREMENT

Homan (1991) opined that executing the principle of informed consent is easier said than done. There are several challenges bedeviling the acquirement of informed consent in a semi-illiterate society. They are as follow:

- i. It is difficult (if not impossible) to acquire informed consent from a population sample that has a large chunk of participants who are illiterates. The true and noble intention of the researcher may be misconceived. This has the capacity of frustrating or shrinking the informed consent dimensions of knowledgeability, voluntary participation, and competent choice as espoused by Thorne (1980).
- ii. Despite the significance of informed consent, it can easily be affected or hindered by language barrier. For example, in Northern Nigeria, there is language barrier to the extent that a large chunk of the population cannot understand Pidgin English (an abridged form of English language in Nigeria), and getting informed consent is very difficult. A researcher may not be able to explain to the respondent what he or she needs to do due to the incidence of language barrier. It is believed that a respondent who appends his or her signature to consent form does so, having a grasps of the full content of the content form, but it is not always that way.
- iii. There is difficulty in its extreme in presenting prospective participants all the required information to elicit informed decision about their involvement. If the participants are armed with the absolute details, they may not be interested in the research. Also, people tend to behave differently at the slightest notice of being observed thereby altering the results.

- iv. It is problematic seeking informed consent from groups that are classified or characterized as 'vulnerable'. Examples of people that fall into such classification are children, the aged, and people with disabilities especially those with learning impairment (Wiles, *et al*, 2007).
- v. It could provide a safe haven for organizations or cartels or rogue governments which are into illicit deals to remain invincible. This affirmed the reason why Penn and Soothill (2006) pointed out that there are risks in religiously embracing the ethical principle of informed consent. They mused that playing too safe carry its own risks. Bell and Bryman observed thus:

The principle of informed consent can make it difficult to gain understanding of groups that do not want to be studied, such as business and government elites even if it may be argued that it is in the interests of public accountability that such groups should be studied (Bell & Bryman, 2007, p. 68)

- vi. In the face of a large volume of prospective participants, it is difficult to ensure that everyone is availed the chance for informed consent. In an everyday context, it is highly disruptive.
- vii. It can be affected by religious inclinations. Religion plays a vital role in the daily existence of Nigerians. Most times, every individual's behaviour is shaped by the principles of that particular religion. In the face of contradiction with such religion, there is every tendency for refusal. In Northern Nigeria, women are regimented, so it is difficult getting their consent.

MANAGING THE CHALLENGES TO ENSURE RESEARCH VALIDITY

In managing the challenges of getting informed consent to ensure research validity, frantic efforts must be invested by:

- i. Government who is to ensure that a large chunk of the population attains literacy. This can be made possible by Free and Compulsory Education Scheme where government monitors to ensure that people who are supposed to be in school are not on the streets as beggars, urchins or hawkers.
- ii. The researcher should go extra mile to apply sign language or gestures to scale the mountain of language barrier. Also, the researcher can apply for the services of an interpreter to avail undistorted communication.
- iii. The researcher should be able to give the respondents mental reorientation as it relates to the nobility of the research. This is to ensure that the respondents are not compromised at the event of knowing that they are being observed, so as not to alter the ultimate result.
- iv. There should be little flexibility or exemption clauses in research ethics to assist researchers to adequately research on organizations, cartels or rogue governments that are into illicit deals. This will also help researchers who are frustrated due to lack of access to some organizations by powerful or secretive authorities.
- v. Government should budget adequately for research so to ensure researchers are able to handle large volume of prospective participants. This will deal with the envisaged highly disruptive use of informed consent in an everyday context.

- vi. Religious leaders would have to be mentored on the essence of research, so as to give room for liberality and assurance for the people to be advised accordingly.

CONCLUSION

This paper highlighted that informed consent is used for eliciting the consent of respondents, however, using it in real life issues becomes a problem. This is because of the incidences of illiteracy, language barrier, religious inclinations, cost, etc. The concerted efforts of researchers, government, and relevant organizations are required to surmount these difficulties. The use of interpreters, sign languages, etc. is not left out in mitigating the challenges of informed consent in Nigeria.

The various dimensions of Informed consent that were discussed are Knowledgeability or Information, Understanding, Volition or Voluntary Participation, Competent Choice or Comprehension and consent. The application of these elements protects prospective research participants from abuse, injuries, and death. The paper concludes therefore, that irrespective of the challenges of applying the ethical principle of Informed Consent, its advantages are lofty.

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