

**A REPLICATION STUDY OF RACIAL DIFFERENCES IN
PERCEPTIONS OF VOLUNTARINESS OF MEDICAL
RESEARCH PARTICIPANTS**

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A research report submitted to the School of Applied Human Sciences, University of KwaZulu-Natal, in partial fulfilment of the requirements for the degree of Master of Social Science (Clinical Psychology).

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ACKNOWLEDGEMENTS

First and foremost, I extend my sincere gratitude and recognition to my supervisor, Professor Douglas Wassenaar. He journeyed this academic road with me. I thank him for his prompt and constant guidance throughout my academic journey.

My gratitude also goes to Mr. Tsikati for his invaluable time and expertise in analysing data for this study.

To my husband, Mr. Mfundo Dube, thank you for rallying behind me throughout this journey. I am humbled by your love and support.

My utmost gratitude goes to my mother, Mrs. Thandekile Dlamini. Thank you for all the sacrifices you made to ensure I get educated. Thank you for believing in me and continuously supporting me even in the most difficult of times.

To my son, Siyabuswa Simelane and my daughter, Siyabusiwa Simelane, your subtle cheering was never unnoticed. You are my pillar of strength and a source of great inspiration. Thank you for understanding that sometimes I needed to be away from you because I had to study. Thank you for your everyday prayers, they have brought me this far.

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ABSTRACT

Oppression of Black people in South Africa created inequalities that rendered Black South Africans vulnerable. Many participants from disadvantaged backgrounds in South Africa are likely to participate in medical studies primarily to earn financial and/or medical incentives. This raises concerns about the voluntariness of research in South Africa and racial perceptions of voluntariness of medical research, given the mistrust created by previous racial oppression. This study aimed to assess racial differences in public perceptions of the voluntariness of medical research participants. The sample size was 120 and consisted of 46 Black, 39 Indian, and 35 White participants. A questionnaire was used to obtain respondents' opinions. Results showed that there were no significant differences in racial perceptions of voluntariness. However, Black people were less willing to volunteer themselves for future medical research compared to White and Indian respondents. Results also showed that participants' level of education, knowledge of medical research procedures, and close or personal experience of medical research were not predictors of perceptions of voluntariness.

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CHAPTER 1. INTRODUCTION AND RATIONALE

1.1 Introduction

There have been many controversies surrounding research studies that involve human participants. A number of guidelines have been published to ensure that research is conducted in an ethical manner. Giving consent to participate in a study is one of the most essential elements of ethical guidelines (Wassenaar, 2006) and for that consent to be valid it has to be informed. The potential participant must also be competent to make that decision to participate and, consent must be voluntary (Foster, 2001). Obtaining voluntary consent from potential research participants is a fundamental ethical requirement (Mamotte & Wassenaar, 2015). Mamotte and Wassenaar (2015) argued that there is minimal consensus amongst researchers in terms of the constituents of voluntary consent to participate in research and the lack of consensus has resulted in a raise of concerns about the voluntariness of consent to research. The lack of consensus is also symptomatic of an underdeveloped position of empirical research on the voluntariness of consent to research (Mamotte & Wassenaar, 2015).

Financial and medical incentives have raised concerns about the voluntariness of consent (Wassenaar & Mamotte, 2015). Additionally, the recruitment of vulnerable populations into research has equally raised concerns about the voluntariness of consent.

Given that health research in South Africa is increasingly in extent and complexity due to the HIV pandemic and other diseases in general, it is clear that local cultures, religions, behaviour patterns and significant influential histories are to be considered if studies are to be conducted ethically. South Africa was characterised by a lengthy reign of racial discrimination and violations of human rights of Black people. This resulted in Black communities being rendered vulnerable due to poverty, illiteracy, historical oppression and poor access to health care. These vulnerabilities may possibly exert some form of pressure for people to participate in medical studies (Manafa, Lindegger & IJsselmuiden, 2007). This suggests that many participants from disadvantaged backgrounds in South Africa are more likely to participate in medical studies

primarily to earn extra money (provided by some researchers as incentives) to help alleviate poverty (Getz & Burfitz, 2002). This, then, raises concerns, not only about the voluntariness of research in South Africa, but also about racial perceptions of voluntariness given the mistrust created by previous racial oppression. This then leads to the research question of this project.

1.2 Aim and Rationale

This project aims to conduct a replication study in order to examine public perceptions of voluntariness of medical research participants in South Africa. The study was done by Barsdorf & Wassenaar (2005) in trying to determine whether the conduct of medical research in South Africa was perceived as being voluntary and whether only socially powerless and disadvantaged people were perceived as subjected to unethical research (Barsdorf & Wassenaar, 2005). This study is being replicated in order to find out if the public still holds similar sentiments (over a decade later) as found in the original study.

Secondary aims of the study are to establish if level of education, knowledge of medical research procedures, and close or personal experience of medical research are predictors of racial perceptions of voluntariness. Lastly, the study aims to investigate whether there are racial differences in participants' willingness to volunteer themselves for medical research.

1.3 Structure of the Report

This research report consists of six chapters outlined below:

Chapter 1 introduces the study. Aims and rationale of this study are outlined and the structure of this research report are described.

Chapter 2 will discuss research ethics as a concept, defining its fundamental purpose. The section further discusses the eight benchmarks of ethical research and how they guide and ensure researchers conduct research in an ethical manner. The literature further discusses the history of unethical research, focusing on how the Tuskegee Syphilis study, the Nazi experiments and

Guatemala STD inoculation could have possibly influenced public perceptions of voluntariness in medical research.

Additionally, the chapter will discuss how apartheid could have possibly influenced and perpetuated the conduct of unethical research in South Africa. It discusses some of the controversial unethical experiments in South Africa, including the Aversion Project and the Virodene PO58 Controversy. Informed consent and voluntariness will then be discussed as critical concepts that are a cornerstone in research ethics. Lastly, a discussion of public perceptions of medical research and voluntariness will conclude the chapter.

Chapter 3 outlines the procedures followed to conduct this research. A discussion on quantitative research will be presented, followed by the description of the participants, the sampling method, and the research instrument utilized in this research. The chapter further describe the data collection procedure, the method of data analysis accompanied by a brief discussion on the validity and reliability of the study. Finally, a discussion of ethical considerations regarding the study will be provided.

Chapter 4 presents and describes the results of this study. The first part presents the demographics of the sample, followed by the differences in perceptions of voluntariness of medical research participants between Black, Indian and White participants. Findings on whether differences in perceptions of voluntariness were independent of participants' education levels, knowledge of medical research procedures, and experience of medical research are presented. Lastly, results on whether there are any racial differences in respondents' willingness to volunteer themselves for medical research are presented.

Chapter 5 of the research report discusses and explains the findings of this study with reference to the literature reviewed.

Chapter 6 presents a summary of the main findings and general conclusions of this study. Limitations of this study are discussed and suggestions for future research into racial perceptions of voluntariness conclude the chapter.

CHAPTER 2. LITERATURE REVIEW

2.1 Introduction

The literature review will begin by addressing research ethics as a concept, defining its fundamental purpose. The section further discusses the eight benchmarks of ethical research and how they guide and ensure that research involving human participants is conducted ethically.

The literature review progresses to discuss the history of unethical research, discussing how the Tuskegee Syphilis study, the Nazi experiments and Guatemala STD inoculation could have possibly influenced public perceptions of voluntariness in medical research.

The literature review will further explore how apartheid in South Africa set in place a framework of discriminatory policies and practices and how those were used as a point of reference in targeting Black people as research participants. The section will discuss some of the controversial unethical experiments in South Africa, including the Aversion Project and the Virodene PO58 Controversy. Informed consent and voluntariness will then be explored as critical concepts that are a cornerstone in research ethics. Lastly, this section will explore public perceptions of medical research and voluntariness.

2.2 Research Ethics

Research evidence has become an important basis of education, policy making and health interventions. Research is imperative and should be done with utmost care. This is more applicable in studies where human participants are involved (Israel & Hay, 2006, in Wassenaar, 2006). Ethical guidelines were established to ensure that human participants are protected when conducting studies involving human participants. Ethical guidelines can be defined as those general judgements that serve as a primary justification for the many ethical prescriptions and evaluations of human actions (Emanuel, Crouch, Arras, Moreno, & Grady, 2003) (Emanuel, Crouch, Arras, Murreno, & Grady, 2003). The fundamental function of research ethics is to ensure that the welfare of research participants is protected and that scientific misconduct is minimised (Wassenaar, 2006). Protecting human participants should be paramount in all social, clinical and health service research (Feussner, Burris, McGlynn & Lavori, 2002). This is

usually achieved through the reviewing of research proposals by an independent Research Ethics Committee (REC) before data are collected (Wassenaar, 2006). The review of research proposals occurs to ensure that exploitation in studies is minimised.

Generally, exploitation can be delineated as acting in an unfair manner in order to benefit from that particular situation or someone. In research, exploitation occurs when X obtains inequitable assumption of benefits or risks consequential to acting together with A (Emanuel et al., 2004). This suggests that during exploitation, benefits are a result of unfair manipulation of situations or of people.

In addition, Emanuel et al. (2004) argue that exploitation is more likely to occur in developing or low and middle income countries than in developed or high income countries. This can be attributed to the fact that in developed countries, society finances research to improve the level of health. In these countries, research fraternities are an element of the society and within those, there are structures in place to translate research findings into practical health interventions that will benefit the entire society (Emanuel et al., 2004). However, in developing countries it is often a different case altogether. The risk of exploitation is likely to be greater because people or communities who participate in studies may assume the risks of research and not gain the benefits of the research. Often, the benefits may be directed to people in developed countries (Emanuel et al., 2004).

Moreover, vulnerable individuals may be susceptible to enticements to participate in research due to minimal or lack of income, limited access to health care and limited access to other significant resources (Nelson & Merz, 2002). For instance, some participants may perceive research participation as a means to access health care they otherwise could not afford.

According to Nelson and Merz (2002), a study of 56 women enrolled in a perinatal HIV study in a hospital in South Africa found that, nearly all of the women felt compelled to participate in order to access enhanced medical care. Vulnerability to exploitation is likely a function of lack of income, disease, desperation for treatment, and lack of alternatives. Additionally, inadequate resources in developing countries may render regulatory structures ineffective in minimising the risk of exploitation of research participants in developing countries (Emanuel et al., 2004).

Ethical guidelines require that research participants must be well informed about the possible risks and benefits of the study and that their consent to be involved as research participants should be informed and voluntary (Feussner, Burris, McGlynn, & Lavori, 2002). Foster (2001) adds that, in trying to establish whether a study is ethical or not, it is imperative to consider what the research aims to achieve and how it can be done in such a way as to minimize harm to the research participants and maximize benefits.

There are eight elements of ethical research that have been proposed by Emanuel et al., (2004) as a framework to guide researchers to more ethical research practices. They are designed to provide researchers and REC members with articulate and consistent considerations to evaluate the ethical standing of a certain study (Wassenaar, 2006). These principles, if carefully considered and applied together, are likely to enhance the ethical standing of the study (Wassenaar, 2006). It is also vital to know that these eight principles are equally important; however, not all of them are going to be applicable to every possible study (Wassenaar, 2006). These are discussed in more detail below.

2.3 Eight Elements of Ethical Research

2.3.1 Collaborative partnership

This element requires that researchers make certain that the development of the research being conducted is done collaboratively with the target community/population (Wassenaar, 2006) and policy makers (Emanuel et al., 2004). This dimension has benchmarks that are essential to this element; firstly, it requires the fair representation of all parties involved in the study and secondly it requires collaboration, which comprises of shared responsibility for conducting a needs assessment for the research and the significance of the research to the community. Collaboration also comprises of disseminating the results, making sure that they are used for health improvements as relevant to that particular community (Emanuel et al. 2004). Thirdly, collaborative partnership requires mutual respect between the research participants' community and the researchers. This means that researchers should be sensitive to the community's values, cultural traditions and practices (Wassenaar, 2006). Also, benefits of the research, tangible or

intangible should be distributed fairly among partners and not just the researchers (Emanuel et al., 2004).

2.3.2 *Social value*

This dimension requires that the research should address challenges that are significant to communities where research is being conducted (Wassenaar, 2006). The study must generate knowledge with the aim of utilizing research outcomes in future health interventions that will result in advanced health systems. The lack of social value in a study means that participants are made vulnerable to risks for no valid rationale and can be a waste of resources (Emanuel et al., 2004). There are four benchmarks important to this dimension: firstly, the research should explicitly state who will benefit from the research (e.g. local community, the host country or people outside the country) (Emanuel et al., 2004), and secondly, the research should specify in what way the prospective beneficiaries might benefit, be it indirectly or directly (Wassenaar, 2006). Thirdly, using collaborative partnerships, strategies should be formulated to disseminate results in appropriate language formats to key stakeholders. This can be done through community gatherings where presentations can be done in such a manner that the community can easily comprehend (Emanuel et al., 2004). Lastly, in conducting the research, researchers should be cognizant of the community's existing health services and should work in collaboration with them (Emanuel et al., 2004).

2.3.3 *Scientific validity*

This element states that the study design, methodology and data analysis should be thorough, justifiable and realistic (Wassenaar, 2006) to ensure reliable and valid findings. The lack of reliability and validity in a study is considered unethical because such studies do not only produce invalid and unreliable results, but also waste resources and expose participants to risks with no foreseeable benefit. (Wassenaar, 2006). Lastly, the scientific validity element suggests that the researchers should ensure that the study is realistic in relation to the social, political, and cultural context or that local health care improvement and physical structures are sustainable (Emanuel et al., 2004).

2.3.4 *Fair selection of participants*

This element of ethical research emphasizes that selection of study participants should be based on the relevancy of the potential participants to the study question (Wassenaar, 2006). This is to make certain that the selection process renders valid findings (Emanuel et al., 2004). Vulnerable populations should be identified and protected from being exploited just because they are easily accessible to the researchers (Emanuel et al., 2004). It is only fair that those who are most likely to benefit from the outcomes of the research are those who should bear the largest burden of the research and vice versa (Wassenaar, 2006). Lastly, the element also states that it is imperative for researchers to employ clarity and transparency when explaining to the participants or host community how participants were selected (Emanuel et al., 2004).

2.3.5 *Favourable risk-benefit ratio*

This dimension requires researchers to carefully assess and identify all the potential risks and benefits of the research, possible anticipated harm as well as costs of the research to the participants. The possible risks, harms and costs should be minimized as much as possible to ensure that the risk-benefit ratio is favourable (Wassenaar, 2006). In addition, there must be protection measures and contingencies in place to deal with anticipated harms (Wassenaar, 2006).

2.3.6 *Independent ethical review*

An independent and competent REC should ensure that all research proposals are reviewed before data collection (Wassenaar, 2006). This is also done to ensure public accountability as a directive by the laws and regulations (Emanuel et al., 2004). Moreover, proficient and independent reviews are conducted to ensure minimum exploitation and increased protection of research participants. Improved quality of the study procedure is also a fundamental purpose of ethics review (Wassenaar, 2006). The REC will also review scientific elements of the study in order to determine whether the methods used in the study are suitable, bear risk of harm or possible benefits, and will consider alternate, safer methods of conducting the research (Wassenaar, 2006).

The significance of RECs in South Africa is also accentuated by legislation. The South African National Health Act 61, of 2003 mandates that all institutions, health agencies and health establishments at which health research is conducted, must establish or have access to a health research ethics committee (REC), which is registered with the National Health Research Ethics Council. The Act instructs that designated RECs must review research proposals and protocols in order to ensure that research conducted by the relevant institution will promote health, contribute to the prevention and cure of diseases or disabilities. RECs are further mandated to grant approval of research in instances where research proposals and protocol meet the ethical standards of that REC.

2.3.7 *Informed consent*

Individual informed consent has been perceived as the most important principle of ethical research for at least sixty years (Emanuel et al., 2004). Factors such as language variations, social traditions and practices are bound to affect the process of informed consent in developing countries and therefore, special attention needs to be paid to this aspect (Emanuel et al., 2004). This can be achieved by providing prospective participant with understandable, in depth and accurate details pertaining the study. Details describing the study's processes, possible risks and benefits, assured voluntariness of participation and liberty to refuse or withdraw without consequence if participating in the study causes discomfort should be disclosed to potential participants (Wassenaar, 2006). Researchers also need to ensure that information pertaining to the research is disclosed using communication formats that are easier to understand, and the same goes for consent; it should be obtained in a culturally and linguistically appropriate manner (Emanuel et al., 2004). It is also imperative for researchers to be cognizant of the complexity, ethically and legally, of research with minors. It is therefore essential that research with minors can only be conducted after consent has be sought with legal guardians or caregivers and assent has been provided by the minor if risks are minimal (Wassenaar, 2006).

2.3.8 *Ongoing respect for participants and study communities*

The ethical conduct of researchers is a continuous process that goes beyond obtaining informed consent or when data has been collected (Emanuel et al., 2004). Researchers have continuing responsibility to participants and the host community. This element, therefore, suggests that participants should be treated with ongoing respect during and after a study (Wassenaar, 2006). This can be achieved through allowing participants to withdraw from the study at any point, ensuring that new emerging details pertaining to the study are provided to participants at any point during the study, monitoring and developing interventions for participants' wellbeing throughout the research and respecting participants' privacy by maintaining confidentiality and anonymity (Wassenaar, 2006). In addition, key stakeholders should be informed of the results or findings of the study in a culturally and linguistically appropriate manner (Emanuel et al., 2004) to empower the community with the knowledge that has been obtained (Wassenaar, 2006).

These principles represent a systematic structure that provides specific fundamental practical considerations obligatory to justify research ethically (Emanuel et al., 2004). Thorough consideration and thoughtful implementation of these eight elements of ethical research will increase the chances that the research is conducted in an ethically appropriate manner and that knowledge is obtained without participants being exposed to avoidable risks and harm (Wassenaar, 2006).

2.4 History of Unethical Experiments

It cannot be disputed that medical research has increased and improved the well-being and standard of living of the human race around the world and in Africa (Emanuel et al., 2003). Through medical studies, the onset, progression and effects of diseases can be determined and treatment can be discovered through therapeutic and so-called non-therapeutic research (Ogungbure, 2011). However, it is also true that there have been instances in the history of medical research where unethical conduct occurred during certain studies. Some of the better known unethical studies are the Tuskegee Syphilis study, the Guatemala STD inoculation study, the Nazi experiment, Milgram's obedience study and the Stanford prison experiment conducted

by Phillip Zimbardo (Wendler et al., 2006). Some of these studies have even played a role in influencing the formulation of certain ethical codes that serve as guidelines for conducting research with human participants (Wendler et al., 2006). These ethical codes provide a regulatory structure which ensures that human participants in medical research are protected from exploitation (Ogungbure, 2011). For instance, the Nuremberg code came as a result of the Nazi experimentation on prisoners and captured populations.

2.4.1 The Nazi experiments

An experiment that has gained notoriety is the Dachau Human Hypothermia experiment conducted at the Dachau concentration camp between August 1942 and May 1943. This was one of many Nazi experiments. The experiment aimed at establishing the most effective treatment for victims of immersion hypothermia, especially members of the German air force who had been shot down into the cold waters of the North Sea (Berger, 1990). There were about 280-300 subjects who were civilian prisoners of different religions and nationalities as well as Russian prisoners of war (Berger, 1990). About 360-400 experiments were done which means that some subjects underwent the immersion more than once.

During experiments, subjects were submerged in a tank of ice water, some anesthetized and others conscious, some dressed and others naked (Berger, 1990). After a specified period, the subjects were removed from the ice water and a number of different re-warming methods were used on the subjects. The Dachau Comprehensive Report suggests that the subject's body temperature continued to fall despite being removed from the ice water and this might have been responsible for the death of many of the subjects (Berger, 1990).

Most of the time, the participation of subjects was forced but sporadically it was "voluntary". Subjects were falsely promised release from camp or commutation of death sentence if they participate in the study (Berger, 1990). Evidently, this information reveals critical shortcomings ethically and scientifically. As a result of the unavailability of ethical guidelines, the Nuremberg Code was promulgated in 1974 (Ogungbure, 2012). This document was drafted by a panel of global experts on medical research, human rights and ethics. The code's main focus is the requirement of voluntary consent of the individual human subject, and evaluating the anticipated

potential human benefits against risks to the participant (Ogungbure, 2012). The document contains ten basic principles that describe requirements for ethical medical research (Emanuel et al., 2003).

In response to the Nuremberg trials and the Nuremberg Code, the World Medical Association drafted the Declaration of Helsinki (last updated in 2013) which aims at providing guidelines for conducting ethical medical research (Emanuel et al., 2003). The code was implemented in 1964 and remains the global criterion for medical research (Blakmer & Haddad, 2005 in Ogungbure, 2012) that emphasises basic ethical requirements such as informed consent, minimized risks to participants.

2.4.2 *The Tuskegee Syphilis study*

One of the most infamous and controversial medical studies in the history of medical research is the Tuskegee Syphilis study that was conducted in 1932. This study was initiated by the US Health Services in untreated African American males (Washington, 2006) in Macon county Alabama USA. The study aimed at looking at the progression of syphilis in black men because earlier it was indicated that the progression of the disease had different outcomes for both black and white people (Washington, 2006). It is imperative to note that when the study was initiated, there was no treatment available for syphilis. The United States of America's government left more than 400 black men who were infected with syphilis untreated in order to study the course and progression of the disease even after effective treatment became available (Villarosa, 2010). The sick men were never told that they are subjects being followed for long-term "no-treatment" study. They were only told that they had "bad blood" and were promised free medical care (Ogungbure, 2011). The men and their families, vulnerable, uneducated and poor, were given free food and were promised money and offered free burial if they allowed the researchers to conduct autopsies on their bodies after they died (Villarosa, 2010).

Some of the participants in this study suffered serious effects as a result of the untreated infection including paralysis of limbs due to severe and dangerous spinal tap procedures used to obtain fluids from the participants' spinal cords, severe neurological damage, death due to advanced syphilitic lesions, infected wives. Many children were born with congenital syphilis (Ogungbure,

2011). Even after such severe consequences, doctors withheld treatment and were determined to observe the subjects through to autopsy (Ogungbure, 2011).

This was the longest experiment on human beings in the history of medicine and public health. Initially, it was anticipated that the study would only last six months but ended up lasting forty years (1932-1972) (Ogungbure, 2011). The study raised many ethical issues which include lack of appropriate informed consent, unfair subject selection, lack of on-going respect for participants, unfavourable risk benefit ratio, paternalism and racism as some of the ethical issues of concern (Ogungbure, 2011).

Due to the Tuskegee Syphilis study, congressional hearings took place in 1973 and in 1974 the United States Congress passed legislation creating the National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research (Ogungbure, 2012). The commission published "*The Belmont Report*" which provides ethical guidelines for discussing issues associated with using human participants in a study. It is more comprehensive than the Nuremberg code and has had a significant influence on regulations regarding human subjects research (Ogungbure, 2012). The Belmont Report consists of three main components (boundaries between research and practice, basic ethical principles, and applications) that are relevant to research involving human participants (Emanuel et al., 2003). Even though these principles are considered comprehensive, they cannot always be applied so as to resolve beyond dispute particular ethical problems (Emanuel et al., 2003).

2.4.3 *Guatemala STD inoculation study*

Similar to the above unethical experiment is the Guatemala Syphilis Experiment that was done in Guatemala from 1946 to 1948. Unlike the Tuskegee study, the scientists in the Guatemala syphilis study deliberately infected Guatemalan prisoners, soldiers, and mental health patients with Syphilis and other sexually transmitted diseases to study the effectiveness of penicillin (Villarosa, 2010). The researchers also aimed at studying the progression of the syphilis and testing new preventative treatments (Minogue & Marshall, 2010). The scientists used incarcerated men as research participants whom they exposed to syphilis by allowing infected

prostitutes to sleep with them and used mental patients, who were infected through injections or had the bacteria poured into wounds (Villarosa, 2010).

According to Lynch (2012), the Guatemala STD study created a false impression that the study was unethical because researchers intentionally infected their subjects with STDs. He argues that the intentional infection is not the key ethical issue because it is not an anomaly in medical/experimental research that human subjects are exposed to disease pathogens, it has been happening for centuries and still remains an important tool even in this day (Lynch, 2012). In addition, this study design shares key characteristics with widely accepted challenge studies on human participants and can be conducted in an ethical manner, provided certain safeguards are implemented (Lynch, 2012). The fact that these protective measures were not implemented in Guatemala is the key ethical issue not the fact of intentional exposure itself.

After conducting a thorough review of the facts, President Obama's recall commission found that there were a number of specific problems concerning the Guatemala study and these include the use of vulnerable subjects without consenting voluntarily to the study, failure to ensure a reasonable balance of risks and benefits, and the lack of scientific justification of most of the procedures done during the study (Lynch, 2012).

Reflecting on this brief history of unethical research studies, it is evident that human participants were exploited and researchers did not take ethical elements sufficiently into consideration. Even though there were no guidelines to guide most of these studies, the researchers did not even make an effort to at least ensure voluntary consent in these studies. These studies are prime examples of medical superiority, abusive state power, unethical behaviour and racism in research (Reverby, 1999). The following discussion reviews some of the unethical experiments conducted in South Africa.

2.5 Unethical Experiments in South Africa

The history of human rights violation is a prominent characteristic in the history of South Africa. It set in place a sophisticated framework of policies and practices that were discriminatory and severely detrimental to the health of black South Africans while directly beneficial to the health of white South Africans (Baldwin-Ragaven, de Gruchy & London, 1999). The development of

policies and services was also regarded as a biased process that did not emerge as a result of reasonable responses to the needs of the community but to the needs of the white South African population. However, their development was more often governed by the viewpoints held by the ruling authorities in the country (Baldwin-Ragaven et al., 1999). Research was not an exception, due to their evident vulnerability, Black populations were easier potential subjects and the fact that this made for easier experimentation in controversial areas (Baldwin-Ragaven et al., 1999). Some reported cases of unethical research done in South Africa, recorded during and after the apartheid era are listed briefly below.

2.5.1 The Aversion Project 1971-1989

South Africa's apartheid army reportedly forced approximately 900 soldiers (mainly White men) to undergo "treatment" to "re-program" their sexual orientation in the 1970s and 1980s in military hospitals (Baldwin-Ragaven et al., 1999). This was conducted as part of a high profile program to eliminate homosexuality from the service. The soldiers were subjected to chemical castration, electric shock and other unethical medical experiments without consent (Baldwin-Ragaven et al., 1999). With the assistance of chaplains, army psychiatrists allegedly aggressively ascertained suspected homosexuals from the armed forces. They were sent discreetly to military psychiatric units where those who could not be 'cured' with drugs, aversion shock therapy, hormone treatment and other psychiatric means were chemically castrated.

2.5.2 The Virodene P058 Controversy 1997-1998

The Virodene controversy began in 1997 when three University of Pretoria scientists announced they had developed a drug that would kill the AIDS virus (Cohen, 1997). The trio were condemned for not following standard research protocol. Their work had never been published or submitted for peer review. They had also failed to submit the trial protocol to the Medicines Control Council or the university's Research Ethics Committee for approval (Cohen, 1997). Worse still, they had already tested Virodene on Aids patients without permission from the university's REC, or the Medicines Control Council. Any further testing of the drug on human participants was suspended by the Medicines Control Council, However, despite the suspension, Virodene trials were reportedly conducted in 1998 on six healthy and 36 HIV-positive

individuals (Cohen, 1997). Later reports suggested that thwarted efforts were also made to test the drug on the military in Tanzania.

2.5.3 *The FTC-302 Trials at Kalafong Hospital 2000*

The Medicines Control Council suspended the AIDS drug FTC-302 trial at Kalafong Hospital in Pretoria. This transpired after deaths of 6 trial participants were reported (Vermaak, 2000). The researcher was accused of coercing trial participants to sign consent forms they did not comprehend. The trial was conducted by Quintiles Clindepharm on behalf of United States-based Triangle Pharmaceuticals (Vermaak, 2000).

Such reports of unethical experiments conducted both abroad and in South Africa reflect the complete disregard of the protocol of informed consent and voluntariness during research. The next section reviews the concepts of informed consent and voluntariness and how these concepts have the ability to validate research practices.

2.6 **Informed Consent**

Informed consent has been set up as the foundation of research ethics. Hewlett (1996) defines informed consent as an independent authorization by one person to another person to carry out an agreed procedure which affects the participant. Therefore, by asking the participants to assent to research, their wishes are respected and it allows for self-governing and upholds the standard of respect for persons. Getz and Borfritz (2002) add that informed consent is the potential participant's bill of rights. These rights were formally recognized in 1979 in the *Belmont Report* which states that in order for informed consent to be fully recognized and valid, it has to meet three requirements (Getz & Borfritz, 2002). These requirements are 1) Research participants should be given all information about the study including benefits and risks in a culturally and linguistically appropriate manner, 2) The information must be easily understood by research participants and 3) Research participants who agree to participate must do so voluntarily and must not be coerced or pressured in any way (Getz & Borfritz, 2002). In addition, the participant should be fully informed about the study in writing and must provide his or her written consent (Manafa et al., 2007).

Even though obtaining informed consent from prospective participants may seem easy, it is not that simple, it can be very complex and it is imperative that researchers are aware of the challenges that they may face while trying to obtain informed consent. In developing countries, cultural, linguistic, economic and social factors may become barriers in obtaining informed consent (Benatar, 2002). Therefore, it is essential to ensure effective communication in order to address such possible barriers (Benatar, 2002).

Anthropologists have documented several drawbacks and difficulties that might be faced when obtaining meaningful informed consent under these circumstances (Lindegger & Richter, 2000; Marshall, 2001 in Benatar, 2002). For instance, work in Uganda has suggested that socio-economic inequity between researchers and participants often result in participants feeling that they have an obligation to participate in research studies and they also encounter challenges with the language in which codes of behaviour are written, as well as errors made in translation (Benatar, 2002).

As mentioned earlier, one of the core elements of informed consent is the freedom of participants to choose to take part in a study without any form of coercion (Manafa et al., 2007). In spite of this, voluntary participation in most clinical studies is difficult to ensure as pressure to participate may present itself in many different but subtle forms. For instance, pressure may come from community leaders, family members, the power and authority of medical professionals and the fear of losing health benefits (Manafa, et al., 2007). These factors (and many more) can inhibit free and individual choice to participate in research. Moreover, informed consent also gives the participant the opportunity to decide what they shall and shall not agree to (Getz & Burfitz, 2002). It is important to know that in any study, voluntariness is achieved through lack of coercion and unjustified influence (Getz & Burfitz, 2002), Freedom from undue pressure should not end at the start of the study but should be maintained for the duration of the study (American Psychological Association, 1973).

2.7 Voluntariness

Even though the significance of voluntariness has been consistently emphasized, a number of reports and news articles have raised concerns that certain recruitment and consent practices may limit the possibility of voluntary informed consent. There is minimal consensus on what constitutes voluntary participation (Mamotte & Wassenaar, 2015). Hewlett (1996) delineates voluntariness as an independent act that is without controlling influences exerted by others. These influences include coercion, manipulation and persuasion. However, this model's definition depends largely on the intentional actions of others. It does not address the influence of circumstances which are common in consent to clinical research and which poses an easily overlooked risk to voluntariness. According to Nelson and Merz (2002), voluntariness is an exercise of free will. It is an act done with intent and deliberateness, and one that is free from coercion and undue influence. According to Hewlett (1996) the absence of controlling influences and the ability to choose either one of at least two options is more likely to ensure that consent to research is sufficiently voluntary. Manafa et al. (2007) argued that voluntary consent is whereby "a person acts voluntarily to the degree that he or she wills the action without being under the control of another's influence" (p. 26). However, Manafa et al. (2007) fail to account for other forms of pressures as indicated by Hewlett (1996).

The lack of consensus in defining voluntary consent to research has resulted in substantial opposing opinions about voluntariness of consent to research participation amongst researchers. Also, without a theoretical background, researchers are likely to rely on their own personal understanding of voluntariness (Mamotte & Wassenaar, 2015). In a review by Mamotte and Wassenaar, (2015) only five out of 15 studies made preliminary attempts to assess validity and reliability of their instruments and only six of the 15 attempted to explain how voluntariness was conceptualized. These findings reflected by Mamotte and Wassenaar (2015) could be a result of the lack of theoretical background and clear definitions of voluntariness of consent. This may also be an indication that the field of voluntariness of consent has not evolved.

To explore the abovementioned problem, researchers have attempted to investigate participants' decisions to participate in medical research. Previous studies have failed to provide a clear

picture of whether most research participants give voluntary informed consent (Pace & Emanuel, 2005). The difficulty in doing so can be partly attributed to the lack of comparability of the survey instruments used in different studies and the small size of most studies. Moreover, divergent opinions about what constitutes voluntary consent to research and what types of ethical transgressions undermine voluntariness still remain a serious conundrum (Mamotte & Wassenaar, 2015).

In their original study, Barsdorf and Wassenaar (2005) assessed 111 black, white, and Indian South African citizens about the racial perceptions of voluntariness of research participation. Their results showed that there were significant racial differences in respondents' perception of voluntariness, and that black respondents displayed low perceived voluntariness compared to their white and Indian counterparts. This suggested that black respondents perceived research participants' consent to be less voluntary than did white or Indian respondents. A review of the survey questionnaire by Pace and Emanuel, (2005) revealed that even though some of the questions in Barsdorf and Wassenaar's questionnaire directly investigated informed consent, other questions did not seem to quite capture perceptions of voluntariness because they seemed unrelated to voluntariness. Pace and Emanuel, (2005) suggested that while some of the questions in the survey were not related to voluntariness, their scores contributed to the overall score that predicted respondents' perceived voluntariness. This need not have a negative bearing on the study, but could be used as data that could reinforce the hypothesis about the influence of apartheid on perceptions of black citizens about medical research. Pace and Emanuel, (2005) further suggested that "the data on perceptions about participant's selection might have broader implications, suggesting a need for educational interventions about the goals and conduct of research, not just the process of informed consent, to change public perceptions" (p. 12.).

2.8 Public Perceptions of Medical Research and Voluntariness

Racism in South Africa was the defining characteristic of the apartheid era and has played a significant role in maintaining power inequalities (Barsdorf & Wassenaar, 2005). Black communities were rendered vulnerable due to poverty, illiteracy, historical oppression and poor access to health care. This has played a role in exerting some form of pressure for people to

participate in medical studies (Manafa et al., 2007) to access better health care. This would mean that poor people were more likely to participate in medical studies primarily to earn extra money (provided by researchers as incentives) to help alleviate poverty (Getz & Burfitz, 2002). A number of participants in a study conducted by Freimuth et al., (2001) on African Americans' views on research suggested that monetary reimbursement was perceived as a significant motive for participating in a study.

Similarly, it is believed that the reason why racial and ethnic minority groups in the US, more especially African-Americans, are less willing than non-Hispanic whites to participate in health studies can be attributed to past abuses like the notorious Tuskegee Syphilis Study (Wendler et al., 2006). Numerous studies have also reflected that African Americans are less likely to get immunizations of any kind due to mistrust (Villarosa, 2010). These instances of minority groups being undermined and abused in health studies might have increased individuals' suspicions and drastically decreased their level of trust. The notion that minority groups are not adequately represented in some medical research studies is validated by studies suggesting that various factors, including historic abuses like the Tuskegee study, may have undermined minority groups' trust in medical research, as measured by survey questions and focus groups (Wendler et al., 2006).

In exploring possible factors that could impede African Americans to participate in medical research, several factors were brought to the fore, and these include mistrust of the medical/scientific fraternity, limited access to medical care, the challenge posed by difficulty to actively recruit African Americans, linguistic and cultural barriers (Shavers-Hornaday, Lynch, Burmeister & Torner, 1997). In addition, Freimuth et al., (2001) suggested that barriers to participation in research can be attributed to broader health care system issues, descriptive of potential participants, public knowledge, perceptions and attitudes towards researchers and research itself, and lastly behaviours and attitudes of providers and researchers. Also, fear of exploitation and the legacy of the Tuskegee Syphilis Study are perceived as very significant barriers to African Americans participating in medical research (Freimuth et al., 2001).

2.9 The Tuskegee Legacy

The perspectives and suspicions that African Americans hold about medical research may be based on historical events which promoted medical misuse and showed no regard for research subjects during medical studies, especially if they were minorities or disadvantaged individuals (Shavers-Hornaday et al., 1997). This at times may outweigh the self-evident truthfulness and commitment of individual researchers who want to conduct reliable and valid medical research that has potential to improve human life. The legacy of the Tuskegee Syphilis Study has come into view as the most frequently cited modern event to justify African Americans' mistrust of medical research (Freimuth et al., 2001). The Tuskegee study is believed to provide justification for common doubts about the ethical concerns in medical research especially where it concerns Black people taking part in studies (Thomas & Quinn, 1991 in Freimuth et al. 2001).

The repercussions of the Tuskegee study still continue to negatively influence African American perceptions and attitudes of the medical and scientific community (Shavers-Hornaday et al., 1997). One of the repercussions is the fact that minorities have a legitimate fear that researchers conduct research in a racial discriminatory approach (Shavers-Hornaday et al., 1997). This information has the ability to hinder minorities from participating in medical research that is fundamental in addressing discrepancies in health status (Freimuth et al., 2001). Also, looking at the compromised relationship brought about as a result of prior history of social and medical abuse by white researchers towards minorities, it is expected that African American are going to be suspicious of the intentions of the white medical/scientific fraternity (Shavers-Hornaday et al., 1997).

In a study done by Shavers-Hornaday et al. (1997), 28 African American, Native American and Hispanic respondents cited fear, mistrust, and unawareness as three major reasons why their respective groups were not willing to take part in medical studies. The study also reflected that respondents stated 'mistrust of white people' as a cultural factor that played a role in their unwillingness to participate in medical research (Shavers-Hornaday et al., 1997). Interestingly though, data from a more recent report by Katz et al. (2008) showed that there was no

statistically significant difference in having in depth knowledge about the Tuskegee study and fear of participation by either Black people or White people.

Moreover, it is also interesting to note that data from a follow-up analysis based on the 1999-2000 4- City Tuskegee Legacy Study failed to show that awareness of the Tuskegee Syphilis Study has a direct effect on willingness to participate in biomedical studies for either Black or White people, across three of the cities studied (Katz et al., 2008). The only statistically significant finding was that in the city of Tuskegee (the historical epicentre of the infamous event), Black people who were aware of the Tuskegee Syphilis Study were less willing to participate compared to Black people who were not aware of the Syphilis study Katz et al., (2008).

Likewise, Katz et al., (2007) in a study that aimed at exploring the willingness of minorities to participate in biomedical studies, found that while both Blacks and Puerto-Rican Hispanics were more likely to report higher levels of fear in relation to participation in biomedical studies than whites, they were nonetheless just as willing as the whites to participate in medical research. This proves to contrast with most studies and what authors have hypothesized especially in relation to the historical medical research which was said to have brought a lot of fear and mistrust among African Americans to participate in medical research. Also, the findings showed that Hispanics were more likely to be willing to participate in biomedical research compared to black people even though the significance was borderline (Katz et al., 2007). These results are also reflected in the original study by Barsdorf and Wassenaar (2005) where they aimed at ascertaining racial differences in public perceptions of voluntariness of medical research participants. Their results showed that even though there were racial differences in perceptions of voluntariness of medical research, more than 50% of the sample were still willing to volunteer themselves for future medical research.

The results reflected above were consistent with those of Brown and Topcu (2003) who also found no statistically significant difference between black and white people who self-reported willingness to participate in biomedical research (Katz et al., 2007). It is interesting that in the same study; results clearly reflected that the same black participants who are willing to

participate in biomedical research also indicate a very high level of distrust in biomedical research among black people compared to white people (Katz et al., 2007), similarly to Barsdorf and Wassenaar (2005). This would suggest that just because people have fear and mistrust surrounding biomedical research does not mean they are less willing to participate in any biomedical research.

2.10 General Perceptions of Medical Research

This part of the literature review will explore some of the perceptions held by the public about medical research. In a study conducted by Freimuth et al., (2001), African Americans, Hispanics, and Native Americans were asked their views of what an experimental study is and respondents perceived it as experimentation in which people were used as guinea pigs. Some perceived an experimental study as a study that facilitates learning about a disease and medication and believed that the benefits of participation in such studies were to help other people and assist in finding a cure for a certain sickness (Freimuth et al., 2001). This shows that while some people may perceive medical research as a forum where people are used as guinea pigs, some people do see the beneficial side of medical research.

Moreover, some respondents perceived medical research as something that is reserved for certain people like middle class white people because most of medical studies conducted are based in universities and therefore many African American respondents felt that university medical facilities are only open and reserved for selected people and not the minority population (Freimuth et al., 2001). This has also acted as a barrier that impeded minority groups from partaking in medical studies (Welsh, Ballard, Nash, Raiford, & Harrell, 1994).

Another significant perception that is held by people that keeps appearing in a number of studies is the argument that black people view medical research as untrustworthy. According to Shavers-Hornaday et al., (1997) this can be attributed to the fact that medical associations were supporting racist social institutions which allowed the use of black people as slaves and easy access to black people in medical research. Gamble (1997) agrees that the history of medical experimentation in African Americans during slavery laid the groundwork of mistrust in medical

research. In addition, theories disseminated by medical/scientists perpetuated the idea of racial inferiority among black people and justified why black people were misused in medical research (Shavers-Hornaday et al., 1997). Freimuth et al., (2001) concur that in medical research, mistrust of white people is a common theme that appeared in his study on African Americans' view of research. It is necessary to be cognizant of the fact that many African Americans perceive research within the context of racism, urban legends and mistrust in health care and the larger society and that their fears and concerns are legitimately based on historical reality (Shavers-Hornaday et al., 1997).

Freimuth et al.'s study that aimed to understand African Americans' attitudes towards research revealed that participants were consequently in agreement from the start that African Americans needed to be very vigilant about their interaction with the medical system. This caution was applied across all areas of involvement with the medical fraternity, treatment and initiatives designed to promote health and well-being of African Americans inclusive. Additionally, given the past abuses and the inability to be certain that past abuses will never occur, African Americans made an agreement that participation in medical research should be avoided (Freimuth et al., 2001). This reflects the level of mistrust against medical research and the perception that African Americans can never be too sure that past abuses will never happen again.

The proliferation of the notion that AIDS is a man-made weapon to destroy the black race is also useful in exploring the attitudes and perceptions of people about the medical/scientific community and also further affirms the extent of distrust that African American have towards the medical and scientific fraternity (Shavers-Hornaday et al., 1997). In 1990, A survey was done by the Southern Christian Leadership Conference to look at African Americans' perception of AIDS. Of the 1056 black church members surveyed, 35% of them revealed that they believed and viewed AIDS as a form of genocide and it is believed that more African Americans hold this belief as true. As a result, the participation of African Americans in AIDS reduction programmes and other medical studies is minimal (Shavers-Hornaday et al., 1997).

From the review of literature, there is little doubt that certain factors have the potential to influence public perceptions about medical research and its voluntariness. One other factor is the influence of education and its role in perceptions of voluntariness of medical research. Noting the limited literature on the influence of participants' education on perceptions of voluntariness, a study by Nyika, Wassenaar and Mamotte (2009) assessed the effects of relationships in decision-making process and autonomy of women which was conducted in Harare, Zimbabwe. From their study, it emerged that higher levels of education amongst participants were associated with less impetus to keep respondents' participation a secret from their husbands. The results reflected that none of participants with vocational or university education were prepared to keep their participation in research secret from their husbands (Nyika et al., 2009). Only less than 3% of women with university education reflected an inclination to keep participation secret from their significant others, which was an indication that women with education were less willing to keep their participation secret from their relatives. About 42% of respondents of women with no formal education were more willing to keep research participation a secret from their relatives.

These results are an indication that improving women's level of autonomy may be achieved by empowering women through education and employment (Nyika et al., 2009). These results could also suggest that not only does education influence perceptions of medical research, but that continuous education can be used as a tool to improve autonomy and voluntariness for research participants.

2.11 Summary

From the literature reviewed, it is clear that in trying to understand the attitudes and perceptions of the public towards medical research, it is imperative to understand that the historical events of past medical studies have had an impact on how people perceive such studies. It is also vital to take into consideration people's willingness to participate in medical studies and reflect on what influences their willingness/unwillingness to participate in medical studies.

CHAPTER 3. METHODOLOGY

3.1 Introduction

This chapter outlines the procedures followed to conduct this research. As a starting point, some work on quantitative research will be presented, followed by the description of the participants, the sampling method, and the research instrument utilized in this research. The chapter further describes the data collection procedure, the method of data analysis accompanied by a brief discussion on the validity and reliability of the study. Finally, a discussion of ethical considerations regarding the study will be provided.

3.2 Aims and Hypotheses

The study aims at examining racial differences in public perceptions of voluntariness of medical research participants in South Africa. The original study was done by Barsdorf and Wassenaar in 2003 and was published in 2005. In their study, they tried to determine whether participation in medical research in South Africa is perceived as voluntary or not. This study is being replicated in order to find out if the public still holds the same sentiments (over a decade later) as found in the original study.

Secondary aims of the study include:

- To establish that the above racial differences are independent of the following variables
 - Respondents' level of education
 - Respondents' knowledge of medical research
 - Respondents' personal or close experience of medical knowledge
- To assess whether there are racial differences in respondents' willingness to volunteer themselves for medical research.

The following hypotheses were generated from the literature review, and were formulated in order to address the research aims outlined above:

3.2.1 *Hypotheses*

Hypothesis 1: This study will yield the same results as the original study i.e. there will be racial differences in respondents' perceptions of voluntariness of medical research participants.

1a: Black respondents will be more likely to display low perceived voluntariness.

1b: Indian respondents will be more likely to display low perceived voluntariness.

1c: White respondents will be more likely to display higher perceived voluntariness than Black and Indian respondents.

Hypothesis 2: The above differences will be independent of respondents' education level.

Hypothesis 3: The above differences will be independent of respondents' knowledge of medical research procedures.

Hypothesis 4: The above differences will be independent of respondents' personal or close experience of medical research

Hypothesis 5: There will be racial differences in respondents' willingness to volunteer themselves for medical research.

3.2.2 *Objectives*

- Assess racial difference in public perceptions of the voluntariness of medical research participants and compare results with findings of original study

- Assess the impact of level of education on perceived voluntariness of medical research participants

3.3 Research Methodology

An overarching theoretical paradigm has been mentioned as fundamental in understanding the overall perspective from which research is considered and executed. Krauss (2005) defined it as the foundational basis on which a scientific analysis is made.

Research philosophy is often characterized according to two extremes; those of positivism and interpretivism. Kim (2003) argues that the groundwork of positivism is based on the notion that certain universal laws directed social events and that when a researcher appreciates these laws, they could predict, describe and control social occurrences. Saunders et al., (2000) suggests that researchers were independent of the research. At the extreme end of the research philosophy continuum is the interpretivist paradigm. This theory is concerned with a need to understand the beliefs, value systems and connotations attached to social phenomenon.

This research report will conform to the positivist paradigm because it allows for deductive reasoning (Hyde, 2000). Furthermore, the question being asked is best addressed in a quantitative way. Further qualitative research can illuminate the meaning of the results

3.4 Research Design

Creswell (1994) describes quantitative research as explaining concepts by collecting mathematical data that are analysed using statistically based methods. Quantitative research design uses deductive reasoning, where a hypothesis is formed by the researcher, after which data are collected in an investigation of the problem. Data are then analysed and conclusions are drawn to prove the hypothesis false or not false.

The aim of quantitative research is to establish the relationship between two variables (an independent variable and dependent variable) in a population, in numerical presentations (Hopkins, 2000). It can be assumed that quantitative research mainly focuses on gathering numerical data and generalising it across a certain population of interest.

There are several essential characteristics of quantitative research that distinguishes it from other research designs. Firstly, quantitative research design has a clearly defined research question to which objective answers are required, meaning that in gaining, analysing and interpreting data, the researcher remains detached and objective (Sibanda, 2009). This is one of the several ways of obtaining a picture of our social world, not necessarily a truly independent objective reality (Sukamolson, 2007).

Quantitative research design is thus characterised by the numerical and statistical nature of its data. Also, findings are more often generalizable and can also be used to investigate causal relationships (Sibanda, 2009). Lastly, quantitative research designs are said to be deductive which means that this design tests theory rather than generating them as is the case with qualitative research (Sibanda, 2009).

This design is most suitable for this study because it seeks to look at the relationship between certain variables (racial differences in public perceptions, impact of education as well as the impact of medical knowledge on voluntariness). Also, one of the objectives is to test the generalisability of the original study, which can be best achieved if a quantitative design is used rather than a qualitative design.

3.5 Sample and Sampling Method

This study utilised purposive sampling. Purposive sampling is a non-probability sampling technique and is most effective when one wants to study a particular domain with knowledgeable informants about that particular topic (Terre Blanche, Durrheim, & Painter, 2006). Purposive sampling can be used in both qualitative and quantitative sampling and choosing this sampling technique is essential to the quality of data gathered and therefore reliability and competence of informant must be ensured (Terre Blanche et al., 2006)

Purposive sampling was suitable for this study because it had a specific set of people that were required as informants or participants of this study. It required equal distribution of races i.e. African, White, and Indian for comparing racial differences in public perceptions of voluntariness. Also, the study required participants that have tertiary education and those that

have no tertiary education in order to ascertain whether education has an impact on the public's perception of voluntariness or not.

The sample consisted of 120 participants, both male and female. Forty-six participants were Black people. Thirty-nine respondents were Indians and thirty-five were White participants. Eighty of the 120 participants have tertiary education and the rest (40) had no tertiary background. The participants' ages ranged from 18 years to 64 years. No incentives were offered to the participants, similarly to the original study by Barsdorf and Wassenaar (2005).

In conducting this research, gatekeeper permission was required and requested in order to access suitable participants. This was sought in two companies in Durban and Pietermaritzburg who had employees who had tertiary education and those that did not have tertiary education. Written letters were sent to the respective companies to request permission to conduct the study. The first point of contact was a 15-minute presentation to supervisors/managers about the study, including its aims, objectives and how much time each interview was estimated to last. The remaining employees were notified by their supervisors about the study before the researcher was given ten minutes during the employees' monthly meeting to briefly present the study. After permission was granted, arrangements about suitable times were made with companies.

In obtaining informed consent from participants, the researcher presented her study to potential participants again, and those who showed interest in taking part were given an information sheet and consent forms to read and sign. The researcher was there at all times to assist with answering any questions that arose while going through the form including language difficulties.

The information sheet gave details of what the study is about and the rights of the participant. The information sheet also provided information on how to complete the questionnaire and mentioned that the questionnaire is anonymous and its contents will be kept confidential and will only be available for viewing by the researcher and the supervisor (See Appendix B). Lastly, the information sheet assured participants that if at any point in the research they wished to withdraw they could do so and they will not be penalised in any form. Participants were informed of every aspect of the study; there were no hidden parts. Complete confidentiality of both the participants and the companies was assured.

Participants did not incur any costs as a result of participating in this study. Even though participants will not directly benefit from this study, it is however hoped that after the study is complete, it may contribute to the relatively limited body of knowledge concerning racial differences in public perceptions of voluntariness of medical research participants in South Africa. The findings could also help in making future medical research more ethical by making researchers more aware of barriers to research participation.

3.6 The Research Instrument and Data Collection

3.6.1 The research instrument

In collecting data, this study used a slightly modified questionnaire to the one that was used in the original study. The questionnaire was specifically constructed for the original study and its construction basis was literature review and the hypothesis of the study (Barsdorf & Wassenaar, 2005). However, the questionnaire was slightly modified because the authors, based on their experience in the original study, felt that some questions were poorly understood by participants and therefore needed to be modified. The questionnaire was made up of four sections containing forced choice items and where applicable, requests for justification of responses (Barsdorf & Wassenaar, 2005).

Section one contained the demographic information of participants which included age, race, gender, occupation and education level (Barsdorf & Wassenaar, 2005). Section two comprised of four questions which sought to elicit participants' knowledge of medical research procedures. Section three was made up of 20 questions that are designed to elicit participants' perception of voluntariness in a variety of research related situation, and lastly section four contains three questions, two eliciting respondents' experience in medical research and one eliciting participants' willingness to volunteer for medical research (Barsdorf & Wassenaar, 2005). (See Appendix C)

3.6.2 *Procedure: data collection*

This research utilised in-person interviews. This consists of an interviewer asking the respondent questions in a face-to-face situation.

The researcher conducted interviews at company A over a period of eight days. A vacant office was used to conduct interviews in various departments. Black respondents had an option of either being interviewed in English, or IsiZulu or SiSwati. Fourteen of the 46 Black respondents chose to be interviewed in English. A brief description of the research was presented to each respondent before committing themselves to taking part in the study. Interviews lasted about 20-25 minutes each.

In company B, interviews had to be postponed from the initial agreed dates to the following week. This was due to the fact that workers were not available as there was a protest that lasted one week. After all issues were resolved, and staff were back to their normal routine, data collection proceeded. Interviews were completed in five days. The same procedure as company A was followed. The questionnaire was administered using a structured, one on one interview, which allowed for the clarification of items that were not clear to respondents.

3.7 Validity and Reliability

All research needs to be justifiable to the study fraternity and all key stakeholders including communities that stand to benefit. It is also imperative that the way in which the research was conducted, analysed and disseminated must be defensible (Onwuegbuzie & Johnson 2006). Reliability and validity are key components to ensure that quantitative research is justifiable.

3.7.1 *External validity*

External validity is delineated as the degree to which study outcomes are applicable beyond the participants of the study (Winter, 2000). It is a notion that is closely linked to that of generalisability (Winter, 2000). External validity can be improved through focusing on having a representative sample. This is achieved through taking larger, and more varied samples.

3.7.2 *Internal validity*

To augment internal validity, researchers should ensure that the research tool measures that which is meant to be measured as well as the extent to which causality can be justified (Easterby-Smith et al., 2008). In designing the original instrument, Barsdorf and Wassenaar, (2005) ensured that that questionnaire avoided ambiguity thereby confusing respondents. This was not specifically re-tested for this current study. Care was taken not to disrupt the normal operations of both companies.

3.7.3 *Reliability*

Reliability in research focuses on the degree to which a measurement is free from random error. A measure is said to be reliable when it produces consistent results (Golafshani, 2003). Internal reliability indicates the degree to which the items in the research tool are consistent and depict the same primary construct (Cooper & Schindler, 2008). Similarly to the original study by Barsdorf and Wassenaar (2005), reliability was not specifically tested.

3.8 Ethical Considerations

Because research ethics is a vital component of ethical research, this research was informed and guided by the eight principles of ethical research as outlined by Wassenaar (2006) and Wassenaar and Mamotte, (2012). These principles assisted in ensuring that the level of participant protection is maximized.

3.8.1 *Collaborative partnership*

According to Wassenaar and Mamotte, (2012), this principle emphasizes the importance of researchers developing research in collaboration with the target communities or population. Collaborative partnerships are established to reduce possible exploitation of research participants and communities and to ensure that the participating community also shares the benefits of the research (Wassenaar & Mamotte, 2012). This study made an effort to build

positive relations with the companies where participants were recruited and ensured that participants were not exploited. While the respective companies will not benefit directly from this study, the results of this study may be used at a broader level to inform future interventions where research is concerned.

3.8.2 *Social value*

This dimension requires that the research should address challenges that are significant to communities where research is being conducted (Wassenaar, 2006). The study must generate knowledge with the aim of utilizing research outcomes in future health interventions that will result in advanced health systems. Also, the research questions should inform future interventions that will be accessible to research participants and relevant populations (Wassenaar & Mamotte, 2012). Once this study is complete, it will be stored at the UKZN library so that results will be made accessible to the medical research fraternity in order to be more aware of barriers to research.

3.8.3 *Scientific validity*

This element states that the study design, methodology and data analysis should be thorough, justifiable and realistic (Wassenaar, 2006) to ensure reliable and valid findings (Wassenaar & Mamotte, 2012). The methodology should be rigorous, appropriate, and systematic, whether quantitative or qualitative designs are being used. This study has attempted to adhere to a more rigorous and systematic methodology. The questionnaire used to collect data was developed by the authors of the original study and it does gather the information it set out to collect.

3.8.4 *Fair selection of participants*

This principle suggests that potential participants should be selected on the basis of relevancy to the research question (Wassenaar & Mamotte, 2012). This research was interested in racial perceptions of voluntariness of medical research. This meant that participants would be

representative of the racial demographics of South Africa. Participants were selected on the basis of their race as required by the objectives of this study.

3.8.5 *Favourable risk/benefit ratio*

This principle states that all potential risks, harms and ‘costs’ of the research incurred by the participants should be identified by researchers (Wassenaar, 2006). Additionally, researchers should ensure minimal risks and costs in order to ensure a balance in the risk/benefit ratio (Wassenaar, 2006). This study ensured that participants are not exposed to physical and emotional risks and in the event they did encounter any physical and/or emotional problems, measures to assist participants as much as possible were put in place. For instance, counselling arrangements were made for participants who encountered emotional problems.

3.8.6 *Ongoing respect for participants and communities*

This principle indicates that researchers have a continuing obligation to treat participants with respect during and after the research (Wassenaar & Mamotte, 2012). This can be achieved by allowing participants to withdraw from the research at any stage, new information should be disclosed to participants during the research, monitoring participants’ welfare during the research, and respecting participants’ privacy by maintaining confidentiality and anonymity (Wassenaar & Mamotte, 2012). Participants in this study were respected throughout the study. Participants were informed through the information sheet and verbally that they may withdraw from the research at any stage. Participants were also assured of confidentiality.

3.8.7 *Informed consent*

Informed consent is an important factor that helps to ensure that research is conducted ethically. There are three components of consent; disclosure of accurate information, participants’ ability to understand, and lastly participation should be voluntary and they should be at liberty to withdraw from the study at any point (Wassenaar, 2006). In this study, participants were informed about the study and were given clarity when it was needed. In addition to that, the consent forms that they signed had an attached information sheet that provided even more

information about the study. Participants were also informed that they are at liberty to withdraw any time during the study if they feel the need to. This made certain that the principle of informed consent was taken into consideration in this study, hence, making the study ethical.

3.8.8 *Independent ethical review*

This principle suggests that before data collected in a study, an independent and expert research ethics committee should subject all protocols to independent ethical review before data is collected (Wassenaar, 2006). The ethics review should maximise the dignity, welfare and protection of the participants. This study ensured this by submitting the proposal to the University of Kwa-Zulu-Natal Social Sciences and Humanities Research Ethics Committee for approval (Approval number HSS 0323/012M, see Appendix A).

3.9 Data Analysis

In analysing the data, this study was be guided by the data analysis of the original study (Barsdorf & Wassenaar, 2005). The study produced statistical data that was analysed using Statistical Package for the Social Sciences. A one-way ANOVA was conducted to test for any significant racial differences in perceptions of voluntariness between Black, Indian and White participants. Scheffe's *post-hoc* multiple comparisons test was used to ascertain where the variance lies (Barsdorf & Wassenaar, 2005).

Stepwise regressions were used to determine if participants' education levels, knowledge of medical research procedures and experience of medical research are predictors of perceptions of voluntariness (Barsdorf & Wassenaar, 2005). Lastly, Chi-square was used to determine whether there are racial differences in respondents' willingness to volunteer themselves for future medical research(Barsdorf & Wassenaar,2005). Race was cross tabulated against willingness to volunteer and then run a Chi-square test.

3.10 Summary

This section of the thesis addressed the procedure used to conduct this study. It mainly discussed the works around quantitative research, sampling methods, process of data collection and analysis. Validity, reliability and ethical considerations were also considered.

CHAPTER 4. PRESENTATION OF RESULTS

4.1 Introduction

This section presents and describes the results of this study. The first part presents the demographics of the sample, followed by the differences in perceptions of voluntariness of medical research participants between Black, Indian and White participants. In addition, findings on whether participants' education levels, knowledge of medical research procedures, and experience of medical research were predictors of perceptions of voluntariness are presented. Lastly, results on whether there are any racial differences in respondents' willingness to volunteer themselves for medical research are presented.

4.2 Demographic Profile of Respondents

4.2.1 Gender and age distribution

The sample consisted of 120 respondents, of whom 42.5% (51) were male and 57.5% (69) female. Thirty-three percent of the respondents were in the age range 20-24 years: 22% were 25-29 years old: 15.8% were 35-39 years old: 14.2% were 30-34 years old: 5.8% were 15-19 years old, while the rest (8.3%) were between the ages of 44 and 69. Figure 4.1 and Figure 4.2 illustrates gender and age distribution respectively.

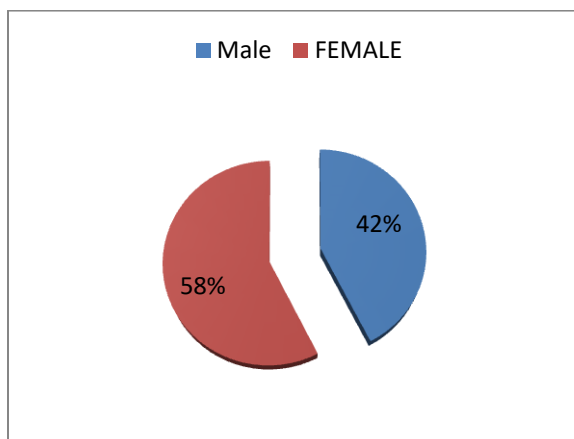


Figure 4.1: Gender distribution of participants

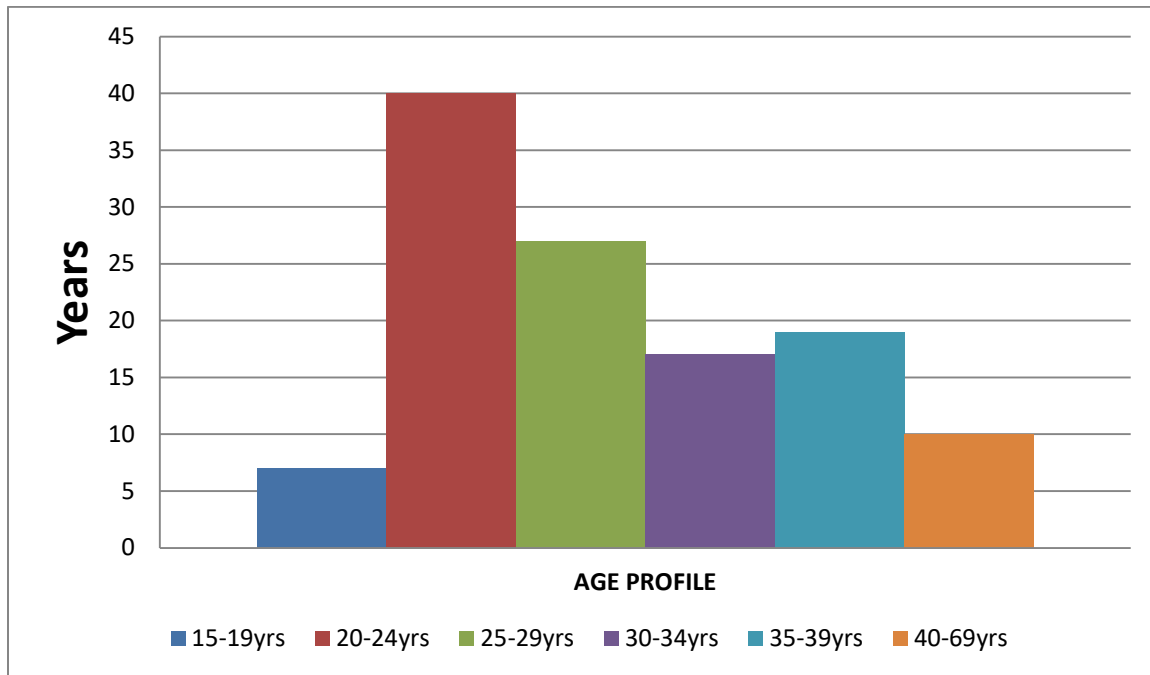


Figure 4.2: Age distribution of participants

4.2.2 *Race distribution*

In terms of race, of the 120 participants, 38.3% were Black, 32.5% were Indian and the remaining 29.2% were White respondents. It is interesting to note that the race distribution of the participants in this study does not match that of the South African race distribution as recorded by Statistic South Africa. The general race distribution in South Africa reflects that 79% of the population are Black people, while 9% accounts for White people, another 9% accounts for Coloureds, and 2.5% accounts for Asian/Indian. (StatsSA, 2011). Table 4.1 below illustrates the race distribution as produced by SPSS.

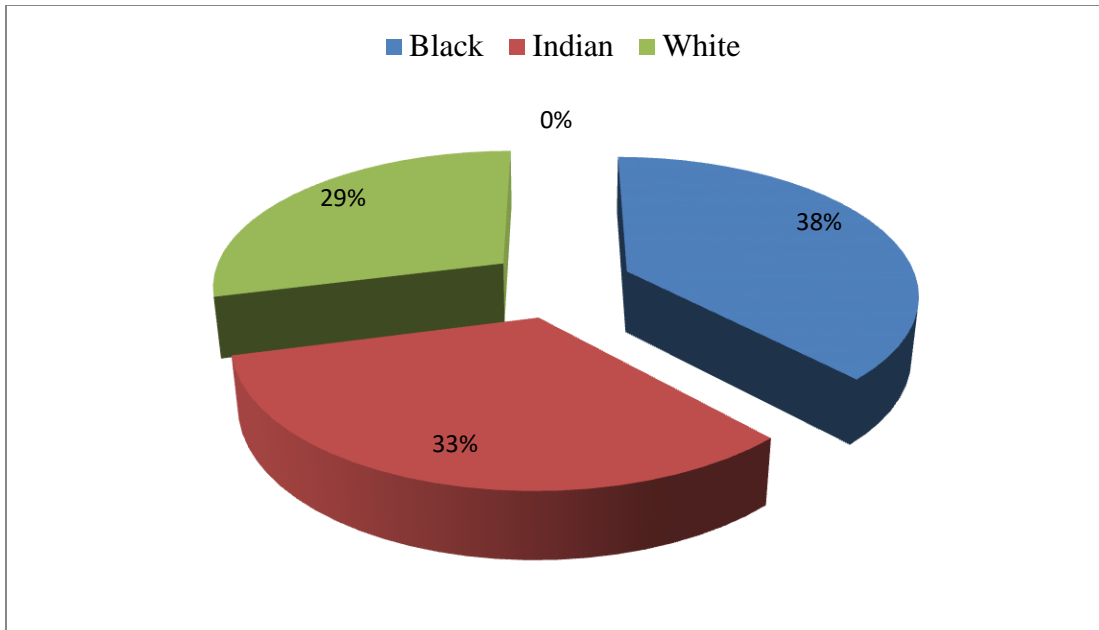


Figure 4.3: Race distribution of participants

4.2.3 *Occupational distribution*

The occupations of the participants were categorized into four groups to allow for easier analysis. These groups were student, unemployed, skilled worker and unskilled worker. Of the 120 respondents, nearly half of them were skilled workers (45.8%), while 26.7% were students, 20.8% were unskilled workers and the remaining 6.7% were unemployed at the time of the data collection process. Figure 4.3 illustrates the distribution of occupations.

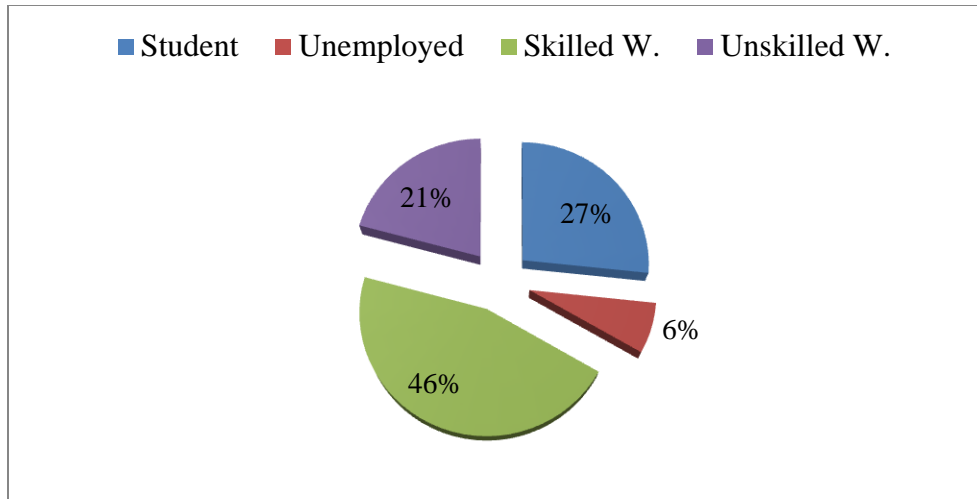


Figure 4.3:

Occupational distribution of participants

4.2.4 Level of education profile

Lastly, the level of education, was also categorized into five groups namely Grade 10, Grade 12, diploma, Bachelor's Degree and postgraduate qualification. Twenty-five percent of the respondents had a Bachelor's degree, 23% had Grade 12, 22% had a diploma, 19% had a postgraduate qualification and 11% had Grade 10. Figure 4.5 illustrates the distribution of level of education.

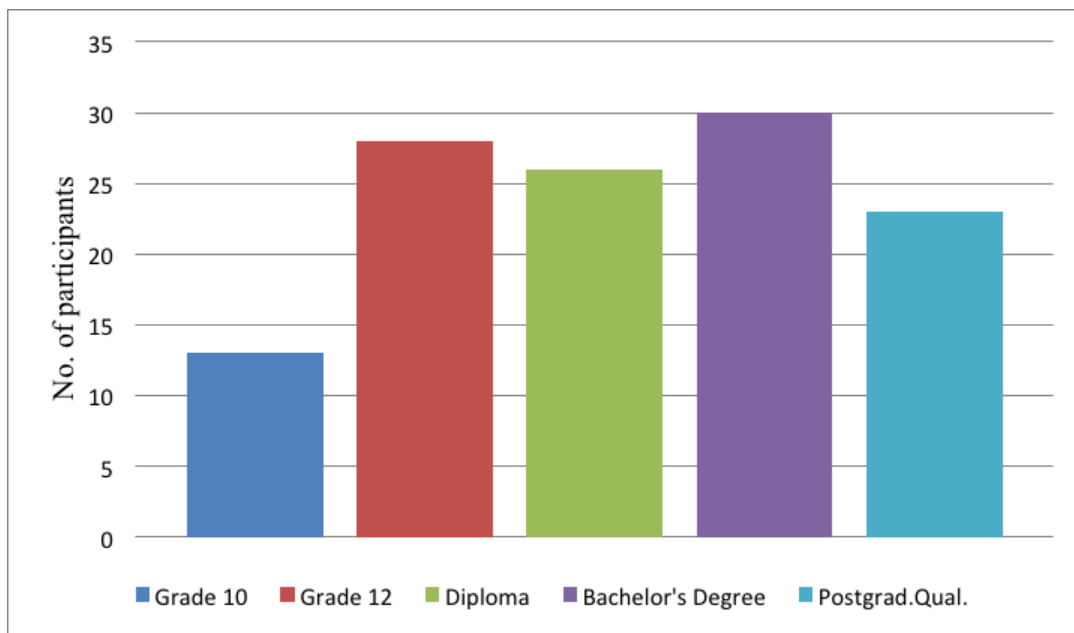


Figure 4.5: Level of education distribution of participants

4.3 Results Pertaining to Hypothesis 1

4.3.1 *Racial differences in perceptions of voluntariness of medical research participants*

To identify significant differences between the dependent variable (perceptions of voluntariness) and the independent variable of race, one-way analysis of variance (ANOVA) was used. The .05 alpha level was used to establish the significance of the results. Table 4.2 shows that there were no significant racial differences in respondents' perceptions of voluntariness of medical research participants ($F=1.634, p=.200$).

Table 4.1: Perceptions of voluntariness (ANOVA)

	Sum of Squares	df	Mean Square	F	Sig.
Between groups	.299	2	.149	1.634	.200
Within groups	10.689	117	.091		
Total	10.988	119			

Since the findings of ANOVA yielded no significant racial difference in respondents' perceptions of voluntariness of medical research participants, there was no need to run a multiple comparisons test. The multiple comparisons test is normally run when there are significant differences between groups as a whole (Brown & Forsythe, 1974). The Tukey post-hoc test is generally the preferred test for conducting post-hoc tests on a one-way ANOVA and it assists determine where the difference lies between groups.

Hypothesis 1: This study will yield the same results as the original study (i.e. the will be racial differences in respondents' perceptions of voluntariness of medical research participants). **Hypothesis rejected.**

1a: Black respondents will be more likely to display low perceived voluntariness. **Hypothesis rejected.**

- 1b:** Indian respondents will be more likely to display low perceived voluntariness. **Hypothesis rejected.**
- 1c:** White respondents will be more likely to display higher perceived voluntariness than Black and Indian respondents. **Hypothesis rejected.**

4.4 Results Pertaining to Hypotheses 2, 3, and 4

4.4.1 Level of education, knowledge of medical research, and experience of medical research as predictors of perceptions of voluntariness

Stepwise regressions were conducted to establish whether racial differences in perceptions of voluntariness were independent of respondents' level of education, knowledge of medical research procedures, and personal or close experience of medical research, respectively.

Stepwise regression yields R , which is a measure of the correlation between the observed value and the predicted value of the criterion variable. As presented by Table 4.3, the correlation between the observed value and predicted value is 0.540, suggesting a substantial positive correlation between race and perception of voluntariness. R -square values determine the amount of cumulative variances accounted for by the independent variables. The accumulative R -square value as presented by Table 4.3 is .292. This suggests that the variable of race accounts for 29.2% of the total variance ($p = .000$).

These results present a different portrait to that presented in hypothesis one, where ANOVA indicated that there were no significant racial differences in perceptions of voluntariness. This difference can be accounted for by the fact that ANOVA assessed differences between groups (Black, White and Indian) while multiple regression was concerned with establishing predictor and explanatory factors. This means that multiple regression was concerned with determining which, out of all factors presented, were more likely to explain/predict perceptions of voluntariness. So while ANOVA did not find any significant differences between the different races, multiple regression was able to ascertain that of all factors presented, race was one factor that was more likely to predict/explain perceptions of voluntariness. In addition, sensitivity of

statistics might also explain the difference. Multiple regression is a more sensitive statistic in presenting predictor variables compared to ANOVA.

Respondents' level of education did thus not emerge as a significant predictor of perceptions of voluntariness. Knowledge of medical research also did not emerge as a significant predictor of voluntariness, nor did personal or close experience of medical research.

Table 4.2: Predictive factors for perceptions of voluntariness by race

Variable	<i>R</i>	<i>R</i> square	<i>R</i> square change	<i>B</i>	β	<i>t</i>	<i>p</i>
Race	.540	.292	.292	.099	-.540	-6.970	.000

Adjusted *R* square = .286 Std. Error = .014 Constant 1.503; $p \leq .05$

Hypothesis 2: Differences in respondents' perceptions of voluntariness of medical research participants will be independent of the respondents' education level. **Hypothesis accepted**

Hypothesis 3: Differences in respondents' perceptions of voluntariness of medical research will be independent of respondents' knowledge of medical research procedures. **Hypothesis accepted**

Hypothesis 4: Differences in respondents' perception of voluntariness of medical research will be independent of respondents' personal or close experience of medical research. **Hypothesis accepted**

4.5 Results Pertaining to Hypothesis 5

4.5.1 *Racial differences in respondents' willingness to volunteer themselves for medical research*

Figure 4.5 below indicates the actual difference in the number of respondents who would volunteer themselves for medical research purposes. Among the Black respondents, 28% reported that they would volunteer themselves, while, 23% of Indian respondents expressed willingness to volunteer themselves for medical research purposes. More than 50% of White participants expressed willingness to volunteer.

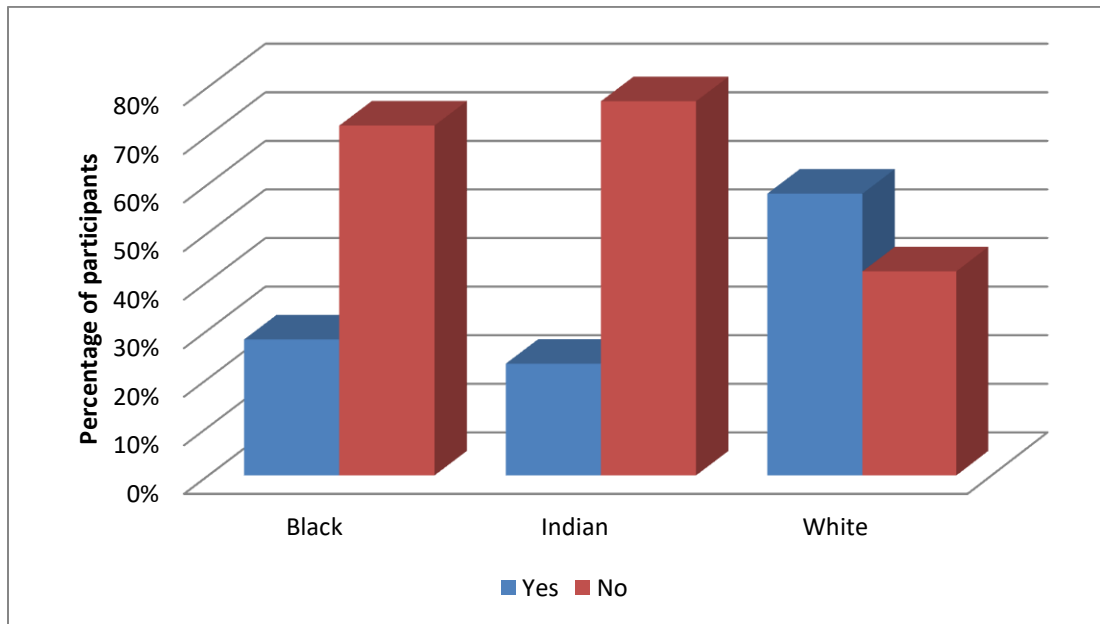


Figure 4.6: Willingness to volunteer for research by race

H5: There will be racial differences in respondents' willingness to volunteer themselves for medical research. **Hypothesis accepted**

The data pertaining to racial differences in respondents' willingness to volunteer themselves for medical research were analyzed using a chi-square test, which was an appropriate test as it is used to discover if there is a correlation between two categorical variables (Lachenicht, 2002).

This test was run in the statistical program SPSS, looking for any statistically significant associations between the variables. For a chi-square test to produce valid results, the expected frequency should be no less than 5 in at least 80% of the cells (Lachenicht, 2002). No cells had a low expected frequency count, and the minimum expected count was 11.67.

Table 4.4 below presents the results of a chi-square test. This shows that there was a statistically significant association between the variables (Pearson chi-square 7.536; $p = .023$). A statistically significant result signifies that the null hypothesis is unlikely to be true, or has a probability of less than 5%. This means that, as illustrated in Table 4.4, there is a statistically significant association between race and whether or not a respondent would volunteer themselves for medical research purposes. White respondents were more likely to volunteer for future medical research than Black or Indian respondents.

Table 4.4: Chi-square analysis

	Value	df	Asymp. Sig (2-sided)
Pearson chi-square	7.536	2	.023
Likelihood ratio	7.359	2	.025
Linear-by-linear association	4.190	1	.041
No. of valid cases	120	4.5.2	4.5.3

4.6 Summary of Results

This study did not yield the same results as the original study in terms of racial differences in respondents' perceptions of medical research. This hypothesis and its sub constructs were rejected. On the other hand, stepwise regression illustrated that racial differences in perception of voluntariness were indeed independent of respondents' education level, knowledge of medical research and experience of medical research. Hypothesis 2, 3 and 4 were thus accepted.

Lastly, chi-square analysis revealed that there were significant racial differences in respondents' willingness to volunteer themselves for medical research. The results indicated that more than 50% of White respondents were willing to volunteer themselves for medical research while more than 70% of both Black and Indian respondents were not willing to volunteer themselves for medical research. Hypothesis 5 was thus accepted.

CHAPTER 5. DISCUSSION

5.1 Introduction

This section of the research will discuss the findings of this study with reference to the literature reviewed.

5.2 Discussion Pertaining to Hypothesis 1

5.2.1 *Racial differences in perceptions of voluntariness of medical research participants*

The findings yielded no significant racial differences in respondents' perceptions of voluntariness of medical research participants. With reference to the proposed hypothesis, this finding rejects hypothesis 1, which theorized that this replica study will yield the same results as the original study i.e., there will be significant racial differences in respondents' perception of voluntariness of medical research participants. These findings, subsequently, rejected sub-constructs 1a, that Black respondents will be more likely to display low perceived voluntariness. Hypothesis 1b, that Indian respondents' will be more likely to display low perceived voluntariness was thus also not confirmed. Hypothesis 1c, that White respondents will be more likely to display higher perceived voluntariness than Black and Indian respondents was also not confirmed.

The results contrast with the results yielded in the original study (Barsdorf & Wassenaar, 2005). In the original study, Black respondents scored significantly lower on perceptions of voluntariness than both Indian respondents and White respondents. Their findings confirmed hypothesis 1a, that Black respondents will be more likely to display low perceived voluntariness. However, hypothesis 1b, that Indian respondents will be likely to display low perceived voluntariness, was rejected as Indian respondents scored high on perceived voluntariness. Hypothesis 1c, that White respondents will be more likely to display higher perceived voluntariness than both Black and Indian respondents was accepted in their original study

(Barsdorf & Wassenaar, 2005). Scores for perceived voluntariness were slightly higher for White respondents compared to Indian respondents, but Indian respondents scored significantly higher than Black respondents.

There are possible contextual explanations that could substantiate why there were no significant racial differences in respondents' perceptions of voluntariness of medical research participants in the present study. Firstly, during the interviews and from the responses provided by respondents, participants seemed to detach themselves from issues that involve racist attitudes and discrimination. Many participants became defensive when interviewed about race issues and seemed to dismiss the significance attached to race. At one instance, a White participant responded defensively, and in an aggressive manner. This could possibly function as participants presenting themselves in a more socially appropriate way. Additionally, detaching from issues pertaining to race, participants could be distancing themselves from unpleasant self-perceptions associated with racist beliefs. When reflecting on issues pertaining to 'race' and racism many of the participants made a distinction between personal and social loci of control. In addition, it is also possible that this field of study has not evolved yet, therefore this might be associated with safe socially desirable responses from these post-apartheid respondents.

A similar response pattern was observed by Pattman (2007) in a study conducted to explore student identities in a University in KwaZulu-Natal. Pattman (2007) noted that in response to questions about race and identity, students responded defensively, which was attributed to the racial incongruity students are facing. On one end, students' understanding and experiences of race as a significant indicator of identity and, on the other end, students' positioning as young people of the new racially integrated South Africa, for whom race is no longer a basis for discrimination and prejudice.

Age is also discussed as a demographic segmentation variable that has possibly influenced the current results of this thesis. According to the theory of cohorts, generational cohorts are set apart by specific defining events that produce changes in the values, attitudes and predispositions in a society (Mosupyoe, 2014). Generational cohorts are characterized in terms of their life experiences during their transition from childhood to adulthood. That said, South Africa has unique defining moments that discern differential generational cohorts, defined by historical

transformation from the apartheid era to the current democratic era. This historical experience may have influenced and shaped the beliefs, attitudes, values and perceptions of different generational cohorts (Mosupyoe, 2014). South Africans were probably shaped by the on-going trends that characterize each era.

The South African Generation X cohorts born between 1961 and 1981 and Generation Y cohorts born between 1982 and 1994 experienced a political transition in the country (Mosupyoe, 2014). While Generation X and Y were both born prior to 1994, there are historical experiences that differentiate them. Generation X are those who were involved in the liberation struggle while generation Y grew up in an era marked by significant political evolution with considerable social impacts, increased urbanization, and widening globalization (Mosupyoe, 2014). Consequently, generation Y is expected to be more unified and non-racial. While they have childhood memories of protest, violence and inherent distrust of authority, their formative years were also during the intense post-apartheid era of building a new nation and becoming truly democratic (Mosupyoe, 2014)

In addition to generation X and Y, is the generation cohort born post 1994, affectionately known as the “born-frees”(Mattes, 2011). Given the new democracy in South Africa, the “born-free” experience includes recent political emancipations, civil liberties and freedom to participate in any democratic events. The born frees lack any direct remembrance of any racial segregations of schools, inter-personal relations, churches and residences. Also, the born-frees have no direct recollection of apartheid protests and armed resistance against the apartheid regime (Mattes, 2011). Nor do they have any experiential reminiscence of the freedom struggle. In many ways, this new generation confronts a different world than that of their parents. They have been exposed to a progression of post transition adjustments that present new challenges and behaviours.

Analyzing the respondents’ ages and segregating them according to generational cohorts, 39% of the respondents were “born-frees”, 36% were generation Y and 24% of the respondents were classified as generation X. It could be argued that results of this study are predominately informed by the perceptions of born-frees and generation Y. In many ways, their perceptions

may be based on experiences of new political freedoms and civil liberties. For instance, it is expected that when a born-free is asked whether Black people would feel free to choose to be part of a medical study, their socially expected response would probably be yes, based on their historical experiences that have shaped their beliefs, attitudes, values and perceptions. This means that their perception may stem from experiences of political and civil emancipations. This is in contrast to the views from the literature reviewed, where perceptions were predominately based on Generation X. This suggests that their perceptions are rooted in their experiential memory of the liberation struggle. Again, if a similar question was posed to a Generation X respondent, it is highly likely that the response would be no, based on their direct memory of race classifications and all forms of oppression that were apparent during the apartheid era. Therefore, this point of view could substantiate why there were no significant racial differences in respondents' perceptions of voluntariness of medical research participants, especially in reference to both the literature review and the original study.

The results of the present study could also possibly reflect that Black people's perceptions about medical research are changing towards a more positive understanding of how medical research can be used to improve health and finding cures for diseases. This would be congruent with Freimuth et al.'s (2001) study, where African Americans, Hispanics, and Native Americans were asked their views of what an experimental study is. While some respondents perceived it as a platform where people are used as guinea pigs, most people perceived an experimental study as a platform that facilitates learning about a disease and medication and believed in the positive outcomes of participating in such studies i.e. to assist in finding a cure for a certain illnesses (Freimuth et al., 2001). This information demonstrates that while some people may perceive medical research as an untrustworthy activity, some people may, increasingly, acknowledge the beneficial side of medical research.

However, it could also be argued that even though there were no significant differences in perceived voluntariness in medical research in this current study, one must still be cognizant of the possible residual impairment of experienced voluntariness and autonomy (Barsdorf & Wassenaar, 2005). Given the apartheid history of South Africa and how it has shaped the formation of attitudes and beliefs of many South Africans, it is possible that most Black South

Africans still perceive their voluntariness as impaired, even though it did not emerge in this study. Also, the fact that previously, Black populations were susceptible due to poverty, lack of formal education, history of racial oppression and limited access to health care and this played a role in exerting some form of pressure for people to partake in medical studies (Manafa, Lindegger & IJsselmuiden, 2007). This suggests that many participants from disadvantaged backgrounds in South Africa are more likely to participate in medical studies primarily to earn extra money (provided by some researchers as incentives) to help alleviate poverty (Getz & Burfitz, 2002).

It is also worth noting that even in post-apartheid South Africa, there were reported instances of unethical research conducted on the Black population of South Africa (Baldwin-Ragaven et al., 1999). The Virodene P058 controversy that began in 1997 is an example of unethical medical research that occurred post-apartheid. Three University of Pretoria scientists announced they had developed a drug that would kill the AIDS virus. However, the trio was condemned for not following standard research protocol (Cohen, 1997). They had already tested Virodene on AIDS patients without permission from the university's research ethics committee, or the Medicines Control Council (Cohen, 1999). The FTC-302 trial at Kalafong Hospital in 2000 was another reported case of unethical studies that occurred post-apartheid. The Medicines Control Council suspended the AIDS drug FTC-302 trial at Kalafong Hospital in Pretoria after the researcher was accused of coercing trial participants to sign forms they did not understand (Vermaak, 2000).

Such post-apartheid unethical studies may continue to tarnish the representation of medical research. Shavers-Hornaday et al., (1997) argued that African Americans continue to hold negative beliefs and attitudes about the medical research fraternity as a result of the Tuskegee study. One of the repercussions is the fact that minorities fear that researchers conduct research based on racial discrimination, meaning that research is done differently when the participants are African American (Shavers-Hornaday et al., 1997). This fear could possibly also hold true for South Africans, given the historical experience of apartheid and the reported cases of post-apartheid unethical medical research (Barsdorf & Wassenaar, 2005).

5.3 Discussion Pertaining to Hypotheses 2, 3, and 4

5.3.1 *Level of education, knowledge of medical research procedures, and experience of medical research as predictors of perceptions of voluntariness*

Stepwise regression revealed that respondents' level of education did not emerge as a significant predictor of perceptions of voluntariness. Knowledge of medical research also did not emerge as a significant predictor of voluntariness, nor did personal or close experience of medical research. However, stepwise regression did suggest a substantial positive correlation between race and perception of voluntariness.

The results of this study thus suggest that participants' level of education was not a predictor of perceived voluntariness in research. There are no previous studies that these results can be directly compared with. However, this contrasts with results of a study by Nyika et al. (2009), which aimed at ascertaining the effects of relationships in decision-making process and autonomy of women which was conducted in Harare, Zimbabwe. From their study, it emerged that higher levels of education amongst participants were associated with less impetus to keep respondents' participation a secret from their husbands. The results reflected that none of participants with vocational or university education were prepared to keep their participation in research secret from their husbands (Nyika et al., 2009). Only less than 3% of women with university education reflected an inclination to keep participation secret from their significant others, which was an indication that women with education were less willing to keep their participation secret from their relatives. About 42% of respondents of women with no formal education were more willing to keep research participation a secret from their relatives.

These results are an indication that women's level of independence may be improved through empowering women through education and employment (Nyika et al., 2009). While Nyika et al.'s study was conducted on women exclusively; it could be argued that there is a possibility that the notion of empowerment through education can improve the perceptions of medical research beyond women and across different cultures.

The findings of a positive correlation between race and perception of voluntariness highlight the suggestion that the prolonged progression of racial discrimination and oppression in South Africa has tarnished perceptions of voluntariness of research participation in Black South Africans. The fact that Black populations were an easy target as research participants because of their vulnerability and that this made for easier experimentation in controversial areas has created mistrust of medical research in South Africa (Baldwin-Ragaven et al., 1999). This has not only created mistrust but has also raised concerns in terms of the voluntariness of consent.

Recruitment of participants who are vulnerable (ill, impoverished or otherwise desperate) by researchers and offering of financial or/and medical incentives to these participants is argued by some to potentially compromise the voluntariness of consent (Mamotte & Wassenaar, 2015)

In addition, racial oppression and discrimination of Black South Africans, including the lack of freedom of choice, may have played a vital role in the consequential residual impairment of experienced voluntariness and autonomy (Barsdorf & Wassenaar, 2005). This general mistrust by historically oppressed people for institutions dominated by White “authorities” (Barsdorf & Wassenaar, 2005), coupled with the lack of freedom of choice evident in this era possibly accounts for the positive correlation between race and perception of voluntariness.

As mentioned earlier, the sample population of this study comprises of mostly participants born after the apartheid era. These ‘born frees’ may be perceived as a ‘post-racial generation’ less likely to be governed by racial thinking than their parents were. However, the positive correlation between race and perception of voluntariness in this study may be an indication of the residual impact of apartheid, which may taint their perception of voluntariness in medical research. Despite the end of apartheid, most African born frees face formidable challenges and are still vulnerable due to poverty, illiteracy, and poor access to health care and this, to a certain limit, may be attributed to historical oppression (Manafa, Lindegger & IJsselmuiden, 2007). Moreover, the positive correlation between race and perceptions of voluntariness confirm the findings of numerous studies that African Americans are less likely to participate in any kind of medical research due to mistrust of institutions dominated by White “authorities” (Villarosa, 2010). These instances of minority groups being undermined and abused in health studies might

have increased individuals' suspicions and drastically denting the image of the medical fraternity decreased their level of trust.

5.4 Discussion Pertaining to Hypothesis 5

5.4.1 Racial differences in respondents' willingness to volunteer themselves for medical research

The Chi-square reflected a statistically significant association between race and whether or not a respondent would volunteer themselves for medical research purposes. White participants were more likely to volunteer for future medical research than Black or Indian respondents. Among the Black respondents, only 28% reported that they would volunteer themselves, while, 23% of Indian respondents expressed willingness to volunteer themselves for future medical research purposes. More than 50% of White participants expressed willingness to volunteer. The results of this study contrast with the results presented in the original study (Barsdorf & Wassenaar, 2005). In the original study, about 50% of the whole sample, in the original study, showed themselves willing to volunteer for future medical research.

The results obtained in this section may be a further indication of an influence of apartheid on medical research. As discussed earlier, the apartheid era was marked by violations of Black people's human rights which negatively influenced Black South African's perceptions of voluntariness (Baldwin-Ragaven et al., 1999). The fact that Black people were perceived as easy targets for unethical studies because of the vulnerabilities created mistrust of medical research in South Africa.

South Africa is not an exception when it comes to the significant influence of historical racial violations of human rights on Black populations on medical research. Shavers-Hornaday et al., (1997) argued that African Americans continue to hold negative beliefs and attitudes about the medical research fraternity as a result of the Tuskegee study and one of the repercussions is the fact that minorities fear that researchers conduct research based on racial discrimination,

meaning that research is done differently when the participants are African American(Shavers-Hornaday et al., 1997).Wendler et al., (2006) found that African-Americans were less willing to participate in medical studies compared to non-Hispanic whites. This was attributed to historical abuses like the infamous Tuskegee Syphilis Study. These instances of minority groups being undermined and abused in health studies might have increased doubt and mistrust of the medical research community (Villarosa, 2010).

The results obtained in this study may further confirm that the apartheid era, which was characterised by oppression of Black South Africans, may be responsible for some of the residual mistrust of institutions dominated by White “authorities”(Barsdorf & Wassenaar, 2005). As suggested by Shavers-Hornaday et al., (1997) the mistrust of the medical research fraternity can be attributed to the fact that medical associations supported racist social structures and allowed Black people to be used as slaves and for unethical medical research practices. In addition, theories disseminated by medical/scientist perpetuated the idea of racial inferiority among black people and justified why black people were misused in medical research (Shavers-Hornaday et al, 1997).This general mistrust by Black people may possibly explain why Black and Indian South Africans were not as willing as White people to participate in medical research, as found in the present study.

When reviewing additional reasons why Black people are less willing to participate in medical research, the concept of mistrust of the medical/scientific fraternity is a prominent reason among Black people. Shavers-Hornaday et al., (1997) also cited limited access to health care, the challenge faced by researchers that hinder them from actively recruiting African American, language and cultural barriers as reasons for unwillingness of minority populations to participate in medical research. In addition, as suggested by Freimuth et al. (2001), other barriers to willingness to participate in research can be attributed to broader health care system issues, descriptive of potential participants, public knowledge, perceptions and attitudes towards researchers and research itself, and lastly behaviours and attitudes of providers and researchers. These barriers could also be possible reasons why Black and Indian South Africans people are significantly less willing to participate in medical research as indicated by the results of the present study.

These results are also in accordance with a study done by Shavers-Hornaday et al., (1997), where African American, Native American and Hispanic respondents expressed low willingness to participate in medical research and they cited fear, doubt, and unawareness as three main reasons why these populations were significantly less willing to take part in medical studies. The study also reflected that respondents stated ‘suspicion of white people’ as a cultural factor that played a role in their unwillingness to participate in medical research (Shavers-Hornaday et al. 1997).

Freimuth et al.’s (2001) study also revealed that participants were consequently in agreement from the start that African Americans needed to be very vigilant about their interaction with the medical system. This caution was applied across all areas of involvement with the medical fraternity, treatment and initiatives designed to promote health and well-being of African Americans inclusive. Additionally, given the past abuses and the inability to be certain that past abuses will never occur, African Americans made an agreement that participation in medical research should be avoided (Freimuth et al., 2001). This reflects the level of mistrust against medical research and the perception that African Americans can never be sure that past abuses will never happen again.

These results also confirm the assumption that Black people are not adequately represented in some medical studies due to a variety of factors, including historic unethical studies like the Tuskegee study, which may have damaged minority groups’ trust in medical research (Wendler et al., 2006). This notion could also hold true for South Africa where the experiences of apartheid by Black people are concerned. Such experiences and information have the ability to hinder minorities from participating in medical research as reflected by the results of this study (Freimuth et al, 2001). In addition, Shavers-Hornaday et al., (1997) suggested that looking at the compromised relationship brought about as a result of prior history of social and medical abuse by white researchers towards minorities, it is expected that African Americans are going to be suspicious of the motives of the white medical/scientific community.

However, in direct contrast to the above results and discussion, a follow up analysis based on the City Tuskegee Legacy project Study failed to indicate that awareness of the Tuskegee Syphilis

Study had a direct effect on willingness to participate in biomedical studies for either Black or White people, across three of the cities studied (Katz et al., 2008). The only statistically significant finding was that in the city of Tuskegee (the historical epicentre of the infamous event), Black people who were aware of the Tuskegee Syphilis Study were less willing to participate compared to Black people who were not aware of the Syphilis study (Katz et al., 2008) which further emphasizes the significant influence of racial historical events on perceptions of medical research.

Similarly, Katz et al. (2007) in a study that aimed at exploring the willingness of minorities to participate in biomedical studies, also found that while both Blacks and Puerto-Rican Hispanics were more likely to report higher levels of fear in relation to participation in biomedical studies than whites, they were nonetheless just as willing as the whites to participate in medical research, similar to findings of Barsdorf and Wassenaar, (2005). This contrasts with the results of the present study and what most studies and authors have hypothesized, especially in relation to the historical medical research which was said to have seeded fear and mistrust among African Americans regarding participation in medical research. Also, the findings showed that Hispanics were more willing to participate in biomedical research compared to black people even though the significance was borderline (Katz et al., 2007). These results are also reflected in the study by Barsdorf and Wassenaar (2005) where they aimed at ascertaining racial differences in public perceptions of voluntariness of medical research participants.

The results reflected in the original study by Barsdorf and Wassenaar (2005) were also consistent with those of Brown and Topcu (2003) who also found no statistically significant difference between black and white people who self-reported willingness to participate as subjects in biomedical research (Katz et al., 2007). It is interesting that in the same study results clearly reflected that the same black participants who are willing to participate in biomedical research also indicate a very high level of distrust in biomedical research among black people compared to white people (Katz et al., 2007) similar to Barsdorf and Wassenaar (2005). This would suggest that just because people have a lot of fear and mistrust surrounding biomedical research does not mean they are less willing to participate in any biomedical research. Again, this is in contrast to the findings of this study and that of other authors who argue that the reason most Black people

are under-represented in most medical studies is due to fear and mistrust brought about by history of human rights violations of Black people. It could be argued that the inconsistency among results demonstrates that attitudes can be complex and inconsistent at times.

5.5 Summary

This section aimed at discussing the results in relation to the literature review. The lack of significant differences in racial perceptions of voluntariness was discussed on the basis of age as a possible causative factor. The different generational cohorts were discussed in relation to their experiences of apartheid in South Africa and how those differences in experiences could have influenced the results of this study. It was argued that the results of this study appear to be informed by the perceptions of born-frees and generation Y (who have experiences of new political freedoms and civil liberties) while the literature review was predominately informed by the views of generation X (who have experiential memory of the liberation struggle).

However, the findings of a positive correlation between race and perception of voluntariness was discussed as a reflection of the impact of the historical oppression and discrimination of Black people in South Africa and how it has tarnished the perceptions of voluntariness in Black South Africans, especially where medical research is concerned. This was also reiterated in the last part of the chapter where the discussion about Black people and Indian people being less willing to participate in medical research compared to White participants. This was attributed to historical events that have shaped the formation of attitudes, values, perception and beliefs of people.

CHAPTER 6. CONCLUSIONS AND RECOMMENDATIONS

6.1 Introduction

In this chapter, the main findings are summarised and general conclusions of this study are presented. Furthermore, limitations of this study are considered and suggestions for further research into racial perceptions of voluntariness conclude the chapter.

6.2 Summary of Findings

The main aim of this study was to examine racial differences in public perceptions of voluntariness of medical research participants in South Africa. This is a replica study. The original study was done by Barsdorf and Wassenaar in 2003 and published in 2005. In their study, they tried to determine whether the conduct of medical research in South Africa is perceived as voluntary or not. This study was replicated in order to find out if the public still holds the same sentiments (over a decade later) as found in the original study.

The study also aimed to determine if respondents' level of education, knowledge of health research and personal or close experience of medical research were predictors of perceptions of voluntariness. The study finally assessed whether there are racial differences in respondents' willingness to volunteer themselves for medical research.

Hypothesis 1 suggested that this study would yield the same results as the original study i.e. there will be racial differences in respondents' perceptions of voluntariness of medical research participants. Hypotheses 2, 3, & 4 indicated that respondents' level of education, knowledge of medical research procedures and personal or close experience of medical research will not be predictors of respondents' perceptions of voluntariness. Hypotheses 5 suggested that there will be racial differences in respondents' willingness to volunteer themselves for medical research.

The sample ($N=120$) consisted of 46 Black respondents, 39 Indian respondents, and 35 White respondents. Eighty respondents had tertiary education while 40 respondents did not have any tertiary education. Data was collected using a slightly modified questionnaire that was administered through interviews. The questionnaire was made up of four sections containing

forced choice items and where applicable, requests for justification of responses (Barsdorf & Wassenaar, 2005).

6.2.1 Results pertaining to hypothesis 1

One-way analysis of variance (ANOVA) was used to establish the significance of the results and showed that there were no significant racial differences in respondents' perceptions of voluntariness of medical research participants. These results contrasted with the results of the original study. Hypothesis 1 suggested that, similarly to the original study, there will be significant racial differences in respondents' perceptions of voluntariness of research participants. Hypothesis 1 was thus rejected.

6.2.2 Results pertaining to hypotheses 2, 3, and 4

Stepwise regressions were conducted to determine whether racial differences in perceptions of voluntariness were independent of respondents' level of education, knowledge of medical research procedures, and personal or close experience of medical research, respectively. Stepwise regressions revealed that respondents' level of education, knowledge of medical research procedures, and personal or close experience of medical research were not predictors of perceptions of voluntariness of medical research. However, there was a substantial positive correlation between race and perception of voluntariness. In the original study, respondents' level of education did account for some variance in perception of voluntariness which is in contrast to the results of this study. Knowledge of medical research and personal or close experience of medical research were not predictors of perceptions of voluntariness, similarly to this study. Hypotheses 2, 3, and 4 were thus accepted.

6.2.3 Results pertaining to hypothesis 5

A chi-square test was used to analyse racial differences in respondents' willingness to volunteer themselves for medical research. White respondents were more likely to volunteer for future medical research than Black or Indian respondents. More than 50% of White participants were willing to volunteer themselves for future medical research while only 28% of Black participants

and 23% of Indian participants were willing to volunteer themselves for future medical research. These results were in contrast to those of the original study, thus, hypothesis 5 was accepted.

6.3 General Conclusions

6.3.1 Conclusions of hypothesis 1

The lack of significant racial differences in respondents' perceptions of voluntariness of medical research participants was accounted for by possible contextual explanations. Firstly, during the interviews and from the responses provided by respondents, participants seemed to detach themselves from issues that involve racist attitudes and discrimination. It was argued that the tendency to be defensive and dismiss the significance of race amongst participants possibly functioned as participants presenting themselves in a more socially appropriate way.

Additionally, detaching from issues pertaining to race, participants could have been distancing themselves from unpleasant self-perceptions associated with racist beliefs. Age was also discussed as a demographic segmentation variable that possibly influenced the results of this study. It was argued that results of this study were predominately informed by the perceptions of 'born-frees' and generation Y whose perceptions may be based on experiences of new political freedoms and civil liberties (Mosupyoe, 2014). This is in contrast to the views of literature reviewed, where perceptions were predominately based on Generation X whose perceptions are rooted in their experiential memory of the liberation struggle (Mosupyoe, 2014). From this perspective, age was understood as a factor that accounted for the difference from the perceptions of the literature reviewed (that there will be racial differences in perceptions of voluntariness of medical research participants) and those reflected by the results of this study (no significant racial differences in perceptions of voluntariness of medical research participants).

Lastly, it was argued that the results of this study could also possibly reflect that Black people's perceptions about medical research are changing towards a more positive understanding of how medical research can be used to improve health and finding cures for diseases.

6.3.2 *Conclusions of hypotheses 2, 3, and 4*

Respondents' level of education, knowledge of medical research procedures, and personal or close experience of medical research did not emerge as predictors of perceptions of voluntariness of medical research. However, there was a substantial positive correlation between race and perception of voluntariness.

The lack of literature on level of education and its influence on perceptions of voluntariness posed a challenge in discussing the results of this study. However, the results were argued in relation to results of a study by Nyika et al. (2009) where it emerged that women respondents who had higher levels of education also had higher levels of autonomy where participation in research was concerned (Nyika et al., 2009). These results were an indication that the level of independency in women may be improved through empowering women through education and employment (Nyika et al., 2009). It was then concluded that while Nyika et al.'s (2009) study was conducted exclusively on women, it could be argued that there is a possibility that the notion of empowerment through education can improve the perceptions of medical research beyond women and across different cultures.

In addition, the positive correlation between race and perceptions of voluntariness was a possible indication of the impact of apartheid in South Africa and how it has tainted the perceptions of voluntariness of research participation of Black South Africans. Black South Africans were a vulnerable population and this made them convenient participants even for controversial medical research practices. This caused mistrust and also raised concerns about the voluntariness of consent as highlighted by Mamotte and Wassenaar (2015).

6.3.3 *Conclusions of hypothesis 5*

Results showed a statistically significant association between race and whether or not a respondent would volunteer themselves for medical research purposes. White respondents were more likely to volunteer for future medical research than Black or Indian respondents. The results of this study contrasted with the results of the original study where about 50% of the whole sample showed willingness to volunteer themselves for future medical research.

These results were a further indication of the possible residual mistrust of the medical fraternity created by apartheid in South Africa. This was a discussion consistent with most authors who argued that the history of medical experimentation of African Americans, like the Tuskegee study, laid the foundation of mistrust in medical research making Black people significantly less willing to volunteer themselves for future medical research.

However, a study by Katz et al. (2006) indicated that while both Blacks and Puerto-Rican Hispanics were more likely to report higher levels of fear in relation to participation in biomedical studies than whites, they were nonetheless just as willing as the whites to participate in medical research, similar to findings of Barsdorf and Wassenaar (2005). This contrasted with the results of the present study and what most studies and authors have hypothesized, especially in relation to the historical medical research which was said to have seeded fear and mistrust among African Americans regarding participation in medical research. This argument suggests that fear and mistrust of the medical research fraternity may not always mean that participants will be less willing to participate in medical research. It could be argued that the inconsistency of these results demonstrates that attitudes can be complex and inconsistent at times.

6.4 Limitations

The first limitation of this study is its generalisability. Data was collected from a relatively small sample size from two local companies in Durban and Pietermaritzburg. As such, the results of this study do not address the public perceptions of voluntariness in the general South African populations, even Black populations. Also, due to the lack of a suitable sampling frame, a convenience sampling approach was used. This use of a non-probability sampling approach further limits the generalisability of the results of this study.

Gender differences in perception of voluntariness and willingness to volunteer for future research were not assessed.

6.5 Recommendation for Future Research

A prominent challenge while conducting this research was limited literature on public perceptions of medical research in South Africa. In a country where race and racial issues are significant, given past racial discrimination and human rights violations, it could be argued that racial perceptions about research remain a critical area for future research. Also, in a country where gender issues and inequalities are fundamental, it would be useful to assess gender differences in perceptions of voluntariness and willingness to volunteer for future medical research.

Additionally, the impact of education on perceptions of voluntariness needs further exploring on a larger scale. Advanced, generalizable knowledge about the influence of education on perceptions of voluntariness and autonomy would be very instrumental in informing future research and recruitment and community engagement practices, interventions and advocacy tasks. Future research could also pilot empowering participants with ongoing education prior and during research to observe any changes in perceptions of voluntariness. It is also recommended that future research focuses on rural populations to assess perceptions about medical research and willingness to volunteer for medical research.

As mentioned earlier, the difference in results obtained in the original study to those obtained in this study suggests the complexity and inconsistency of attitudes. This does seem to warrant a national study that would assess racial perceptions of voluntariness of medical research in South Africa.

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APPENDICES

APPENDIX A: ETHICAL CLEARANCE LETTER



8 August 2012

Ms Zanele Zakithi Mzethi Dlamini 208503133
School of Applied Human Sciences – Psychology

Dear Ms Dlamini

Protocol reference number: HSS/0323/012M

Project title: A replication of a study of a racial differences in public perceptions of voluntariness of medical research participants in South Africa.

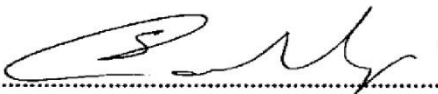
EXPEDITED APPROVAL

I wish to inform you that your application has been granted Full Approval through an expedited review process.

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number. PLEASE NOTE: Research data should be securely stored in the school/department for a period of 5 years.

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully



.....
Professor Steven Collings (Chair)

/px

cc Supervisor Professor Doug Wassenaar
cc Academic leader Professor JH Buitendach
cc School Admin. Ms Nondumiso Khanyile

Professor S Collings (Chair)
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APPENDIX B: PARTICIPANT CONSENT LETTER

RE: Consent to participate in the research study.

Good day

My name is Zanele Dlamini and I am currently studying for a Masters Degree in Clinical Psychology at the University of KwaZulu-Natal, Pietermaritzburg campus. As part of my degree requirements, I need to conduct a research study or thesis. My research is supervised by Professor Douglas Wassenaar. This letter seeks to obtain your written consent for your participation in the research.

The study aims at finding out if there are any racial differences in whether the public views participation in medical research as voluntary or not.

If you agree, participation in the study will require you to complete a questionnaire in which you will be asked about your knowledge of medical research procedures and be able to give opinions on various aspects and practices of medical research, including willingness to volunteer in medical research. The questionnaire is anonymous and the contents of the questionnaire will be kept confidential and will only be available for viewing by me and my supervisor. The questionnaire should take you no more than 10 minutes to complete. The results of the study will be published as a master's dissertation in the first instance, and possibly a conference or journal paper later. The results will be presented in anonymized summary form without any personal details.

If at any point during the research process you feel the need to withdraw, you may do so and you will not be penalised for your actions. If you consent to participate in the study, it must be of your own free will and desire to do so. There are no benefits that will accrue directly to you by participating in this study. However, it is hoped that the study will contribute to the general body of knowledge concerning the public's perception of voluntariness in medical research which could assist researchers in identifying possible barriers to voluntariness in medical research. While the study does not pose any foreseeable risks to you, should you feel uncomfortable as a result of participating in this study, please feel free to consult me or my supervisor immediately so we can make arrangements to assist.

This research has been ethically approved by the Humanities and Social Sciences Research Ethics Committee of the University of KwaZulu-Natal, approval number HSS/0323/012M. If you wish to get more information regarding your ethical rights as a participant, please feel free to contact Miss Phumelele Ximba from the UKZN Humanities and Social Sciences Research Ethics Committee at (031) 260 3587. Email:ximba@ukzn.ac.za

It is important that you understand everything in this letter before you give consent to participate in the study. If you have any questions concerning this study, then you can contact me or my supervisor:

Contact Details:

Prof. D. Wassenaar Tel; 033 260 5853 E-mail: wassenaar@ukzn.ac.za

Zanele Dlamini Tel: 082 0630584 E-mail: 208503133@stu.ukzn.ac.za

Thank you for your time. If you do wish to participate in the study please read carefully and sign the consent form.

Consent Form.

I (.....) Herby confirm that I understand the contents and the nature of this study and I agree to participate. I understand that I am participating freely and without being forced to do so. I also understand that I can withdraw from this study at any point should I not wish to continue and that my name will remain confidential.

.....

.....

Signature of participant

Date

APPENDIX C: RESEARCH QUESTIONNAIRE

SECTION 1: DEMOGRAPHICS

Age: 15-19, 20-24, 25-29, 30-34, 35-39, 40-44, 45-49, 50-54, 55-59, 60-64, 65-69

Gender: male, female

Race Group: Black, Indian, White, Coloured, Other.....

Occupation:

Education: Highest level completed.....

SECTION 2:

1. How do certain medicines (e.g. Panado, Grandpa, Eno's, antibiotics, vaccines, etc) come to be known by the people as medicines that work and are safe?
 - a. Read package insert
 - b. Tradition/word of mouth/reputation
 - c. Research/testing
 - d. Advertising
 - e. Other.....

2. Do you know how new medications are tested?

Yes

No

If Yes, How?.....

3. Do you know that most new medicines are first tested on animals in a laboratory?

Yes

No

4. Do you know that after new medicines are found to be safe on laboratory animals, they need to be tested on people before they can be sold or used by the public?

Yes

No

SECTION 3:

5. Do you think that people have been treated well or abused when medications are tested on humans?

Well

Abused

Give reasons for your

answer:.....

6. Do you know of any people who have been harmed or disadvantaged because medicines were tested on them?

Yes

No

If yes, describe what you

know/heard:.....

7. Do you think that, in general, people's rights are or have been abused or protected when medicines are tested on humans?

Abused

Protected

Give reasons for your

answer:.....

8. What group of people do you think get used most often in medical research?

White

Black

Indian

Coloured

No specific group

Don't know

Give reasons for your

answer.....

9. How do you think people get involved or chosen for medical research?

Do you think people get chosen for medical research because:

(Tick what respondent gives, then ask about others)

a. They are poor

b. They are ill

- c. They cannot understand what researchers want them to do
- d. They are illiterate
- e. They are asked to volunteer to help their community
- f. They trust the doctors/scientists and do not want to offend them
- g. They will be offered better medical care if they volunteer
- h. They hope that they will be offered jobs/employment by the researchers/scientists
- i. They will feel respected by the doctors/scientists/researchers
- j. They want future generations to be protected against illness
- k. They are bribed
- l. They are offered fair payment for their time and effort
- m. Other reasons:.....
- ..

10. Which people do you think should be used in medical research?

(Tick what respondent gives, then ask about others)

- a. People who are poor
- b. People who are ill
- c. People who want to help their community
- d. People who trust doctors and scientists
- e. People who are looking for jobs/employment
- f. People who want the benefits of the treatment being tested
- g. People who are bribed
- h. People who are offered fair payment for their time and effort

- i. People who want to feel good about helping future generations
- j. Any people who wish to volunteer
- k. Other types of people:.....
- l. Any reasons for your answer?.....

11. If there was research on a new medicine for treating headaches, and the scientists wanted to test the medicine on Black people, how do you think Black people would feel?

a: Do you think Black people would feel free to choose to be part of this research?

Yes

No

b: Do you think Black people would feel free to refuse to be part of this research?

Yes

No

Give reason for any of your answers.....

12. If there was research on a new medicine for treating headaches, and the scientists wanted to test the medicine on White people, how do you think White people would feel?

a: Do you think White people would feel free to choose to be part of this research?

Yes

No

b: Do you think White people would feel free to refuse to be part of this research?

Yes

No

Give reason for any of your answers.....

13. If there was medical research on a malaria vaccine and the scientists wanted to test the vaccine on Black people, how do you think Black people would feel?

a: Do you think Black people would feel free to choose to be part of this research?

Yes

No

b: Do you think Black people would feel free to refuse to be part of this research?

Yes

No

Give reason for any of your answers.....

14. If there was medical research on a malaria vaccine and the scientists wanted to test the vaccine on White people, how do you think White people would feel?

a: Do you think White people would feel free to choose to be part of this research?

Yes

No

b: Do you think White people would feel free to refuse to be part of this research?

Yes

No

Give reason for any of your answers.....

15. If there was medical research on an HIV/AIDS vaccine and the scientists wanted to test the vaccine on Black people, how do you think Black people would feel?

a: Do you think Black people would feel free to choose to be part of this research?

Yes

No

b: Do you think Black people would feel free to refuse be part of this research?

Yes

No

Give reason for any of your
answers.....

16. If there was medical research on an HIV/AIDS vaccine and the scientists wanted to test the vaccine on White people, how do you think White people would feel?

a: Do you think White people would feel free to choose to be part of this research?

Yes

No

b: Do you think White people would feel free to refuse to be part of this research?

Yes

No

Give reason for any of your
answers.....

17. Do you think that medical researchers or scientists get permission from Black people to do medical research?

Yes

No

Reason for your
answer:.....

18. Do you think that medical researchers or scientists get permission from White people to do medical research?

Yes

No

Reason for your
answer:.....

19. Do you think that Black people must give signed permission before research can be done on them?

Yes

No

20. Do you think that White people must give signed permission before research can be done on them?

Yes

No

21. Do you think that Black people are put into research without being given much choice?

Yes

No

22. Do you think that White people are put into research without being given much choice?

Yes

No

23. Do you think that it is fair to use one race group in medical research more than any other?

Yes

No

Give reasons for your

answer:.....

SECTION 4:

24. Have you ever been in a medication/treatment trial or included in medical research in South Africa?

Yes

No

If Yes, Was it by choice?

Were you forced?

Other

reasons:.....

25. Have you ever been given the option of participating in a medication/treatment trial or in medical research in South Africa?

Yes

No

If Yes, did you accept?

Yes

No

Why?.....

Other details you wish to
add:.....

26. Have any of your family members/anyone you know ever been in or participated in a medication/treatment trial or in medical research in South Africa?

Yes

No

If Yes, Was it by choice?

Were they forced?

Other reasons:
.....

27. If you were asked to participate in testing a medication or vaccine or other medical research, would you be willing to volunteer?

Yes

No

If Yes, why..... (or options: to benefit self, to help others, to further medical knowledge)

If No, why (or options: fear, suspicious)

“Thank you for your time and effort in cooperating with this survey.”

APPENDIX D: PERMISSION TO CONDUCT RESEARCH LETTER

RE: Permission to Conduct Research

Dear Sir/Madam

My name is Zanele Dlamini and I am a student studying at the University of KwaZulu Natal. I am conducting research on ‘public perceptions of voluntariness of medical research participants in South Africa’ in partial fulfilment of my Masters degree in Clinical Psychology.

This letter seeks to obtain your permission to conduct my study at your organisation by recruiting your employees as participants for my research. Participation in the study will involve completing a questionnaire which will take approximately 20 minutes of the participants’ time. Information obtained in this study will remain completely anonymous and personal information will not be revealed, pseudo-names will be used.

Participation in this study is completely voluntary and participants are free to withdraw at any point and they will not be penalised for doing so. Upon withdrawal, participants may choose whether obtained information should be used or discarded. Participation in this study does not involve any physical or emotional risk to the participants. There are no direct benefits to be obtained by research participants in this study. In the case where participants wish to find out more about the findings of this study, a flyer or leaflet will be made available to them through your organisation.

Thank you in advance.

Kind Regards,

Zanele Dlamini

APPENDIX E: SPSS DATA OUTPUT

[DataSet1] C:\Users\user\Documents\Alfa Thesis Consultancy\UKZN\Dube Zanele\Raw Data Zanele Dlamini.sav

Statistics

		Age	Gender	Race	Occupation	Levelofeducatio n
N	Valid	120	120	120	120	120
	Missing	0	0	0	0	0

Frequency Table

Age

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	15 - 19 years	7	5.8	5.8	5.8
	20 - 24 years	40	33.3	33.3	39.2
	25 - 29 years	27	22.5	22.5	61.7
	30 - 34 years	17	14.2	14.2	75.8
	35 - 39 years	19	15.8	15.8	91.7
	40 - 44 years	5	4.2	4.2	95.8
	45 - 49 years	3	2.5	2.5	98.3
	60 - 64 years	1	.8	.8	99.2
	65 - 69 years	1	.8	.8	100.0
Total		120	100.0	100.0	

Gender

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid Male	51	42.5	42.5	42.5
Valid Female	69	57.5	57.5	100.0
Total	120	100.0	100.0	

Race

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid Black	46	38.3	38.3	38.3
Valid Indian	39	32.5	32.5	70.8
Valid White	35	29.2	29.2	100.0
Total	120	100.0	100.0	

Occupation

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid Student	32	26.7	26.7	26.7
Valid Unemployed	8	6.7	6.7	33.3
Valid Skilled worker	55	45.8	45.8	79.2
Valid Unskilled worker	25	20.8	20.8	100.0

Total	120	100.0	100.0
-------	-----	-------	-------

Levelofeducation

	Frequency	Percent	Valid Percent	Cumulative Percent
Grade 10	13	10.8	10.8	10.8
Grade 12	28	23.3	23.3	34.2
Diploma	26	21.7	21.7	55.8
Valid Bachelor's Degree	30	25.0	25.0	80.8
Postgraduate Qualification	23	19.2	19.2	100.0
Total	120	100.0	100.0	

GET

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REGRESSION

/MISSING LISTWISE

/STATISTICS COEFF OUTS R ANOVA CHANGE

/CRITERIA=PIN(.05) POUT(.10)

/NOORIGIN

/DEPENDENT Perceptionstwo

/METHOD=STEPWISE Knowledge Age Race Levelofeducation.

Regression

Notes

Output Created	15-JUN-2016 19:12:36
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Active Dataset	DataSet1
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Split File	<none>
N of Rows in Working Data File	121
Definition of Missing	User-defined missing values are treated as missing.
Missing Value Handling	Statistics are based on cases with no missing values for any variable used.
Cases Used	

Syntax	REGRESSION		
	/MISSING LISTWISE		
Resources	/STATISTICS COEFF OUTS R ANOVA CHANGE		
	/CRITERIA=PIN(.05) POUT(.10)		
	/NOORIGIN		
	/DEPENDENT Perceptionstwo		
	/METHOD=STEPWISE Knowledge Age Race Levelofeducation.		
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	Additional Memory Required for Residual Plots		0 bytes

[DataSet1] C:\Users\user\Documents\Alfa Thesis Consultancy\UKZN\Dube Zanele\Raw Data Zanele Dlamini.sav

Variables Entered/Removed^a

Model	Variables Entered	Variables Removed	Method
1	Race		Stepwise (Criteria: Probability-of-F- to-enter <= .050, Probability-of-F- to-remove >= .100).

a. Dependent Variable: Perceptionstwo

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics		
					R Square Change	F Change	df1
1	.540 ^a	.292	.286	.12732	.292	48.579	1

Model Summary

Model	Change Statistics	
	df2	Sig. F Change
1	118 ^a	.000

a. Predictors: (Constant), Race

ANOVA^a

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	.787	1	.787	48.579	.000 ^b
	Residual	1.913	118	.016		
	Total	2.700	119			

a. Dependent Variable: Perceptionstwo

b. Predictors: (Constant), Race

Coefficients^a

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.	
	B	Std. Error	Beta			
1	(Constant)	1.503	.030		50.861	.000
	Race	-.099	.014	-.540	-6.970	.000

a. Dependent Variable: Perceptionstwo

Excluded Variables^a

Model	Beta In	t	Sig.	Partial Correlation	Collinearity Statistics	
					Tolerance	
1	Knowledge	-.018 ^b	-.225	.822	-.021	.993
	Age	-.049 ^b	-.616	.539	-.057	.970
	Levelofeducation	-.048 ^b	-.480	.632	-.044	.606

a. Dependent Variable: Perceptionstwo

b. Predictors in the Model: (Constant), Race

Oneway

Notes

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	Definition of Missing	User-defined missing values are treated as missing.
Missing Value Handling	Cases Used	Statistics for each analysis are based on cases with no missing data for any variable in the analysis.
		ONEWAY PerceptionTrue BY Race
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[DataSet1] C:\Users\user\Documents\Alfa Thesis Consultancy\UKZN\Dube Zanele\Raw Data Zanele Dlamini.sav

ANOVA

PerceptionTrue

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	.299	2	.149	1.634	.200
Within Groups	10.689	117	.091		
Total	10.988	119			

Post Hoc Tests

Multiple Comparisons

Dependent Variable: PerceptionTrue

Scheffe

(I) Race	(J) Race	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
Black	Indian	.04124	.06579	.822	-.1219	.2044
	White	.12186	.06780	.203	-.0462	.2900
Indian	Black	-.04124	.06579	.822	-.2044	.1219
	White	.08062	.07038	.521	-.0939	.2551
White	Black	-.12186	.06780	.203	-.2900	.0462
	Indian	-.08062	.07038	.521	-.2551	.0939

Homogeneous Subsets

PerceptionTrue

Scheffe

Race	N	Subset for alpha = 0.05
		1
White	35	1.7276
Indian	39	1.8082
Black	46	1.8494
Sig.		.205

Means for groups in homogeneous subsets are displayed.

a. Uses Harmonic Mean Sample Size = 39.499.

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

GET

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CROSSTABS

/TABLES=Race BY Wouldyouvolunteertoparticipateinmedicalresearch

/FORMAT=AVALUE TABLES

/CELLS=COUNT

/COUNT ROUND CELL.

Crosstabs

Notes

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Split File	<none>
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Definition of Missing	User-defined missing values are treated as missing.
Missing Value Handling	Statistics for each table are based on all the cases with valid data in the specified range(s) for all variables in each table.
Cases Used	

Syntax	CROSSTABS	
	/TABLES=Race BY Wouldyouvolunteertopartic ateinmedicalresearch	
	/FORMAT=AVALUE TABLES	
	/CELLS=COUNT	
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Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Race *						
Wouldyouvolunteertopartic ateinmedicalresearch	120	99.2%	1	0.8%	121	100.0%

Race *

Would you volunteer to participate in medical research Crosstabulation

Count

	Would you volunteer to participate in medical research		Total
	Yes	No	
Black	13	33	46
Race Indian	9	30	39
White	18	17	35
Total	40	80	120

CROSSTABS

/TABLES=Race BY Would you volunteer to participate in medical research

/FORMAT=AVALUE TABLES

/STATISTICS=CHISQ

/CELLS=COUNT

/COUNT ROUND CELL.

Crosstabs

Notes

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Split File	<none>
N of Rows in Working Data File	121
Definition of Missing	User-defined missing values are treated as missing.
Missing Value Handling	Statistics for each table are based on all the cases with valid data in the specified range(s) for all variables in each table.
Cases Used	

Syntax	CROSSTABS	
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	/FORMAT=AVALUE TABLES	
	/STATISTICS=CHISQ	
	/CELLS=COUNT	
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Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Race *						
Wouldyouvolunteertopartic ateinmedicalresearch	120	99.2%	1	0.8%	121	100.0%

Race *

Would you volunteer to participate in medical research Crosstabulation

Count

		Would you volunteer to participate in medical research		Total
		Yes	No	
Race	Black	13	33	46
	Indian	9	30	39
	White	18	17	35
Total		40	80	120

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	7.536 ^a	2	.023
Likelihood Ratio	7.359	2	.025
Linear-by-Linear Association	4.190	1	.041
N of Valid Cases	120		

a. 0 cells (.0%) have expected count less than 5. The minimum expected count is 11.67.

FREQUENCIES VARIABLES=Age Gender Race Occupation Level of education

/ORDER=ANALYSIS.

Frequencies

Notes

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	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	120
Missing Value Handling	Definition of Missing	User-defined missing values are treated as missing.
	Cases Used	Statistics are based on all cases with valid data.
Syntax		FREQUENCIES VARIABLES=Age Gender Race Occupation Levelofeducation /ORDER=ANALYSIS.
Resources	Processor Time	00:00:00.00
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