

**Participants not subjects: A case for research participants to share
in profits generated from the use of their genetic material**

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“If you want to go fast, go alone. If you want to go far, go together”. Another African proverb that confirms that truly Umuntu ngumuntu ngabantu. This journey would not have been possible without the community of people who both guided me and supported me when I could not do that for myself. To:

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Abstract

The history of medical research is rife with instances of exploitation and injustice towards research participants. Considering the significant progress made in this field, one would not expect such issues to persist in modern times.

However, while benefit-sharing is a widely accepted principle and plays a significant role in ensuring a fair and equitable distribution of benefits arising from the utilisation of genetic resources, human genetic resources remain excluded and not covered by current international regulations and domestic laws.

As a result, research participants who contribute their genetic material to medical research are deprived of some benefits that flow from these research projects. This research report illuminates that this practice is immoral, unjust and exploitative because researchers and research sponsors accumulate wealth through the same genetic material.

In this report, I take the position that research participants should be entitled to share in profits that result from the use of their genetic material. This is done by providing an evaluative descriptive account of the key ethical issues and conceptions related to benefit sharing, giving a critical and evaluative discussion on this challenge. I will argue using Western traditional moral theories such as deontology and utilitarianism and, ultimately, discussing and giving an Ubuntu-based argument on the issue. This will also position this principle as a needed perspective in understanding the principle of benefit sharing.

Keywords: Ubuntu, Benefit-sharing, common heritage of humankind, altruism, commodification, deontology, utilitarianism, mere means, community, Goodwill, and shared identity.

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Chapter 1

Introduction

The history of research is riddled with exploitation, especially targeting society's most vulnerable. Consider the story of Henrietta Lacks, a poor African American woman whose cancer cells were taken without her knowledge or consent (Skloot 2010, pp. 4-5). These cells, known as HeLa cells, became a cornerstone of medical research, leading to countless breakthroughs such as the polio vaccine, an enhanced understanding of the effects of radiation, gene mapping, and cancer research, to name a few (Khan, 2011; Skloot 2010, pp. 4-5). Yet, Henrietta's family remained impoverished, unaware of her contribution to science.

This example, along with the horrors of Nazi medical experiments and the infamous Tuskegee syphilis study, highlights a troubling legacy of medical injustices inflicted on the vulnerable (Manoach, 2002).

Without a doubt, there is a lot that has been done to address these issues.

The Nuremberg Code, the Declaration of Helsinki, the Belmont Report and many sets of bioethical principles and theories; as well as legislations in many jurisdictions are evidence of how medical research ethics have evolved in an effort to protect participants and others (Bhatt, 2010).

These developments in medical and bioethics are very crucial as they afford research participants the ability to decide and make decisions on matters relating to their bodies in research. This is achieved through respecting principles such as autonomy, justice, and consent and other safeguards aimed at protecting human dignity and human rights. However, while their significance cannot be denied, these documents, practices and principles fail to address some remaining ethical issues within the medical research field. In this research report, I explore and

suggest a possible solution to one of these issues. I ask the question; *Should research participants be entitled to a share in profits generated from the use of their body tissue in research?* To better understand and explore this topic, I refer to the famous Henrietta Lacks case - a story of how one woman's cancerous cells (now known as HeLa cells) contributed to medicine and became a multimillion-dollar industry (Skloot 2010 p. 4). While on one hand, cells grown from those of Henrietta Lacks continue to generate multimillions of dollars, on the other, Deborah Lacks, Henrietta's Daughter, is quoted saying "I always have thought it was strange, if our mother's cells done so much for medicine, how come her family can't afford to see no doctors? Don't make no sense. People got rich off my mother without us even knowing about them taking her cells, now we don't even get a dime [sic]." (Skloot 2010 p. 10). That an individual whose cells have contributed so much to medicine and the health of others was deprived of any of the commercial benefits derived from her cells is surely unacceptable exploitation and morally wrong.

1.2 Background Literature Analysis and Critique

It is against this background that this research paper came to be, to address questions such as, 'Is the argument on unfair exploitation and the moral wrong in depriving research participants profits of research enough to justify that they should benefit from the use of their genetic material in research?

Who should be entitled to benefit from human genetic material - a resource so precious that it has been dubbed by some as the "Biotechnology 'gold rush', in which the human genome or the human body is the territory"? (Dickenson 2004, p.110). These are some of the questions that must be answered if research participants are to be participants of research in the true sense of the word.

Scholars against the idea of benefits sharing and paying of research participants are of the view that everyone should share in and have access to the benefits that result from human genetic research (Knoppers et al., 2000).

This argument is premised on the idea that the human genome is the common heritage of humanity (Knoppers et al., 2000). According to their argument “human beings share 99.9 % of their genome; as such, human genes are considered to be resources of the common heritage of humankind” (Dauda and Dierickx 2013, p.3). As a result, one should not be entitled to benefit from genetic material they committed to medical research.

In the Moore case, the defendant, UCLA, claimed that even if Moore’s cells were his property, as a state university, it had a right to take the cells under eminent domain (Gilmour 1993).

There are two points that this argument makes on the human genome being the common heritage of humanity. The first point is that of access to the benefits of human genetic research and the other is the actual sharing of the benefits of the research. The second view is that, as with every other human being, research participants may have access to the benefits of research but not share in the financial profits of the same.

However, those who argue for benefits sharing such as Melodie Slabbert rightfully note that while “access and benefit-sharing are normally referred to as one concept (with the acronym ABS), access itself refers to the ability of individuals to acquire, exchange, or use genetic resources for a multitude of purpose, not necessarily limited to commercial application” (Slabbert 2011, p. 609).

Doris Schroeder defines the concept of benefit sharing as:

“the action of giving a portion of advantage/profit derived from the use of human genetic resources to the resource providers in order to achieve justice in exchange, with a particular emphasis on the clear provision of benefits to those who may lack reasonable access to resulting healthcare products and services without providing unethical inducement (Schroeder 2007, p. 207)”.

Therefore, from both arguments by Slabbert and Schroeder, it is evident that both the research participants and the researcher are mutually reliant on the other, the first to provide access to the genetic material necessary for the research and the latter a portion of the benefit to the other.

This, according to the two, is what benefit sharing is, which brings us to the reason why others are not in support of this principle as it relates to human genetic research.

The arguments against benefit sharing can be summed up in two arguments; the first relates to the ownership and legal rights to human genetic material. Referring to research participants who contribute their genetic material for research purposes, Kare Berg argues that “the people themselves have not performed any act of competence to create DNA. Thus, they cannot have a right similar to that based on intellectual property or patent acts” (Berg 2001, p. 240).

The argument is that the human genome is sacred therefore any profit from its use is inherently immoral (Slabbert, 2011).

The second argument intersects with the first, and it is the emphasis on altruism in human genetic research (Slabbert, 2011). Commodifying human tissue is argued to be “troubling because it threatens the wellbeing of individuals and violates social assumptions about the body” (Andrews and Nelkin 1998, p. 35).

The greatest fear for those who argue against commodification of the human genetic material is that products that have commercial value are often susceptible to theft, which is a common form of redistribution (Andrews and Nelkin, 1998). It is also argued that commodification could lead to significant consequences in the fields of both science and medical practice (Andrews and Nelkin, 1998).

While noting these arguments, proponents of benefit sharing such as Kadri Simm believe that discussions on benefits sharing are necessary even if one disagrees with the underlying trends of commercialising the genome. She argues, “Closing one’s eye to a certain existing evil does not make it disappear” (Simm 2005, p. 30). Promising a share of benefits derived from the use of one’s genetic material to participants appears to be against what society considers a commodity, treating the body as something to be sold as one wishes (Varjavand, 2013). However, it is also insincere to demand altruistic donations from poor research participants whilst industry-led researchers reap all the benefits (Slabbert, 2011).

For instance, in the Henrietta case, neither she nor her family has ever received anything from the proceeds of her cell line yet there are approximately 11000 patents involving the HeLa cells (Khan, 2011).

This means that, while expecting her family to be content with her or their altruistic gesture and unable to afford the very medicine that her cells contributed to, someone somewhere has a monopoly and profits from research outcomes that would not have been possible without Henrietta Lacks and her family.

There is nothing wrong with altruism; the issue as expressed by Dickenson is that it has “too often tended to be one-way – from research population to researchers – and one way altruism is

better called exploitation” (Dickenson 2004, p. 113). Therefore, benefit sharing seeks to address these issues.

As noted from Schroeder’s definition, benefit sharing not only advocates for the sharing of benefits but seeks to prevent exploitation and ensure justice in genetic research. Exploring literature on this issue has also revealed that it has never been considered through an African lens. Using the principle of Ubuntu, I hope to contribute to the literature by giving a fresh dimension to the discussion on profit sharing.

1.3 Thesis

In this research report, I argue that research participants should share in profits generated from the use of their body tissue in research.

1.4 Research Objectives

The objectives of this research are:

1. to provide an evaluative descriptive account of the key ethical issues and conceptions related to benefit sharing for research participants whose body tissues are used in research.,
2. to critically discuss and evaluate South Africa’s current legal position, which prohibits research participants from sharing in benefits generated from the use of their body tissue in research,
3. to defend the position that research participants should share in profits generated from the use of their body tissue in research using conventional moral theories and principles in the Western tradition,
4. to give an account of Ubuntu as an alternative moral theory directing right action and to show how Ubuntu can deepen and enrich the moral defense of the position that research participants should share in profits generated from the use of their body tissue in research.

1.5 Research Methods

This research is a purely normative study and relies on the standard methods of this kind of research. It is based on reviewing current legal frameworks and work done on Benefit sharing, considering arguments for and against it and exploring African perspectives such as Ubuntu in relation to the issue. This is done to support the thesis that research participants must partake in profits generated through the use of their body tissue. This research is based purely on secondary data. Thus, there was no collection or analysis of new data for use in this research.

1.6 Rationale for the Study

This research seeks to respond to injustices and clear exploitations of vulnerable individuals such as Henrietta Lacks whose cells have been continuously cultured since 1951 and has created a multimillion-dollar industry with corporations continuously enriched while the participant or her family are not partaking in any of those profits. Her story provides a clear indication of why this research is necessary. This type of research is even more important for Africa as the continent has seen a dramatic increase in the number of registered clinical trials in the past decades and arguably, houses a huge portion of the poor and vulnerable (Patra and Muchie, 2017). A lot is written on this issue, what is lacking is an African perspective. I believe that the principle of Ubuntu will provide a much-needed alternative to the issue, particularly in addressing the main arguments against benefit sharing. This perspective may also contribute to the formulation of policy and law on the topic in a Southern African context.

1.7 Research Report Overview

This research paper consists of six chapters, following this brief introduction and introductory chapter (**Chapter 1**), are chapters 2-6.

In **Chapter 2**, titled, ‘**Key Ethical issues and conceptions relating to benefit sharing and sharing of research profit with research participants**’, I provide an evaluative and descriptive account of some of the key ethical issues and conceptions relating to benefit sharing for research participants whose body tissues are used in research. I show how these ethical issues are used to deprive research participants of their moral right to share in these benefits. I also argue and show that these issues are misinterpreted therefore not enough to support the argument that research participants are not entitled to benefit from research that makes use of their genetic material;

Chapter 3 is titled, ‘**South African law as it relates to benefit sharing in the area of human genetic material**’ and provides a critical discussion and evaluation of South Africa’s current legal position which prohibits research participants from sharing in the benefits generated from the use of their genetic material in research. I argue that the law, as it stands, fails to protect research participants whose genetic materials are used in research, instead, it protects those who exploit them.

I conclude this chapter by suggesting that there is a need to find innovative ways that will ensure the maintenance of an uncompromised research environment while making sure that participants are not exploited but protected;

Chapter 4 is titled, ‘**Conventional Western moral reasons for research participants to share in research profits for their contribution**’. Here, I use two conventional Western theories, deontology and utilitarianism, to defend the position that research participants should share in profits generated from the use of their genetic material.

Chapter 5 is titled, ‘**Ubuntu as an alternative moral theory directing right and wrong and informing decisions relating to benefit sharing**’, and it defines and introduces the principle of Ubuntu as an alternative perspective towards a morally just benefit sharing for research

participants who share their genetic material for medical research. I argue that principles of harmony and community demand that research participants should share in these benefits.

Chapter 6 and the final chapter is titled, '**Conclusion**', is a detailed synopsis of the key arguments advanced in this research. It is an emphasis on two points. Firstly, research participants must share in research that makes use of their genetic material and lastly, because of its potential to humanise and enrich the principle, Ubuntu should be considered when considering benefit sharing.

1.8 Conclusion

In this chapter, I set out the foundation of the research by providing background literature on the topic, setting out the thesis statement, the objectives of the research and outlining the methodology of the research. I also provide the rationale for the study and end the chapter by giving an overview of the research report.

Chapter 2

Key Ethical issues and conceptions relating to benefit sharing and sharing of research profit with research participants

2.1 Introduction

The conception and desire to introduce the principle of benefits sharing in medical research arose as an intuitive response to the fact that at face value, it seems unfair and unjust that a nation, company or person should make money using someone else's resources without paying for them (Berg, 2001, p 240).

According to Slabbert, it was introduced to medical research "as a mechanism to restore equilibrium to the asymmetry between researcher and participant in the spirit of deontological consideration of fairness" (Slabbert, 2011, p 609).

It is a principle with its foundation in social justice and human rights (Slabbert, 2011). Some cases that highlight the necessity of benefits sharing include the HeLa cell line and the HTLV-I Leukemia virus antibodies which both resulted in patents granted to the benefit and enrichment of researchers and other stakeholders but not the parties that contributed to the genetic material (Khan, 2011; Skloot, 2010 and Dickenson, 2004).

While benefit sharing promises to introduce justice and fairness in medical research, it is presented with many ethical challenges. As a result, the very objectives of this principle are not fully achieved.

In this chapter, I give both a descriptive and evaluative account of these challenges / arguments, I show how they are used to deprive research participants of their moral right to benefit from

research that makes use of their genetic material and why these arguments are not enough to support this practice.

Some of these challenges include the *commodification of the human body*, *ownership and the human body as property*, the potential *undermining of altruism* and the *limits to and undermining of the principle of respect for autonomy*. As I discuss these ethical issues, it will be apparent that some, if not all, are connected in one way or another.

2.2 Commodification of the human body: a misplaced argument against the principle of benefit sharing

On the argument that benefits sharing undermines the ethical and moral understanding of the human body as something that cannot be commercialized or treated as a commodity, Mark Nelson argues that it finds its foundation from religious arguments that the body is of God's ownership and not our own (Nelson, 1991).

Reza Varjavand, in his paper titled '*Legalized Market for Human Kidneys: A Wrong Solution to a Right Problem*', quotes the Muslim phrase "To God we Belong, To Him is our Return" and argues that this phrase implies that we belong to God and our body is not equivalent to the pieces of property we own, which can be sold at our discretion (Varjavand, 2013).

Warning against the dangers of selling human organs, Pope Benedict XVI of the Christian faith makes a comparable statement, he argues that "the body can never be considered as a mere object" so the "logic of the market" cannot be applied to organ donation (Varjavand 2013, p. 94). Upon considering Immanuel Kant's thinking, a similar conclusion is reached, yet on a different line of reasoning.

For Kant, what makes the commodification of the human body immoral is a person's inherent dignity, "that is, an unconditional, incomparable worth" (Fasoro 2019, p. 91).

Because of this dignity, it is morally wrong for any person including the “self” to sell persons (Nelson, 1991).

It is a similar reason that led Andrews and Nelkin to believe that commercialising human tissue is problematic, they conclude that it jeopardizes individual well-being and violates societal norms regarding the body. (Andrews and Nelkin, 1998). It is also feared that commodification can have devastating consequences for science and medical practice and may introduce illicit markets in the distribution of human tissue (Andrews and Nelkin, 1998).

Kare Berg holds a view similar to Andrews and Nelkin’s, he also argues that requiring financial compensation for study participants at the outset of research could pose serious problems as it could prevent university scientists from participating in drug discovery (Berg, 2001).

While the argument against the commodification of the body is a valid one. A view that I also unequivocally hold is that human tissue should not be open for sale, be it privately or commercially. The challenge with this argument, however, is that it is not well placed in relation to benefit sharing. As indicated above, benefit sharing concerns itself with the maintenance of equity and a just distribution of research benefits. It is not an argument advocating for the sale of human organs or genetic material.

Those who advocate for denying research benefits to participants often use the "commodification" argument to deflect attention from the real issue: the unfairness of allowing researchers and their sponsors to benefit from medical research while excluding the very individuals who contribute to it.

They do this knowing that the human body is sacred to most, if not all, cultural and religious systems. By misrepresenting benefit sharing as an argument for the sale of the human body, they

know that most people will certainly be against the principle. This is evident in the arguments already discussed above.

Is benefit sharing really a form of commodification? Should it be relevant in medical research?

The answer to these questions is no, and a definite yes, respectively.

As a concept founded on the principle of justice, benefit sharing suggests that those who contribute to scientific research should also receive a share of its benefits. This is especially important in the case of health research, where the exploitation of developing countries, such as South Africa, by developed countries is a major concern (Mahomed & Sanne, 2015).

Because it aims to redefine benefit sharing rather than provide a valid justification for the differentiation between research participants, researchers and research sponsors, the argument presented fails to establish why it is morally acceptable to deny research participants certain benefits while allowing researchers and research sponsors to receive those same benefits.

Furthermore, the argument does not provide adequate justification for allowing research sponsors to financially benefit from medical research that utilises genetic materials without being accused of commercialising the human body while benefit sharing is. Therefore, the commodification argument does not suffice as a moral justification against benefit sharing.

2.3 The human body as property: an unreasonable argument against benefit-sharing

The argument that benefits sharing encourages or will encourage viewing of the human body as property is directly linked to the arguments advanced above on benefit sharing as a form of commodification. These arguments on commodification are often based on the idea that we (people/ persons) do not own our bodies, hence we should not be able to subject it or use it as a commodity. Some of the arguments furnished above speak directly to the concept of the body not

constituting a person's property. To avoid redundancy, I will not restate them here. Varjavand's argument could be one example, "To God we Belong, To Him is our Return ... Accordingly, you belong to God and your body parts are not like the pieces of property you own and thus can be sold at your discretion" (Varjavand 2013, p. 94). It provides a clear example of how an argument against commodification can be based on people's inability to own their own bodies.

Notwithstanding the arguments provided above, however, the prominent rationale for depriving research participants of any property right to their body or genetic material is the argument that the human genome is of common heritage to humanity (Knoppers et al., 2000). It is argued by some scholars that genetic information is shared among family members hence prohibiting any entitlement to ownership rights by one member of that family (Marchant, 2005).

Research participation is therefore considered as a contribution to the benefit of all mankind.

This argument is not convincing at all. As an example, it is a commonly accepted fact that parents have a responsibility to care for their children due to the close genetic similarities shared between them. However, this responsibility cannot be extended to strangers, even though they share genetic similarities with these children (all human beings share at least 99% genetic makeup). If strangers were expected to take care of children in the same way as parents, the world would not have any poor people, unfortunately, that is not the case.

Let us take this further and consider another scenario. Assume that a wealthy farmer dies and leaves his fortune to his 10-year-old child.

From our previous example, it should be clear that the father had a responsibility towards his child, and leaving his wealth to the child was the right thing to do. However, it would be

unreasonable for every human being to expect a share of the distribution of the father's estate, just because they are human beings too and are genetically related to the father.

This would, with no doubt, make sense if it were practised universally, no person would be disadvantaged, and society at large would be on equal footing.

The issue with the common heritage principle as applied in the distribution of medical research benefits generated using participants' genetic material is that it is not applied equally to research participants, researchers, and research sponsors alike. As a result, research participants are treated unjustly which is what benefit sharing seeks to resolve.

Berg argues against benefit sharing and the sharing of proceeds from research with research participants on the basis that “the people themselves have not performed any act of competence to create DNA. Thus, they cannot have a right similar to that based on intellectual property or patent acts. Their body has simply synthesized a compound based on hereditary instructions passed on from the parents” (Berg 2001, p. 242). This is unsurprisingly consistent with the argument by the HUGO Ethics Committee on the common heritage of humankind which he was party to. The committee believes that because we share about 99.9% of our genetic make-up with other human beings “In the interests of human solidarity, we owe each other a share in common goods, such as health” (Knoppers et al. 2000, p. 90).

Berg argues further that “the people who make a person’s DNA sample valuable must have some stake in it, a right that is more like that of a holder of intellectual property than any right that the donor of the sample could claim” (Berg 2001, p. 242).

This is a generally held view in medical research. Human tissue donors and donors of genetic material reserve no property rights, or patent rights to inventions derived from the use of their

genetic material. They do not have any claim on revenues from commercial products resulting from the use of their genetic material (Marchant, 2005).

On the other hand, researchers and research investors are not only rewarded for their contribution to the same research but also make significant profits, despite sharing the same 99.9% genetic make-up as the research participants.

Of course, Berg will argue this to be a reward for their contribution to making the genetic material valuable. However, the problem with this argument is that the pharmaceutical industry is reportedly making significantly higher revenues when compared with other non-pharmaceutical companies in the S&P 500 Index (Ledley et al., 2020).

This is significantly more than just a reward for their contribution, which means that researchers, research sponsors and pharmaceutical companies do not only benefit from 'health as a common good' but also share in the profits made through medical research, yet research participants are expected to only contribute to, and expect health as their only good or reward.

As will be discussed a little later in this paper, the South African National Health Act and the South African law in general takes a similar position. It explicitly prohibits research participants from receiving monetary compensation or benefits resulting from donation of tissue or genetic material and participation in research. The Act, however, allows for remuneration of health professionals for services rendered, which amounts to benefits from tissues or genetic materials (see S 60 of the NHA, 2003). While the act does not consider benefits after the research, it creates an impression that it is acceptable for researchers and research sponsors to garner wealth from the products of research but strictly prohibited for participants.

Amie Devlin, considering the contributions made by firefighters and those by research participants, argues that both clinical trial participants and firefighters assume risks for societal

benefit. However, only research is accused of immorality for considering paying its participants. (Devlin 2020,) Therefore, according to Devlin, there is no reasonable justification that research participants are deprived of profits resulting from their participation using the argument that it is to the benefit of society (Devlin, 2020).

If this argument was indeed reasonable, researchers and research sponsors would also be contributing to medical research only to benefit society and would not be entitled to further enrichment as a result of their contribution to research. However, as shown above, this is not the case.

2.4 Benefit sharing a complement to altruism: not an undermining force

Altruism refers to selfless behaviour that is motivated by the desire to benefit others and not oneself (Richard, 2020). Health research has and is widely understood to take an altruistic posture, where research participation is viewed as a contribution to the advancement of medicine and for the benefit of others (Dauda & Dierickx, 2016).

Some researchers, including Berg, are of the view that altruism is at the heart of medical research, he argues that a focus on sharing financial benefits with research participants will threaten their willingness to participate for idealistic reasons (Berg, 2001).

Sassy Molyneux et al. argues that the concern around using money as a benefit, beyond undue inducement, has the potential to commercialise an altruistic endeavour. (Molyneux et al., 2012).

On the contrary, Slabbert argues that it is disingenuous to demand selfless contributions from poor research participants while industry-lead researchers enjoy all the benefits (Slabbert, 2011). Even those who argue for benefit sharing seem to agree with the necessity and importance of altruism.

However, the issue with altruism in medical research, according to Dickenson, is that it has often been one-way, from the research population to the researchers, which she argues to be exploitation (Dickenson, 2004).

Lynn Jansen argues that an act may be altruistic and still be to the benefit of research participants, she argues that “A person who has an altruistic goal is not motivated to pursue the goal because she thinks success will redound to her benefit, she pursues the goal for altruistic reasons. That she benefits from the success of the goal does not change this fact” (Jansen 2009, p. 31).

While unpacking the ‘ethics of altruism in clinical research’, Jansen also explores the concept of exploitation as the “unfair treatment of one party that furthers the interest of or ends of another party” and argues that for an altruistic participation by the participant not to be considered as exploitation on the part of the researcher, both experimenter or researcher and the participant must share the same end or goal (Jansen 2009, p. 31).

In other words, the research participant must be aware that the research may or will result in commercial benefits to the researcher and intend for his or her contribution to bring about that result.

Therefore, it is not enough that the research participant renders their contributions solely for medical and scientific development, save where the research is solely for that reason. Their end must also align with the intended ends of the research, which more often is not only for the advancement of human health but also to bring about financial profits to the researchers and their sponsors. This results in what I shall refer to as ‘exploitative pseudo altruism’ for lack of a better word. To avoid this exploitative pseudo altruism, research participants must share in research

profits just as researchers and research sponsors do, taking into account the payments for their research skills and initial investments.

2.5 Benefit sharing and the compensation of research participants as a threat to the principle of respect for autonomy

The principle of autonomy refers to the concept of self-rule or self-governance. The autonomous individual, according to Tom Beauchamp and James Childress, “acts freely in accordance with a self-chosen plan” (Beauchamp and Childress 2019, p. 37).

The argument in this regard is that paying research participants might compromise informed consent by coercing or unduly influencing participants to enroll in studies against their better judgement (Resnik, 2020).

Devlin argues against this; her stance is that it is unreasonable to deprive research participants financial benefits on the fear that they may be unduly induced, while providing financial rewards to participants of other industries that have the same or even more risk, industries such as firefighting.

Her argument is based on the fact that fighter fighting is inherently risky, and that the risk is offset by a high societal benefit and financial reward (Devlin, 2020).

Notwithstanding the fact that empirical research does not support the prima facie view that payment for participating in research adversely impacts their judgment and decision making, it is still the commonly held view and it is still common practice that participants are deprived of just monetary benefits for fear of “coercion” or “undue influence” (Gelinis et al., 2018; Resnik, 2020). According to Emily Largent and Holly Fernandez Lynch, this is resultant of the lack of definitional agreement on what ‘coercion’ and ‘undue influence’ mean in the context of human research participants (Largent and Lynch, 2017). They argue that, because of this deficiency of a

generally accepted definition and the lack of laws, regulations and ethical guidelines governing what constitutes an ethically acceptable payment to research participants and what does not, research ethics committees and Institutional review boards encounter confusion when evaluating offers of payment. As a result, they lean towards conservative approaches, what she calls the “better safe than sorry” approaches (Largent and Lynch 2017, p. 66). Their stance, however, is that “the ‘better safe than sorry’ approach is not necessarily safer at all” (Largent and Lynch 2017, p. 66). A great example can be seen in the Canadians Division of the Vice-Presidents Research and Innovation document titled ‘*Compensation & Reimbursement of Research Participants*’ (Zand, 2019). In this document, the authors view some payments to be acceptable when considering Canadian citizens but seem to be of the view that similar payments would result to undue inducement if given to international participants, particularly those in low- and middle-income countries (Zand, 2019). They argue that “compensation at Canadian rate may pose an undue influence on communities to participate, while compensating at rates typical to those host countries hourly wage may give the appearance of outsourcing for low cost (Zand 2019, International research para. 1). To provide some sort of definition, potentially resolving the issue as identified by Largent and Lynch, in a paper titled ‘*how payment for research participation can be coercive*’ Joseph Millum and Michael Garnett make an argument for two distinct types of coercion in medical research; one that is consent undermining (consent-undermining coercion) and what they coin as ‘coercion as subjection’ which is described as “a way in which someone’s interests can be partially set back, a form of unfreedom whereby a person is subjected to another person’s foreign will” (Millum & Garnett 2019, p. 21). On this background, the duo makes the argument that “coercive offers do not impact the ethics of

research studies by means of invalidating participants' consent" (Millum & Garnett 2019, p. 22).

Devlin makes a similar point, still using the example of fire fighters, she argues that:

“While some firefighters assume the role because of a sense of altruism, others choose to pursue firefighting as their profession. Receipt of financial compensation for their services does not diminish the nobility of their action. Among career firefighters, it is reasonable to assume that they may have made a different choice if there were no payment, yet rarely is a firefighter's salary seen as coercive.

Similarly, research has shown that many research participants join clinical trials due to a sense of altruism, yet many others do so for financial compensation. Even among those primarily motivated by financial gain, many factors play into their decision. Both firefighters and clinical research participants accept financial compensation for their service, yet it is only research participant compensation that is viewed as coercive.

(Devlin 2020, p. 2).”

Therefore, from Devlin, Millum and Garnett's view, it would seem as if depriving participants of payment for participating in research projects would be unjustified and unfair exploitation.

2.6 Conclusion

In this chapter, I have considered some of the main arguments used to object benefit-sharing.

While I agree that issues such as the commodification of the human body and the undermining of altruism should be avoided, I also note that these arguments are not well placed in the argument against benefit sharing. It is therefore unreasonable to deny research participants the opportunity to share research benefits based on these arguments.

Chapter 3

South African law as it relates to benefit sharing in the area of human genetic material

3.1 Introduction

In this chapter, I focus on the South African law and how it relates to benefits sharing. I examine the effectiveness of the law in regulating benefit sharing and compensatory practices in medical research. I also consider whether the law is right or wrong in disallowing research participants to share in research profits where their genetic material is used, particularly where the research results in profits beyond the reward for skills and investments by researchers and their sponsors.

As one of the many measures in place to protect research participants from exploitative practices in medical research and to understand benefits sharing in the South African context, it is important that I explore, holistically, the country's history of medical research and the protection offered to research participants thereof.

South Africa has a long history in health research and has been playing a leading role on the international stage in this regard since the 1800s (Dhai, 2017). Despite their presence in the international arena, there is no evidence of any legislation aimed at protecting research participants, that is, until the promulgation of the Constitution of the Republic of South Africa in 1996, which was subsequently followed by the National Health Act of 2003 (Dhai, 2017; Cleaton-Jones and Wassenaar, 2010). Although Research Ethics Committees were well established in the country, at least since 1977, and as important as they were and still are, these institutions were unable to provide adequate protection to research participants.

Prior to the Constitution and the NHA, “compliance with ethical clearance of health research was a moral decision for South African researchers” (Cleaton-Jones and Wassenaar 2010, p. 710).

In the same breath, one should acknowledge the Human Tissue Act 65 of 1983 as predecessor to the NHA, which provided some protection such as mandating receipt of consent from a donor prior to removal of their tissue, blood or gametes (Human Tissue Act 65 of 1983).

While they could be applied in research settings, the provisions of this Act were not specific to medical research and had no section aimed at protecting research participants from any conceivable exploitation.

This has since changed as the South African Constitution is now clear and specific on this matter. Section 10 sets the tone by stating that “everyone has inherent dignity and the right to have their dignity respected and protected” (The Constitution of South Africa 1996, Section 10). In section 12(2) the drafters of the Constitution were even more explicit, specific and deliberate when they added that;

“everyone has the right to bodily and psychological integrity, which includes the right

(a) to make decisions concerning reproduction;

(b) to security in and control over their bodies; and

(c) not to be subjected to medical or scientific experiments without their informed consent

(The Constitution of South Africa, 1996).”

Subsections (b) and (c) are important for our discussion as they provide for the same protections that benefit sharing seeks to provide.

It is worth noting that in its preamble, the Constitution is proclaimed as the supreme law of the republic (The Constitution of South Africa, 1996). What this means is that no law or regulation will be above what is codified in the constitution. Hence, the National Health Act and any other

law or regulations applicable in South Africa should be consistent and align with the values of the Constitution (National Health Act, 2003).

This is reiterated in S (2) of the Constitution which adds that, “law or conduct inconsistent with the constitution is invalid, and the obligations imposed by it must be fulfilled” (The Constitution of South Africa 1996, Section 2).

The NHA sets out provisions that are intended for the protection, promotion and fulfillment of the right to access to health care as set out in S 27 of the Constitution together with the right not to be subjected to medical or scientific research without consent as set out in S 12. Most importantly, S 73(1)(a) and (b) of the Act read together with S 6.2 of the South African Medical Research Council Guidelines on the Responsible Conduct of Research (SAMRC) make the prior approval of research by a registered Research Ethics Committee (REC) a legal requirement. This, Sassy Molyneux et al. argues is inadequate, “protection of research participants through reviewing research proposals before they begin is inadequate; that there is a need to look beyond the design of studies and to see how research is actually being conducted on the ground” (Molyneux et al. 2012, p. 2). While I agree with Sassy’s point, it is important to note that unlike in the past, researchers are now obligated to obtain ethical clearance from a registered ethics committee before proceeding with medical research.

This is essential as ethics committees play a very crucial role in protecting the rights of research participants and ensuring that all research projects are ethically sound, in line with medical research regulations, the Constitution, domestic laws and international human rights laws or principles.

While these developments must be celebrated (particularly in relation to the protection of research participants), they should not be viewed as the destination. More should still be done,

especially because of the changing landscape in medical or health research. The advancement of genetic research and technologies in this field requires a constant review of the legislations and tools aimed at protecting research participants.

An important area that requires revision is the area relating to compensation for research-related harm and benefit sharing, in particular, how to deal with profits that result from the use of genetic material from research participants.

3.2 South African law in relation to benefit sharing and participation in medical research

The concept of benefit sharing is part of South African law and was introduced to our law through the National Environmental Management Biodiversity Act of 2004 and the Bioprospecting, Access and Benefit Sharing Regulations of 2008.

This came after South Africa had already been a signatory to the Convention on Biological Diversity (CBD) which opened for signatures at the 1992 United Nations Conference on Environment and Development and was ratified by the country in 1996 (Convention on Biological Diversity, 1992 ; South Africa-Main Details, 2022). Notwithstanding the fact that benefit sharing had been effectively made law internationally and locally through these documents, the principle had not and is still not recognized as such in relation to human genetic resources.

In 1995, parties to the CBD agreed to exclude human genetic resources from its scope, therefore leaving these resources unregulated and without adequate legal safeguards (Schroeder and Lasen-Diaz, 2006). As a result, there is no legal obligation for research participants to benefit from the use of their genetic materials, instead, there is ample evidence that shows the law to be against such benefits.

3.3 The legal argument against research participants benefiting from the use of their genetic material in medical research

As it stands, South African law prohibits research participants from receiving monetary compensation or benefits resulting from their participation in research. There is however an exception for reimbursement towards reasonable costs incurred because of participating in the research. This approach is in line with the recommendations of the Human Genome Organization Ethics Committee which suggested that “undue inducement through compensation for individual participants, families and populations should be prohibited” (HUGO 2000, no pagination).

In prohibiting such compensation, the committee included benefits such as “technology transfer, local training, joint ventures, and provision of health care or of information, infrastructures, reimbursement of costs, and the possible use of a percentage of any royalties for humanitarian purposes (HUGO,2000).

However, the committee also explicitly prohibits the receipt of any financial gains that may result from participating in research, stating, “The actual or future benefits discussed should not serve as an inducement to participation. Nor should there be any financial gain from participation in genetic research” (HUGO 2000, no pagination).

It is evident, therefore, that the South African law, on paying research participants, aligns with this view, providing for payment towards expenses incurred as a result of participating in medical research, advocating for other benefits similar to those recommended by the HUGO Ethics Committee, yet against financial benefit for research participation.

This is in contradiction, to a certain extent, with sections 10 and 12 of the Constitution, which respectively intend to protect the dignity of research participants, their right to bodily integrity and the right to security in and control of their bodies (The Constitution of South Africa, 1996). Providing research participants with reasonable benefits may be seen as respecting their dignity and right to security and control over their bodies.

While denying research participants these benefits may seem to serve a worthwhile purpose such as preventing the creation of an unregulated market in human tissue and genetic material (where individuals sell their or others' genetic material) it produces both immoral and unconstitutional consequences, where research participants are used as a means to an end and their dignity is disregarded.

The NHA, Department of Health (2020) South African Good Clinical Practice (SAGCP): Clinical Trial Guidelines; Department of Health (2015) Ethics in research: Principles, Processes and Structure; and the Medical Research Council (2001) guidelines on ethics for medical research: General Principles, allows for researchers and research sponsors to benefit from the use of the same genetic materials yet denies research participants that same right.

The case of *Venter v Roche Products (Pty) Ltd* shows how reluctant the Courts are to grant orders for participants to receive monetary compensation or benefits as a result of their participation in research, even where such benefits are sought on the basis of injury incurred as a result of participating in the research (*Venter v Roche Products (Pty) Ltd*, 2014).

In this case, the appellant, Mr. Petrus Albertus Venter, was a research participant in an international medical trial conducted by a Swiss company, F Hoffman-Le Roche AG ('FHLR'). As a result of suffering a series of 'trial-related serious adverse events' also referred to as trial related medical injuries, Mr. Venter sought compensation for medical expenses and other

damages arising from his injuries. FHLR was willing to pay for his direct medical expenses but not for other related damages such as pain and suffering, loss of income and general damages.

The court ruled in FHLR's favor, stating that "the PIL-ICON, when read together with the provisions of the ABPI guidelines, such compensation as was offered by FHLR fell short of a legal commitment. It amounted to the possibility of compensation on an *ex gratia* basis..."

(*Venter v Roche Products (Pty) Ltd* 2014, para 72). By 'PIL-ICON', the Court was referring to the *Patient Information Leaflet and Informed Consent form* that the appellant signed prior to his participation in the research. The ABPI is the *Association of the British Pharmaceutical Industry code of practice*, its relevance in this case is informed by the fact that the South African clinical trial compensation guidelines are adopted directly from the ABPI (DoH 2015 Ethics in Health Research).

Even though this case was decided mainly on contract law, particularly the law relating to tacit contracts, what is particularly important for our discussion is the point that was raised by the respondents and affirmed by the court which is that "the compensation provisions in neither the ABPI nor the SAGCP guidelines imposed a legally enforceable obligation on the sponsor of a clinical trial in relation to the payment of compensation for a trial-related injury" (*Venter v Roche Products (Pty) Ltd* 2014, para 72).

According to this court, there is no legal duty for researchers or research sponsors to pay any compensation to participants.

This is a clear disregard to both the worth and dignity of research participants, it is acceptable that they contribute to the research, but their safety is not worth protection by the law. If their well-being and safety can easily be disregarded, an argument for payment for profits resulting from the research would be even less important.

Discussions on this issue are contentious. Like me, some argue that research participants deserve appropriate compensation for their contribution to clinical trials.

On the other hand, others argue that “even the modest payments may cause participants to enroll in trials without duly considering the risks, thereby acting as an undue incentive and exploiting the situation of vulnerable participants” (NHREC 2012, no pagination).

Some of the arguments include the concern that paying research participants may cause some participants to conceal information that would disqualify them from the study, putting their own lives at risk and potentially jeopardizing the integrity of the study (Bentley, 2004). The challenge with these arguments is the attempt to settle one moral issue by disregarding or creating another. It makes no moral sense that researchers and their sponsors should generate multimillions or sometimes billions at the expense of their participants.

While the objection to appropriate compensation and sharing of benefits with research participants is suggested as a measure to protect their interests, what about the fact that they are treated unfairly when researchers and their sponsors make profits at their expense?

In response to the Venter case, however, the 2015 version of the Department of Health Ethics in Health Research: Principles, Processes and Structures, puts an emphasis that in South African law, when a participant consents to or accepts the risk of harm, they lose their right in law to claim compensation or damages if that harm materializes. This view is outrightly in conflict with section 12 of the constitution and with their opening statement in relation to this issue.

In the opening line of S 3.5.3 of the regulations with the subheading ‘Insurance against research-related bodily injury,’ the drafters of the regulations acknowledge that “Research Participants should not have to bear the financial cost of rectifying harms that occur when something goes

wrong during the study” (Department of Health Ethics in Health Research: Principles, Processes and Structures 2015, Section 3.5.3)

In an attempt to reconcile this inconsistency, the regulations acknowledge that there is a moral duty for sponsors responsible for causing bodily injury to “assist the participant by paying for reasonable medical expenses needed to treat the bodily injury that materialises through participation in research” (Department of Health Ethics in Health Research: Principles, Processes and Structures 2015, Section 3.5.3.2).

However, I argue that the same moral duty is owed to research participants even when they do not experience any injury, but to also share in profits when the research results in profits beyond compensation for skills and initial investment by researchers and their sponsors.

This portion of the regulation strengthens my argument by providing further evidence that the drafters of the regulation also recognize the unfairness and unjust effects of their position.

However, in my view, by only recognizing this as a moral duty and not a legal one, they leave participants unprotected. This is because researchers and research sponsors may decide not to honour moral duties but would be obligated to abide by legal ones, as they often attract legal consequences for noncompliance.

Therefore, while research participants are called ‘participants’ evidence on how the law relates to them, particularly in the issue of compensation and benefit sharing, shows that participants are seen as subjects - only useful for their contribution but not beyond that.

While intended for the protection of research participants, the laws and regulation around this issue seem to be protecting the interest of research sponsors instead. This illuminates both the necessity and need to review the issue of compensation and benefit sharing in South Africa.

As it is evident from the arguments laid down above, the main contentions on Benefits sharing or the compensation of research participants for their participation in research is that deriving benefits from their participation in research may result in undue influence and exploitation of research participants.

While this position could be interpreted as a protective safeguard for research participants, I argue that research participants are prejudiced instead. They are excluded from recovering losses that result from their participation in research and from fully participating in the benefits of the research, which is wrong. Not only are they prejudiced by this, their constitutional and moral rights are violated. This is exacerbated when the research results in a commercial product, where researchers, research sponsors and pharmaceutical companies are enriched in the process and participants are expected to be content with being altruistic.

This view is against the principles of fairness and justice and amounts to exploitation.

The paternalistic assumption that research participants will be unduly influenced to participate in research if there are promises of profit does not account for all possible circumstances therefore it cannot justify the denial of benefits.

While the promise of a financial breakthrough has the potential of encouraging vulnerable participants to participate in research without fully considering the potential risk and harm that may result, it does not justify the current status quo- where it is considered “ethical and legally” acceptable for corporations and pharmaceutical companies to profit from human genetic materials while, at the same time, it is considered morally and legally unjustifiable for research participants to have a similar benefit.

This is why I argue that we must find innovative ways that ensure the maintenance of an uncompromised research environment while strictly making sure that research participants are full participants in the true sense of the word, not merely used as a means to an end.

I propose that research participants should share in research proceeds where such research results in commercially (own word) products or where it results in excessive monetary benefits beyond the understanding of the research being an altruistic act for the general good of the public.

This does not, in any way, take away from what is suggested by the HUGO ethics committee which proposes that “profit-making entities dedicate a percentage (e.g., 1-3%) of their annual net profit to healthcare infrastructure and/or to humanitarian efforts” (HUGO 2000, no pagination).

I suggest that these types of benefits should be reserved for circumstances where the research results in commercial products or where it generates an income that is beyond what can reasonably be considered an altruistic act for the general good of the public.

A perfect example of circumstances that may qualify as research being ‘beyond what can reasonably be considered as an altruistic act for the general good of the public is the HeLa cell line. In the development of that cell line, Henrietta Lacks (whose cells were taken without her consent - an issue that will not be discussed here for the purposes of this argument, there is no distinction between participants who voluntarily donated their genetic materials and those whose cells were taken without their consent) contributed her cancerous cells which were eventually used for multiple research purposes. As a result, her cell line generated and is still generating multi-millions of dollars to the benefit of researchers, research sponsors and pharmaceutical companies but not her or any of her descendants.

3.4 Conclusion

In this chapter, I have explored the concept of benefit sharing as it relates to South African legal instruments and other related international laws or regulations. In so doing, it became apparent that while benefit sharing forms part of our legal system, it does not extend to human genetic resources.

Consequently, researchers are not legally obligated to compensate research participants for their contribution to health research, save for very minor exceptions such as reimbursement towards costs incurred because of participating in the research. However, even in these circumstances, the case *Venter v Roche Products (Pty) Ltd* has revealed that courts are reluctant to order that participants are compensated for their involvement in health research.

Chapter 4

Conventional Western moral reasons for research participants to share in research profits for their contribution

4.1 Introduction

In this chapter, using the principles of deontology and utilitarianism, I advance the argument that research participants are morally entitled to, and should share in profits generated from the use of their body tissue or genetic material in research. As expressed in the previous chapters, it is important to be reminded that this argument is specific to circumstances where the research yields financial profit, where researchers and research sponsors reap benefits beyond just the benefit to medicine and their investment in skills and money, respectively.

Having explored the moral issues that surround benefit sharing and the evidence that both South African and international laws and principles are generally against research participants benefiting from research that makes use of their genetic material, it is an appropriate time to look at this question considering applicable conventional moral theories.

The first theory to be considered is deontology, followed by the consequentialist theory of utilitarianism. The two theories are like polar opposites and are often in conflict with each other. One focuses on the outcome of an act and the other strictly on the rules and duties concerning that act, yet both are very helpful in determining if the act is morally right or wrong.

Despite their polarity, both theories suggest that it is morally wrong for research participants to be deprived of research benefits and make it a moral imperative that research participants share in benefits resulting from the use of their genetic material in research.

4.2 Deontology

In deontology, right or wrong is determined through duty, obligation or responsibility (de Campos et al., 2019). Through works such as *The Critique of Pure Reason* and his formulation of the categorical imperatives, Immanuel Kant was instrumental in laying down most of the foundational deontological rules or obligations applied today.

One such obligation is the duty to have regard for the intrinsic value of all of mankind, an essential rule or value in many democratic settings today. One of the core Kantian principles relating to the intrinsic value of all humankind is the rule that no one should ever be used as a mere means to an end (Samuel et al., 2019).

4.2.1 Research participants as mere means to an end

The argument I make in this regard is that biomedical research in South Africa, and internationally, violates this rule. Research participants are merely used as a means to an end, to further researchers and their sponsor's interests. According to Kant, that is not only unacceptable but immoral.

To support this argument, it may be important to look closely at what using another as a mere means to an end entails and compare that with the actions of researchers and research sponsors towards medical research participants.

In short terms, using another as a mere means to an end is to use a person to advance one's interest while disregarding their value or worth.

Stijn Bruers, suggests that for research participants to be used as mere means to an end, two conditions must exist, the first condition being that “they must not want the treatment” and the

second condition is that their presence or participation must be required to achieve the intended end (Bruers 2016, p. 407).

Kirstein Samuel argues that for an agent to count as using another, it is not enough that they do something to the other to realise some end, they must also intend the presence or participation of some aspect of the other to contribute to the realisation of such an end (Samuel, 2019).

The interest or intended end in medical research includes the advancement of science, medicine, and the saving of lives.

However, with most medical research funded by industry and pharmaceutical companies,' profits have become one of the interests of importance (Joel Lexchin, 2012).

Keeping in mind Bruers' conditions, not only are research participants essential for the achieving of this end, but it is also intended for them to do so.

Secondly, most participants are not interested in participating in research that seeks to enrich researchers and their sponsors, especially if it is at their expense.

In a study by Marily Guillem, some participants expressed repugnance towards research corporations making money at their expense (Guillemin et al., 2018).

One participant was quoted saying, "... the fact that I know it's being used for academic purposes not for market research and things like that, which is worthwhile, I have less desire to be involved in it, less desire to help big companies make money basically. I don't think they need my help [sic]" (Guillemin et al. 2018, p. 288).

With Bruers conditions met, I have firstly shown that research participants are generally not interested in participating in research that seeks to enrich researchers and their sponsors at their expense. Secondly, it is notable that they are needed for the research and consequently for the financial success of the research. It is therefore reasonable to argue that they are used to achieve

this end. Denying them reasonable benefits while providing the same to other research contributors amounts to using them as mere means to an end, disregarding their worth.

While the use of genetic material contributed by these participants does not automatically translate to being used as mere means to an end, the fact that most research sponsors are making use of business models, only interested in funding research that has potential returns and sometimes manipulate research results for profits, indicates that their main goal is not just the advancement of science and medicine (Joel Lexchin, 2012).

Several research studies in the past have been reported to have been terminated for purely commercial and economic reasons such as a “limited commercial market or insufficient anticipated return on investment” (Joel Lexchin, 2012 p 223; Psaty & Rennie, 2003).

If that is the case as suggested, research participants are undoubtedly being used as a mere means to an end. There is no other conclusion because if truly the intention was to advance medicine, safeguard life and ensure its continuity, such studies would continue even when they do not promise a sound financial reward at the end.

Whether intentionally or not, South African legislation such as the NHA is complicit in this exploitation of research. Section 60(4) of the NHA states that “It is an offence for a person - (a) who has donated tissue, a gamete, blood or a blood product to receive any form of financial or other reward for such donation, except for the reimbursement of reasonable costs incurred by him or her to provide such donation” (NHA 2003, Section 60(4)).

While the intentions of the Act may be good and aimed at regulating the control and distribution of human genetic material, it fails to consider that some genetic material contributed to medical research like that of Henrietta Lacks may lead to a profit beyond just paying researchers. At the

same time, it fails to acknowledge that medical research has often taken a business model driven by profits and incomes. A blanket prohibition on financial benefits for sharing tissue and genetic material such as the one in s 60(4) has serious consequences as it facilitates and protects an immoral environment where research participants are used as mere means to an end. Because the concept of a mere means to an end is layered, as further argued below, when used merely as a means to an end, research participants are also unfairly exploited.

4.2.2 Unfair exploitation of research participants

The ethical issues discussed in Chapter 2 form a critical foundation of the conception of the current and prevailing understanding of what constitutes ethical benefits in medical research. They also illuminate the main challenges to benefit sharing, mainly the challenges with paying research participants.

While these issues are widely discussed in bioethics, particularly the danger of coercion and undue influence, the impacts of not paying or underpaying research participants such as exploitation are not discussed enough (Resnik, 2020).

Influential structures such as the Hugo ethics committee suggest specific forms of benefits which include technological transfer, local training, joint ventures, infrastructure, reimbursement of costs, provision of health care or infrastructure and the use of a fraction of royalties for humanitarian purposes as some of the acceptable research benefits for research participants. At the same time, they strongly reject financial gains for participating in research as an acceptable benefit, a ‘better safe than sorry’ approach, as described by Largent and Lynch (HUGO, 2000; Largent and Lynch, 2017)

As a result, while the currently recognized forms of benefits are commendable, they fail to fully address the issue of unfairness and exploitation of medical research participants.

However, according to an international working group on fair benefits for research in developing countries, they “increase paternalism in relation to communities or populations living under extremely constrained socioeconomic conditions” (Schulz-Baldes et al. 2007, p.9)

As understood by Alan Wertheimer, transactions are exploitative when they fail to achieve fairness between interacting parties, not because they fail to provide a particular type of benefit to a particular party (Wertheimer, 1996).

Hence, the provision of the benefits outlined above does not negate the exploitation of research participants. The failure to allow research participants financial benefits, while making such provisions available to research participants and their sponsors, is unfair and therefore amounts to exploitation.

Annette Schulz-Baldes, Effy Vayana and Nikola Biller-Andorno argue that “for the ethical conduct of a study, it is essential to provide participants and communities with a fair level research benefit- goods, services or money” (Schulz-Baldes et al. 2007, p.9). as will be evident below in my discussion of the principle of justice, fairness is a central principle of human dignity.

4.2.3 The Principle of Justice

Justice is commonly defined as fair, equitable and appropriate treatment of persons in light of what is due or owed to them (Varkey, 2020; Beauchamp and Childress, 2019). John Rawls defined it as the elimination of arbitrary distinctions and the establishment of a proper balance between competing claims (Rawls, 1958).

In a fair and just world, owing to their contribution to research, research participants should be entitled to research profit as well. As collaborators in research, they should not be seen as different from researchers and research sponsors as they all are important in the different roles

they play. This is why I argue that after all expenses are covered, researchers paid for their role, and research sponsors theirs, if there are any continuous profits, they should be shared with research participants.

Angela Ballantyne argues the same, her position is that it is widely agreed that individuals and communities who participate in research ought to have some benefits from the research, especially when such research is on commercial products that generate profits for the sponsors (Ballantyne, 2010). For Schulz-Baldes et al., this is so essential that if a fair level of research benefits - goods, services or money - are not provided, the research is unethical (Schulz-Baldes et al., 2007).

From the arguments outlined above already, it is clear that the principle of justice demands that research participants are entitled to and should share in profits generated from the use of their genetic material in research.

If it is generally agreed as a matter of justice that research participants are entitled to fair, equitable and appropriate benefits, yet they are deprived of the same, the question is whether the arguments advanced by those against this point of view, as discussed above in chapter 2, are more compelling than the principle of justice.

Thana de De Campos is of the view that the issue is how justice has been viewed in health research (de Campos et al., 2019). She argues that current discussions in medical law and bioethical debates have been heavily concerned and framed around individual rights and the autonomy of patients. This, she argues, is the reason why there is a failure to understand and implement justice fully (de Campos et al., 2019). She further argues that justice should and has always been defined as a “relational idea between right-holders and duty-bearers” (De Campos et al. 2019, p. 90). Justice as rights and responsibilities/obligations would mean the rights for

research participants not to be harmed, coerced or unduly influenced to participate in harmful research. However, researchers and research sponsors would simultaneously have a complementary duty not to exploit research participants (De Campos et al., 2019).

Therefore, the deprivation of research profits to participants based on “avoiding undue influence” would not stand, as the second leg of justice would not be satisfied.

In many discussions on the issue of sharing profits with research participants, as established above, the pursuit of justice has been one-sided (as identified by De Campos et al., 2019) it gravitates towards arguments on preventing coercion and undue influence while failing to consider the complementary duty for researchers and research sponsors not to exploit research participants. This is not true when dealing with non-human genetic resources, where the Nagoya Protocol on Access and Benefit-sharing, which regulates the sharing of non-human genetic material in Article 5, specifically provides that “benefits arising from the utilization of genetic resources, as well as subsequent applications and commercialization, shall be shared in a fair and equitable way with the Party providing such resource” (Parties to the Nagoya Protocol 2015, Article 5). The protocol further states in paragraph 4, “Benefits may include monetary and non-monetary benefits” (Parties to the Nagoya Protocol 2015, para 4).

The HUGO Ethics Committee statement, on the other hand, while acknowledging the commercialization of the human genetic research industry, the inequality and injustice impact associated with that shift, fails to provide research participants adequate protection as seen in the Nagoya Protocol.

HUGO seems to be operating on the one-sided conceptualization of justice, on one hand, there seems to be an obsession to prevent undue influence towards participants and on the other, the failure to safeguard participants from exploitation by researchers and the pharmaceutical

industry. As discussed earlier in this paper, in the case of the HELA cells alone, approximately 11,000 patents were registered thereby creating a multi-billion-dollar industry (Khan, 2011).

That was just one cell line and only one participant who did not receive any gain from her participation in that research. It is not surprising that the pharmaceutical industry grosses significantly higher when compared to other industries (Ledley et al., 2020).

Yet, HUGO states that “The actual or future benefits discussed should not serve as an inducement to participation nor should there be any financial gain from participation in genetic research” (HUGO 2000, no pagination).

In an attempt to address the clear injustice and lack of protection for research participants involved in research which is exploitative as it only benefits researchers and research sponsors at their expense, the committee suggests that “profit-making entities dedicate a percentage (e.g., 1-3%) of their annual net profit to healthcare infrastructure and/or to humanitarian efforts” (HUGO 2000, no pagination).

The issue with this is that it is merely a suggestive statement, a non-binding recommendation. Secondly, it is a vague statement because it refers to annual net profit without a detailed explanation as to what that means. The statement fails to give clear guidance on what should happen when profits manifest later and not within the financial year when the research was concluded.

Lastly, it relates to research participants in a paternalistic manner, dictating how they should receive their benefits as though they are incapable of making their own autonomous decisions.

4.3 Consequentialism

Before we dive into to the question of morality - in allowing research participants to share in profits resulting from the use of their genetic material - let us first look at consequentialism as a moral theory.

Consequentialism is a normative ethical theory meaning it can be used to determine whether a particular action is ethical or not (Sinnott-Armstrong et al., 2023).

To determine the morality of a particular action, according to this theory, we must evaluate all possible consequences of that action and the one that yields the most good is the ethical or morally correct action to take (Stephen Nathanson, 2014). It is important to note that in consequentialism, “good” can be interpreted differently by different people. For that reason, in this research, I limit myself to Utilitarianism, a branch of consequentialism that has a clear and unambiguous “good”. The two will sometimes be used interchangeably throughout this paper hence consequentialism must be understood in its narrow interpretation which is utilitarianism.

‘Good’, according to Jeremy Bentham, is pleasure and happiness, he in fact saw these as intrinsic good as they are good in and of themselves - “not producing any further valuable thing” (Stephen Nathanson 2014, a. what is good).

While on common sense alone it seems reasonable and morally justifiable to argue for research participants to share in benefits that result from the use of their genetic material, in consequentialism as the name suggests, the consequences flowing from research participants sharing in these profits determines its moral justification. Because the consequences are to the benefit of many, doing so is considered a morally right thing to do. However, if the consequences were not to the benefits of society, sharing profits with participants would be considered immoral. As expressed in previous chapters, there are two qualifications to my argument: firstly, my argument should not be understood to mean that research participants must

get an equal share to that of the researchers or those who fund the research. Secondly, it is not an argument that research participants should always receive monetary benefits. It is, however, that both researchers and research participants should receive fair benefits. According to Annette Schulz-Baldes et al. benefits should include “not only medical treatment of participants during the study and availability of proven intervention afterwards, but also collateral health services, public health measures, employment and economic activity, capacity development and financial rewards” (Schulz-Baldes et al. 2007, p. 9). Where a research project results in large profits or monetary benefits, participants must be able to benefit as well.

There are a number of consequences that follow from research participants benefitting, where their genetic material is used for medical research. Public confidence and trust is the backbone of medical research, without it, medical advancement and development would cease.

4.3.1 Loss of Public confidence and trust between researchers and research participants

Trust is one of the most crucial factors in biomedical research, without it, the institution of research would not be able to survive (Kerasidou, 2016). The failure of medical research would mean that fewer developments will be made, if any. Consequently, the medical system will crumble leading to many deaths.

Addressing the lack of trust in COVID-19 vaccines Professor Charles Wiysonge, Director-General of the World Health Organization, argued that “vaccine beliefs are often rooted in distrust of institutions, and associated with historical and contemporary experiences of inequality, injustice and exploitation” (SAMRC 2021, Para. 6).

This was confirmed in countries such as the United States of America, where distrust in the government and the medical profession was cited as one of the main reasons for vaccine hesitancy (Laurencin, 2021).

Similarly, when research participants are not treated with respect and as equal partners in the entire research project, they will eventually grow weary. That will result in a decline in their participation and affect medical research and its benefits (Marchant, 2005).

In a study by Marilys Guillemin et. al., it was established that “a number of research participants contrasted trust in research being conducted by universities to a lack of trust in market research, or research being conducted for profit-making purposes,” (Guillemin et al. 2018, p. 288).

Given this background, a utilitarian rule would be that acts that undermine public confidence and trust in medical research are immoral and should be avoided. In the inverse, those that facilitate trust and confidence are morally right and should be encouraged.

Therefore, because denying research benefits to research participants undermines their confidence and trust towards researchers and the medical research institution, it is immoral and must be avoided.

On the other hand, since allowing research participants to partake in financial benefits has the potential to foster trust and confidence, it is morally right and should be encouraged. Scholars such as Gary Marchant confirm that “compensation for genetic donors may actually help research by increasing the supply of available donors” (Marchant 2005, p. 169). Allowing research participants to share in the benefits of research will encourage trust between participants and researchers, improving the willingness to participate and ultimately resulting in the ease of developing new drugs, innovative medical techniques and improved health care interventions and public health measures.

A great example of the impact of not valuing research participants can be seen in the 2007 Indonesian avian flu case. Indonesia stopped sharing H5N1 avian flu samples with the World Health Organization's reference labs due to fear that its population was highly unlikely to get access to vaccines in the event of a flu pandemic despite its contribution (Millum, 2011; Sedyaningsih et al., 2008).

As seen from the arguments above, sharing benefits with research participants will encourage more trust and willingness to partner with researchers, ultimately leading to the well-being of all people.

Denying them these benefits, however, will lead to a lack of trust and similar to what happened in Indonesia, research participants will withhold their contribution in fear of making pharmaceutical companies wealthier at their expense. This will impact research and lead to poor development of medical resources and an unnecessary loss of many lives. Therefore, according to the principle of consequentialism, for the benefit of many lives, research participants must share in the profits of research.

4.3.2 Conclusion

In this chapter, I have argued that it is not morally justifiable to exclude research participants from receiving financial benefits that come from their contributions to medical research. Using the deontological rule that people must not be used as a mere means to an end, the principle of justice and the rule against exploitation I have shown that excluding research participants from these benefits is exploitative and unjust.

In the second part of the chapter, I focused on the theory of utility where I further solidified my argument. Here, I showed that this exclusion of participants will erode their trust towards

researchers and medical research. Resulting in a decline in medical advancement and ultimately leading to the deterioration of healthcare and the loss of lives.

Chapter 5

Ubuntu as an alternative moral theory directing right and wrong and informing decisions relating to benefit sharing

5.1 Introduction

In the previous chapter, I discussed how both deontology and consequentialism point to the conclusion that it is morally unacceptable for research participants to be excluded from profits resulting from their contribution and use of their genetic material, while researchers and research sponsors benefit from it. Despite these traditional moral theories clearly indicating that research participants should share in these profits, this is still a matter of debate.

This may be because these principles are sometimes distorted by those who argue for the ongoing exclusion of research participants from these profits, mostly for their own capitalistic gains and enrichment.

The argument that paying individuals to participate in research studies may lead them to hide information that could disqualify them from the study, while also putting their own safety at risk and compromising the study's integrity, is backed by moral principles of both deontology and

consequentialism. It serves as a prime example of how these theories can be used to justify these capitalistic and exploitative practices.

The African principle of Ubuntu differs from Western ethics in that it emphasises our human nature, promoting a sense of communal unity and discouraging exploitative behaviors.

Therefore, this principle would work better as an alternative basis to benefits sharing. It proves to be incapable or at least not easy to pervert for the arguing of the continued exploitation of research participants, it is either you act in a way that demonstrates ubuntu or you do not.

In research, Ubuntu requires that all participants be treated as equals and deserving of respect. Ultimately, it encourages a shift away from greed and towards a more equitable and compassionate way of relating to others, making it very important to consider in studies on benefit sharing.

In this chapter, I introduce and define the concept of Ubuntu. I use the principles of community and harmony to argue that research participants should benefit from the use of their genetic material in research. Through this discussion, it will also be apparent that incorporating Ubuntu can benefit biomedical ethics and improve benefit sharing in South Africa.

5.2 Ubuntu as an alternative moral theory directing right action

As one of the biggest continents in the world, Africa has diverse cultures. In that diversity, however, there are significant commonalities in areas such as value systems, beliefs and practices throughout the continent (Munyaka and Motlhabi, 2009).

As such, while in this paper my focus is on the concept of Ubuntu, a well-known South African principle, it should be understood that its principles or values are not unique to South Africa but extends to the larger parts of the continent.

Nkonko Kamwangamalu attests to this fact by holding that “the concept of *ubuntu* is also found in many African languages, though not necessarily under the same name” (Kamwangamalu 1999, p. 25; Munyaka and Motlhabi, 2009, p. 214-215).

He elaborates on this statement by pointing out some of these Ubuntu equivalents:

“umundu in Kukuya and umuntu in Kimeru, both languages spoken in Kenya; *bumuntu* in KiSukuma and KiHaya, both spoken in Tanzania; *vumuntu* in shiTsonga and shiTswa of Mozambique; *bomoto* in Babangi, spoken in the Democratic republic of Congo; *gimuntu* in Kikongo and giKwese, spoken in the Democratic Republic of Congo and Angola, respectively” (Kamwangamalu 1999, p. 25; Munyaka and Motlhabi 2009, p. 215).

Quoting from Mogobe Ramose’s *African philosophy through ubuntu*, Michael Onyebuchi Eze takes it further and says that “Ubuntu as a socio-ethical imperative of African people is not merely restricted to Bantu-speaking people who use the word ‘ubuntu’ or its equivalent thereof, it also includes the worldview of other ethnic groups of sub-Saharan Africa who share similar ideals embodied in ubuntu” (Eze 2008, p. 387).

Now that I have shown that Ubuntu or its principles are generally applied within African communities, it is evident that it is important to consider when making moral decisions in

African or where African parties are involved. Thus, I argue for an Ubuntu informed benefit sharing when considering deciding issues of benefit sharing in South Africa.

At this juncture, I will attempt to define the concept and give context to its potential use in benefit sharing. Having lived by the principles my whole life, while tempted, I am intimidated to define the concept. This is because the spiritual element and depth of Ubuntu is something that cannot be captured fully through words. The principle is therefore, better appreciated through lived experience.

In Nhlanhla Mkhize's words, "the traditional African view is that ethical concerns are practical and experiential; they cannot be separated from the lived experiences of the people in question" (Mkhize 2008, p. 35). Ubuntu, therefore, is a holistic principle, allowing people to know what the right thing to do is, considering not only the philosophical but also the spiritual.

In A survey by John Eliastam, two participants capture these sentiments well: one believes that "Ubuntu cannot be defined but speaks for itself in action" and the other that "Ubuntu is a general term, and it is associated with your heart" (Eliastam 2015, p. 4). It is something in a person's heart propelling them to both act and react in a certain manner, usually benevolently.

Mluleki Munyaka and Mokgethi Motlhabi attest to the spiritual element of the principle, they state that "Ubuntu is more than just a manifestation of individual acts. It is a spiritual foundation, an inner state, an orientation and a disposition towards good which motivates, challenges and makes one perceive, feel and act in a humane way towards others" (Munyaka and Motlhabi 2009, p. 65)

Fainos Mangena describes this as the Common Moral Position and argues that it is a moral imperative because, "once implanted in the mind of a person; they no longer need rules that are

in black and white to remind them that what they have done is right or wrong” (Mangena 2016, p. 67). While referring to Ubuntu as a Common Moral Position, he further writes, “This CMP is not some kind of principle or norm that is comparable to deontological, teleological, or even virtue-based principles as they obtain in the West, it is more than a mere principle, norm or even quality; it is a way of life” (Mangena 2016, p. 75).

I bring this complexity about the principle not because this paper seeks to make a spiritual argument but because it is important for the reader to understand that ubuntu as a theory can be visualised as a full circle where human life is completed. It is a principle that allows African ethics, morality, spirituality and all other aspects of human life and experiences to find expression. Hence, this brief overview is important, it shows the gravity and the significance of the principles we discuss going forward.

Acknowledging this complexity in defining this principle, Mogobe Ramose does so and holds that “it is best, philosophically, to approach this term as a hyphenated word, namely *ubu-ntu*” (Ramose 2002, p. 230) “with *Ubu* evoking the idea of being itself and *ntu* as the nodal point at which be-ing assumes concrete form” (Ramose 2002, p.230).

Ramose draws from the maxim “*umuntu ngumuntu ngabantu*,” which can “be construed to mean that to be a human being is to affirm one’s humanity by recognizing the humanity of others and, on that basis, establish human relations with others” (Ramose 2002, p.231). He further defines “Ubuntu as be-ing human (humaneness); a humane, respectful, and polite attitude towards others” (Ramose 2002, p.231).

After considering several definitions including Chikanda's "the word defines a positive quality supposedly possessed by a person. It is an internal state of being or the very essence of being human" (Munyaka and Motlhabi 2009, p 64). Munyaka and Motlhabi define the principle by holding that "*Ubuntu* is a person's self-realisation and manifestation as a human being. Having *Ubuntu*, or being human, is identified with behaving according to one's human nature and, by implication, in a manner that benefits a human being" (Munyaka and Motlhabi 2009, p. 65).

While the intentions are good, as a concept informed mainly by western norms and values, benefits sharing does not fully embody the values of Ubuntu. Unlike African ethics and principles, "Western societies stress the individualistic nature of a person and put emphasis on the individual's rights, autonomy, self-determination and privacy" (Christakis 1992, p. 1086). The essence of benefit sharing is commutative justice, where the view is to give a person what is due to them based on their contribution.

This is evident in Schroder's definition where, benefit sharing is considered as "the action of giving a portion of advantage/profit derived from the use of human genetic resources to the resource providers in order to achieve justice in exchange" (Schroeder 2007, 207).

Ubuntu requires more than distributing what a person is entitled to. Above all, it requires a shared identity and the provision of justice as a means to achieve harmonious living and as a community. I discuss this in greater length later in the chapter; it suffices at this point to simply say that in Ubuntu, equity, justice and human worth is serenely embedded in the concept of being. Therefore, by virtue of being human, at least in the sense of being umuntu where umuntu

ngumuntu ngabantu, research participants should be able to fully participate in research profits resulting from the use of their genetic material.

It is therefore imperative to explore what viewing benefit sharing through an alternative lens (a lens informed by the principles of Ubuntu) would entail. Executed correctly, this exercise may well be a contribution to the fulfilment of Biko's prophecy; Africa through its principles bestowing to the world "a more human face" (Biko 2017, p. 108).

To understand the ethics of ubuntu, two important concepts must be considered, that is the concept of community and that of harmony, which are integral to the principles of Ubuntu. For purpose of this discussion, I presented them separately, however, the principle of harmony is one with the principle of community and the two should not be understood as separate parts. They all contribute to Ubuntu's ethical principles that what is right to do is what connects people together and not what separates them (Metz, 2007).

5.2.1 Harmony

Harmony in the African ethical view, according to Metz, is a composite of two parts, shared identity and good-will (Metz, 2007). Shared identity is the view that a person exists and shares common ends with others. Good-will, on the other hand, Metz argues, is embodied by a person who;

wishes another person well (conation); believes that another person is worthy of help (cognition); aims to help another person (intention); acts so as to help another person (volition); acts for the other's sake (motivation); and, finally, feels good upon the knowledge that another person has benefited and feels bad upon learning she has been harmed (affection) (Metz 2007, p. 336).

As previously argued, although the advancement of medicine is a goal of research, financial gains and the creation of patentable products appears to be the primary driving force behind many medical research projects, especially those involving genetic material.

The act of denying research benefits to research participants who share their genetic material is lacking ubuntu, hence immoral. It is void of goodwill and cannot be seen as sharing of identity. Researchers and their sponsors fail to show compassion or they fail to recognise research participants' worth. As argued earlier, they are more content with gaining profits and patentable products than they desire to be in a community or having a shared identity with their participants. While the concept of community may not be familiar in the science world, it is very important in the ubuntu way of life and can be attributed to harmonious relations that allow every person to be afforded their self-worth.

5.2.2 Community

Munyaka and Motlhabi argue that in the African view, a person's value and dignity are best realized in a relationship with others (Munyaka and Motlhabi, 2009). One cannot be a human being alone, only in community, (Mligo 2021).

In the ubuntu way of life, communal living and sharing an identity with others is an ideal. It is a desirable interaction that can be used to indicate if a person is taking an undesirable action or not (Metz, 2011).

In contrast to the Western theories we discussed earlier, actions are not considered wrong merely for causing harm to people or violating an individual's autonomy as argued by utilitarians and Kantians respectively. Instead, "An action is right just insofar as it produces harmony and reduces discord; an act is wrong to the extent that it fails to develop community" (Metz, 2011;

Metz 2007, p. 334). It is this viewpoint that will help us understand why research participants should share in research benefits.

Anchored on the notion of Umuntu ngumuntu ngabantu, which means that a person is a person because of others, it is a proclamation that one's value is intrinsically linked to others in the community. Therefore, by denying research participants their share of the benefits, researchers and their sponsors violate the principle of community. They put their own interests ahead of the community's, which is wrong and immoral according to the ethics of ubuntu.

It is an act that communicates an exaggerated importance and value of these researchers and their sponsors, an assumption of superiority over others, particularly research participants.

Any action such as this one, an act that disregards community and harmony among people in a community, is immoral and goes against the values and principles of ubuntu (Metz, 2011).

Ubuntu values everyone as an important player in the community, this is evident in simple acts such as greetings; the Zulu and SiSwati languages both use the word 'Sawubona' in greetings which when literally interpreted, affirms to the other person that we see you (Munyaka and Motlhabi 2009).

In its values, Ubuntu reflects an unceasing, constant and deliberate acknowledgement of one's dignity and value, what Biko calls a "true man-centered society". "The basic tenants of our culture... demonstrated that we appreciate a man for himself. Ours is a true man-centered society whose sacred tradition is that of sharing" argues Biko (Steve Biko 2017, p. 106).

When research participants contribute their genetic material to research, they do so for the benefit of the community.

Arguably, this point of view has similar grounds to the ‘heritage of humankind’ argument which also states that research participants contribute to research for the benefit of society.

The distinguishing factor is that the ‘heritage of humankind’ argument makes the claim that because humans share a significantly high percentage of genes in common, their genetic material also belongs to society and may be exploited to the benefit of that society.

On the other hand, in ubuntu, the concept of community does not negate the individual, their value or their dignity. As argued by Micheal Onyebuchi Eze, African communitarianism is a “discursive formation between the individual and the community” (Eze 2008, p. 386).

It is the acknowledgement that individuals are an integral part of the community, an understanding that the community does not precede the individual and that there cannot be a community without people (Eze, 2008). At the same time, it is an understanding that an individual's subjectivity is shaped and expressed within community (Eze, 2008).

While it is important that individuals contribute to the survival and well-being of the community, the community has a responsibility to nature and provide an environment that allows the individual to flourish within the community.

It is anticipated that some may also claim that, by arguing for benefit sharing and the sharing of benefit with research participants, I promote a more individualistic approach, an approach that contradicts the whole notion of ubuntu.

Yes, community plays a crucial role in the principle of ubuntu. However, one must understand this concept as practised through African values. Some people tend to have a limited and inflexible understanding of the concept, one that does not align with ubuntu. They mistakenly reduce the principle to a superficial interpretation of ‘community’ that often equates it with ‘society’; what Augustine Shutte refers to as the mechanistic theory of society as he argues that it is comparable to a vast machine with the people that compose it as simply parts (Augustine, 2009). Thaddeus Metz argues well when he points out that “to seek out community with others is not best understood as equivalent to doing whatever a majority of people in society want” (Metz 2011, p 538). Elia Shabani Mligo takes the argument even further by arguing that there is a distinction between “community” and “society” (Mligo 2021, p. 9). Many are either not aware of this distinction or simply ignore it.

It is this failure to understand this distinction that would result in a contestation and misinterpretation of the argument I am putting forward in this paper, that research participants must share in profits derived from the use of their genetic material.

Such an argument can easily be misconstrued to advocate for individualistic benefits, which would be a deviation from the collective interest orientated ubuntu way of life.

However, by the end of this section, it will become abundantly clear that such a view is incorrect.

A proper understanding of community from the perspective of ubuntu will help greatly in bringing that clarity.

While quoting Agulanna (2010, p.287) Mligo, discusses the distinction between society and community. Pertaining to society, he argues that it merely describes the people and their way of

life. The argument is that the concept is devoid of intimate interaction among people, with individuals prioritizing their autonomy and life realized fully, when they concentrate on actualizing their own lives (Mligo, 2021).

Community, on the other hand, is described in five contemporaneous parts, “as a sub-society whose members (1) are in personal contact, (2) are concerned for one another’s welfare, (3) are committed to common purpose and procedures, (4) share responsibility for joint action, and (5) value membership in the community as an end worth pursuing” (Mligo 2021, p. 10-11).

For the common heritage of humankind argument to be equivalent to Ubuntu’s communal living, there must be a reflection of these 5 factors.

Unfortunately, other than the claim based on all human beings sharing similarities in genetic material, there is no other substantiating basis for the argument therefore it cannot be on the same footing as Ubuntu.

On the argument that advocating for benefit sharing is not in line with Ubuntu, sharing benefits with the research participant will not only enrich the individual participant but also those in community with them. The five elements show that a benefit to one participant will infiltrate to the community, therefore sharing benefits with participants is sharing them with the community. However, depriving research participants of these benefits and allowing research participants to profit, on the other hand, ensures that the community does not benefit at all. As a result, the act of sharing benefits with participants is consistent with ubuntu and not doing so is contrary to the principle.

Looking only at the second and fourth elements that describe community as listed above, ‘concerned for one another’s welfare’ and ‘share responsibility for joint action,’ we can see the manifestation of reciprocity which necessitates that researchers and research sponsors in pursuit of a harmonious community and playing their part in contributing to the community must share research benefits with research participants.

This does not only amount to the acknowledgment of the important role played by research participants in medical research and the advancement of medicine, Ubuntu further requires that they are treated morally and with dignity when participating in research. Sharing benefits with them is one such way.

To deny them the opportunity to share in benefits that result from the use of their genetic material is an immoral and exploitative act that can have devastating impact if allowed to continue. One of the major impacts would be research participants becoming more unwilling to share their genetic material.

Despite the challenges against the concept, benefit sharing is the correct way to value research participants for their contribution, paying research participants who share their genetic material to medical research is not only the right thing to do, but also a symbol of ubuntu. This is a principle that is very important to consider, especially in the context of South Africa, where it is practiced widely and introduces a much-needed enrichment to the principle of Benefit sharing.

Chapter 6

Conclusion

Human genetic material contributes significantly to the understanding of diseases, development of much needed drugs and the advancement of medicine. To the exclusion of research participants, researchers, pharmaceutical companies and medical research sponsors often generate great financial benefits from their involvement in these research projects.

Using both traditional Western ethical theories and the African ethics of Ubuntu, this research report has painted a clear picture that it is immoral, wrong, and exploitative that researchers and their sponsors are entitled to benefits from medical research that makes use of human genetic material, while research participants who contribute the same genetic materials are prohibited from doing so.

The main argument advanced is that benefit sharing, which requires a just, equitable and reasonable sharing of research benefits, must be the main principle applied in these situations.

The research further appreciates and suggests that benefit sharing requires a new perspective, one that does not focus merely on the exchange of resources i.e. research participants being rewarded for their participation. It suggests that benefit sharing should be applied in consideration of the African principles of community and harmony, that it must not be a tick box exercise but a humane and harmonious act that encourages good relations and continuous communal engagements. In that way, research participants are not exploited and used merely as a means to an end but valued as dignified beings and co-contributors to a mutual goal that seeks to advance human health.

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