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Health data as a public good?

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of Laws in Medical Law

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ABSTRACT

This dissertation critically analyses whether health data should be publicly owned in South Africa. South Africa is crumbling under a high rate of non-communicable diseases, such as diabetes. Access to health data for research purposes could combat this problem. This is why it is essential to identify the private or public owners. Private owners may restrict data access, but solutions are available. Incorporating evidence from South African legislation, journal articles, academic textbooks, online sources, and international literature, it was found that single data instances of genomic data, a type of health data, can be controlled and owned privately by storing them on computer files. Therefore, they meet the property requirements of the common law. This fact has been disputed by the Academy of Science of South Africa, as it believes that health data should not be owned and should be treated as a natural resource, with the state as its custodian. This aligns with academics who support genomic sovereignty, where the state, group, or nation controls access to and use of a population's genetics. This approach was counterproductive to a public good objective of open science: sharing health data with the public without restriction in order to enhance research. This is because the state decides who gets access to the data, which will not be freely accessible. There are also administrative inefficiency issues and political interference risks with the state. Furthermore, the state will have to use many resources to expropriate the data from private owners and then compensate them. Therefore, the more straightforward approach of an open science policy for private entities is proposed.

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LIST OF ABBREVIATIONS/ ACRONYMS

ANC	African National Congress
ARV	Antiretroviral
ASSAf	Academy of Science of South Africa
COPD	Chronic Obstructive Pulmonary Disease
COVID-19	Coronavirus disease 2019
DAC	Data Access Committees
DNA	Deoxyribonucleic acid
DSI	Department of Science and Innovation
EA	Expropriating authority
ENCODE	Encyclopaedia of DNA elements
FAIR	Findable, accessible, interoperable, and reusable
HapMap	The Haplotype Map
HGP	Human Genome Project
HIV	Human Immunodeficiency Virus
ICESCR	International Covenant on Economic, Social and Cultural Rights
IPR	Intellectual property rights
NHA	National Health Act
NIPMO	National Intellectual Property Management Office
PAIA	Promotion of Access to Information Act
PGP	Personal Genomic Project
PM	Precision medicine
POPIA	Protection of Personal Information Act
SAMRC	South African Medical Research Council

SA MTA

South African Material Transfer Agreement

UNESCO

United Nations Educational, Scientific and Cultural Organization

CHAPTER ONE: INTRODUCTION TO DATA GOVERNANCE AND THE VALUE OF DATA OWNERSHIP

I BACKGROUND

Data governance helps entities to optimise the value of their data's lifespan.¹ This is done by creating guidelines, practices, data safeguard standards, good data management, and data integrity.² Data governance provides entities with a system for maintaining data that is accurate, dependable, and consistent.³ In addition, it ensures that data breaches are prevented by solid compliance with regulatory obligations.⁴

A vital element of data governance is data ownership,⁵ which is linked to accountability and responsibility.⁶ It also helps to determine which person or entity is responsible for maintaining and accessing the data.⁷ Therefore, it clarifies who owns the data.⁸ Having a data owner ensures the data's accuracy, dependability, and security. However, organisations and individuals who are reluctant to share responsibility or relinquish control may oppose data ownership roles and procedures.⁹ Data ownership is also challenging to establish and manage as it requires clear definitions of roles, duties, and authority.¹⁰ This is difficult, especially in large multifunctional organisations. Furthermore, data ownership needs to be effectively implemented, or it will result in data silos, which are the process of several teams independently handling the data, impeding data sharing and cross-functional cooperation. Thus, effective ownership is vital for data governance.¹¹ The ownership status of health data may affect medical research, individual liberties, and the free-market economy.¹² The capacity or legal

¹ X Jolas 'The Importance of Data Ownership in Data Governance' 23 October 2023, available at <https://dainstudios.com/insights/importance-data-ownership-data-governance/>, accessed on 01 October 2024.

² J Smith & D Alexander 'Data Governance Strategies for Maintaining Data Integrity' (2023) 1 *Department of Computer Science, University of California* available at https://www.researchgate.net/publication/374534993_Data_Governance_Strategies_for_Maintaining_Data_Integrity, accessed on 01 October 2024.

³ RR Koilakonda 'Implementing Data Governance Frameworks for Enhanced Decision Making' (2024) 14(6) *International Journal of Science and Research* 1239.

⁴ Ibid.

⁵ Jolas op cit note 1.

⁶ Ibid.

⁷ Smith & Alexander op cit note 2.

⁸ Ibid.

⁹ BMV Bernardo 'Data governance & quality management—Innovation and breakthroughs across different fields' (2024) 9(4) *Journal of Innovation & Knowledge* 2.

¹⁰ Ibid.

¹¹ Ibid.

¹² J Piasecki & PY Cheah 'Ownership of individual-level health data, data sharing, and data governance' 2022 *BMC Med Ethics* 1.

authority to forbid others from using a particular object depends on who owns it.¹³ This is why the idea of data ownership needs to be addressed. A system of health data ownership must address technological, financial, legal, and ethical obstacles, and also balance the interests of many stakeholders, including sponsors, researchers, data subjects, and society.¹⁴

Health data ownership will help entities ensure that data is not misused, and its accessibility is well-regulated. Therefore, it is vital to know who the owner is because the owner must control access to and security of health data. Research depends on access to data for precision medicine, and data subjects need their personal information protected in that data. Therefore, it will be beneficial to determine which entity can own health data and whether public, private or community ownership is best.

(a) Private ownership

Private ownership of an object or thing means that individuals or an organisation own it.¹⁵ It includes ownership of both material and immaterial objects.¹⁶ The private owner will have the sole authority to use, manage, and transfer his property in any way he wishes as long as it is allowed by law.¹⁷ Private ownership of health data would mean that a person or an entity would have ownership. Therefore, we are considering the data subject or a private institution, such as a research institution, that owns the data. This is explored in more detail when common law property rights are used to assess whether health data meets their requirements to be considered property that can be owned privately in South Africa. This is a view championed by South African writer Thaldar.¹⁸

(b) Public ownership

Public ownership occurs when the state or a group, as a representative of its people, owns and manages a thing or asset.¹⁹ This indicates that the asset is publicly owned to benefit the country's people.²⁰ For health data, this would mean that the state owns it and shares it for the public benefit. This can be done by opening access to health research findings without restrictions. It must be noted that private entities can also give access to their data by making

¹³ Piasecki & Cheah op cit note 12 at 1.

¹⁴ Ibid.

¹⁵ C McConell, S Brue & S Flynn *Economics: Principles, Problems, and Policies* 18th ed (2008) 22.

¹⁶ Ibid.

¹⁷ Ibid.

¹⁸ D Thaldar 'The wisdom of claiming ownership of human genomic data: A cautionary tale for research institutions' 2024 *Developing World Bioethics* 2.

¹⁹ PR Gregory & RC Stuart *Comparing Economic Systems in the Twenty-First Century* 7th ed (2003) 27.

²⁰ Ibid.

the data open or providing paid-for licenses to use the data. Genomic sovereignty fits the public ownership model. It entails that genomic data, which is a type of health data, should be owned by the state, nation, or people. Therefore, the entities above will determine and manage genomic data's access, use, and knowledge—the South African writer Pepper champions this view, which is explored much later in this dissertation.

(c) Community ownership

Community ownership involves collective ownership of an object or asset.²¹ This means a community or group of individuals will manage resources, assets, or services they jointly own²² and the community or group will have joint ownership of health data. Genomic sovereignty will also apply to community ownership because it requires ownership of genomic data by a group of people, nation, or state. The difference between public and community ownership is that the owner is different. For public ownership, the state is the owner. With community ownership, the community jointly owns the data.

(d) What is health data?

Health data includes all data relating to a person's health status, which is special personal information.²³ According to the Protection of Personal Information Act, personal information is an umbrella term that includes any information about an identifiable person.²⁴ In contrast, special personal information is more specialised and contains sensitive data on religion, race, trade union membership, political persuasion, health, biometrics, and criminal behaviour.²⁵ Examples of health data include medical data generated by doctors, medical examinations, tests, and administrative and financial data linked to a person's health status.²⁶ Health data is important because it leads to medical science and public health development.²⁷ This data will be analysed during medical research to detect disease trends, risk factors, treatment outcomes, and more beneficial information leading to precision medicine.²⁸ For example, patients at risk of developing certain diseases will be diagnosed more quickly because medical doctors will be

²¹ 'Community ownership: How Reimagined Economic Development Can Build a More Equitable Future' available at <https://possibilitylabs.org/community-ownership-101/>, accessed on 01 October 2024.

²² Possibility labs op cit note 21.

²³ The Protection of Personal Information Act 4 of 2013, s 1.

²⁴ Ibid

²⁵ The Protection of Personal Information Act, s 26.

²⁶ 'Health data in the workplace' available at https://www.edps.europa.eu/data-protection/data-protection/reference-library/health-data-workplace_en, accessed on 06 June 2024.

²⁷ F Casini et al. 'Health data sharing attitudes towards primary and secondary use of data: a systematic review' (2024) 71(1) *EClinicalMedicine* 2-3.

²⁸ Ibid.

aware of what signs and symptoms to look for, as the health data analysed has made them more knowledgeable.²⁹ Health services will benefit enormously because the data gathered will indicate what course of treatment was successful and what was not. Furthermore, the more data that is collected for medical research, the more advancements can be made.³⁰

(e) Health data and its enhancement of precision medicine

Precision or personalised medicine (PM) involves using technology and data analysis to find treatment and prevention methods that best suit a particular patient's genetic makeup, lifestyle choices, and environmental issues.³¹

In South Africa, the South African Medical Research Council (SAMRC) and the Department of Science and Innovation (DSI) have championed the genomic/precision initiative.³² South Africa has a rising prevalence of non-communicable diseases, such as heart disease, diabetes, and cancer.³³ Furthermore, non-communicable diseases are also present in people diagnosed with HIV who are on antiretroviral (ARV) therapy.³⁴ Therefore, the SAMRC aims to improve precision medicine in South Africa by creating interdisciplinary research and innovation programmes.

Through research, we can obtain large amounts of data on individuals that can be analysed and used to find connections between certain types of people and certain types of health conditions.³⁵ The findings we make from health research can be used to improve healthcare for the public at large. An example would be studies conducted on a particular group of individuals to assess the effects of a specific drug and determine any side effects.³⁶ This study will reveal whether the drug is safe and effective for the public.³⁷ These results will then be used to make treatment and policy changes in medical facilities.

²⁹ Ibid.

³⁰ 'Health data research explained' available <https://www.hdruk.ac.uk/about-us/what-we-do/health-data-research-explained/#:~:text=Using%20health%20data%20for%20research,how%20many%20people%20are%20affected>, accessed on 06 June 2024.

³¹ The South African Medical Research Council 'The South African Precision Medicine Program' 28 May 2023, available at <https://www.samrc.ac.za/sites/default/files/2023-05/PrecisionMedicine.pdf>, accessed on 01 August 2024.

³² The South African Medical Research Council op cit note 31.

³³ Ibid.

³⁴ Ibid.

³⁵ Health data research explained op cit note 30.

³⁶ Ibid.

³⁷ Ibid.

A very recent example of how health research has benefitted the public and improved medical research was a study conducted by First National Level Research in Scotland and Wales to assess the impact that COVID-19 lockdowns would have on patients with Chronic Obstructive Pulmonary Disease (COPD).³⁸ The study revealed that lockdowns were connected with fewer COPD admissions.³⁹ This was because the number of viruses that cause acute COPD exacerbations decreased in prevalence. Even air pollution decreased with lockdowns.⁴⁰ These findings helped medical research identify that patients with COPD could be secluded for a specific period to reduce the risk of respiratory infections.⁴¹

Treatment methods and care plans were also developed for the COVID-19 pandemic by collecting, accessing, and analysing health data.⁴² Health and care services used health data to identify people at risk of developing COVID-19 and to swiftly provide them with treatment and care.⁴³ This was possible only because patients' medical records offered researchers an early warning of what symptoms and risk factors to look for in individuals.

The COVID-19 vaccine was successful because studies were conducted on its effects on people. These studies indicated that the vaccine was safe for the public to use.⁴⁴ Because of these findings, millions of people were vaccinated against COVID-19 to build up their immunity.⁴⁵ Dexamethasone was another treatment drug used in the treatment of COVID-19, as studies showed that it was effective in individuals with breathing difficulties.⁴⁶

The benefits of health data for medical research were not only seen during the COVID-19 pandemic.⁴⁷ Medical research has also improved the treatment and care of individuals who

³⁸ 'Impact of COVID-19 lockdown on the incidence and mortality of acute exacerbations of chronic obstructive pulmonary disease: national interrupted time series analyses for Scotland and Wales' available at <https://www.hdruk.ac.uk/case-studies/impact-committee-selection-impact-of-covid-19-lockdown-on-the-incidence-and-mortality-of-acute-exacerbations-of-chronic-obstructive-pulmonary-disease-national-interrupted-time-series-analyses-for-sco/>, accessed on 01 August 2024.

³⁹ Impact of COVID-19 lockdown on COPD op cit note 38.

⁴⁰ Ibid.

⁴¹ Ibid.

⁴² Coronavirus disease is a respiratory illness caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2). It is a very contagious virus that is transmitted via respiratory droplets. Common symptoms of this virus are fever, cough, and shortness of breath. (M Cascella, M Rajnik, A Aleem et al 'Features, Evaluation, and Treatment of Coronavirus (COVID-19)' 18 Aug 2023, available at <https://www.ncbi.nlm.nih.gov/books/NBK554776/>, accessed on 01 August 2024.

⁴³ Health data research explained op cit note 30.

⁴⁴ Ibid.

⁴⁵ Ibid.

⁴⁶ A Mourad et al 'Dexamethasone for Inpatients With COVID-19 in a National Cohort' (2023) 6(4) *JAMA Netw Open* 1.

⁴⁷ T Bhuiya & AN Makaryus 'The Importance of Engaging in Scientific Research during Medical Training' (2023) 32(3) *International Journal of Angiology* 153-154.

have mental illness, cancer, heart disease, and diabetes.⁴⁸ The medical information in patients' files has excellent scientific and medical research benefits.⁴⁹ That data can be analysed to build on previous research findings or make new findings.⁵⁰ The more data we have on patients' health, the more changes we can make to the treatment and care of patients.⁵¹ Researchers and doctors can use the data from all the different patients to identify similarities.⁵² For example, researchers and doctors can determine whether a specific type of disease is more prominent in a particular race group.⁵³ This will lead to more investigations on the lifestyle and foods eaten by that race group and whether there is a link between them and the specific disease.

(f) Our genetics

According to the International Declaration on Human Genetic Data, genetic data is knowledge that results from nucleic acid or other research.⁵⁴ Examples of this knowledge include data on individuals' inheritable characteristics.⁵⁵

The Declaration also states that genetic data has unique significance for the following reasons: (1) the data can reveal what medical condition the person is susceptible to;⁵⁶ (2) it will have consequences for the offspring and spanning generations of the family;⁵⁷ (3) the data may include information that was unforeseen in importance at the collection stage;⁵⁸ and (4) the data can be culturally relevant to persons.⁵⁹ Therefore, the Declaration acknowledges that this sensitive data needs safeguarding and that scientific and medical advancements require it for research that benefits the public.⁶⁰

⁴⁸ Ibid.

⁴⁹ K Batko & A Slezak 'The use of Big Data Analytics in healthcare' (2022) 9(3) *Journal of big data* 1.

⁵⁰ Ibid.

⁵¹ Ibid.

⁵² A Sharafoddini, JA Dubin & J Lee 'Patient Similarity in Prediction Models Based on Health Data: A Scoping Review' (2017) (5)1 *JMIR medical informatics* 2

⁵³ Ibid.

⁵⁴ United Nations Educational, Scientific and Cultural Organization (2003). *UNESCO International Declaration on Human Genetic Data*.

⁵⁵ Ibid.

⁵⁶ EW Clayton et al. 'The law of genetic privacy: applications, implications, and limitations' (2019) 6(1) *Journal of Law and the Biosciences* 2.

⁵⁷ S Branje et al. 'Intergenerational transmission: Theoretical and methodological issues and an introduction to four Dutch cohorts' (2020) 45(1) *Developmental Cognitive Neuroscience* 3.

⁵⁸ Ibid.

⁵⁹ J Rahnasto 'Genetic data are not always personal-disaggregating the identifiability and sensitivity of genetic data' (2023) 10(2) *J Law Biosci* 6.

⁶⁰ UNESCO International Declaration on Human Genetic Data op cit note 54.

Currently, genomic research databases focus only on European and Asian descent genetics.⁶¹ This means that these databases do not include South African population genetics.⁶² This is a problem because South Africa has a variety of ethnic groups and genetic variations.⁶³ This has led to a minimal understanding of the different kinds of South African genetics and how they affect health and specific diseases found only in South Africa.⁶⁴ Medicine and treatment options will not be created to best suit the South African population, as it is more suited for European and Asian populations.⁶⁵

(g) Ensuring access to research data

Knowledge will only increase if we have a flow of research data.⁶⁶ Researchers rely on available data and research results to verify their credible data and conclusions.⁶⁷ Research data also helps researchers to build on existing data and develop new theories and conclusions.⁶⁸ Results gathered from health data for research will lead to better goods, services, and policies being developed to benefit the wider public.⁶⁹

However, a lot of data is still not freely accessible to the public.⁷⁰ Some reasons for this are confidentiality considerations or national security concerns.⁷¹ Therefore, legitimate reasons for keeping data inaccessible do exist. However, the benefits of accessing and sharing health data for research are enormous.⁷² Section 26 of POPIA prohibits the processing of special personal information. However, section 27(1)(d)(i) and (ii) of the act allows for the processing of special personal information for research, historical, or statistical purposes.⁷³ However, this

⁶¹ Y Wang et al 'Aspiring toward equitable benefits from genomic advances to individuals of ancestrally diverse backgrounds' (2024) 111(5) *The American Journal of Human Genetics* 809-811.

⁶² The South African Medical Research Council op cit note 31.

⁶³ Ibid.

⁶⁴ O Sibomana 'Genetic Diversity Landscape in African Population: A Review of Implications for Personalized and Precision Medicine' (2024) 17(1) *Pharmacogenomics and personalized medicine* 489-491.

⁶⁵ Ibid.

⁶⁶ ProQuest Ebook Central *Ensuring the Integrity, Accessibility, and Stewardship of Research Data in the Digital Age* (2009) available at <https://ebookcentral.proquest.com/lib/ukzn-ebooks/detail.action?docID=3378546#>, accessed on 01 August 2024 para 5.

⁶⁷ ProQuest op cit note 66 at 5.

⁶⁸ Ibid.

⁶⁹ Ibid.

⁷⁰ R Smith & I Roberts 'Time for sharing data to become routine: the seven excuses for not doing so are all invalid' (2016) 5(781) *F1000Research* 2.

⁷¹ Ibid.

⁷² Ibid.

⁷³ The Protection of Personal Information Act, s 27(1)(d)(i) and (ii).

applies only if the processing is in the public interest⁷⁴ or if gaining permission to use the data is impossible or too difficult.⁷⁵ The data subject's privacy must still be protected.⁷⁶

POPIA also states that the responsible party decides why and how the data should be processed.⁷⁷ Therefore, the responsible party must ensure the data is lawfully processed.⁷⁸ If health data was publicly owned, the state would be responsible for carrying out these obligations, and the health data would be a public good. A public good is non-excludable and non-rivalrous, which means that people cannot be excluded or prevented from using the data, and one person's use of the data will not block others from using it.⁷⁹ Therefore, data will be open and freely accessible to all. However, this model also has drawbacks. Nonetheless, it still needs to be determined whether health data should be publicly owned. The ownership type will significantly affect health data sharing and security.

As a result, this dissertation critically analyses whether health data should be owned publicly.

II STATEMENT OF PURPOSE

This dissertation analyses whether health data should be publicly owned in South Africa. It does this by legal analysis of South African legislation and literature relevant to health data ownership, considering the different debates on who should own it, and the various interpretations of ownership regarding handling and care of health data. The international literature was also analysed since South African literature on this topic is scarce.

This dissertation is important as the public or private ownership status of health data affects the way health data is used and shared. If the ownership type is clear, the data owner and their rights and responsibilities to the data subjects can be identified. The owner can exercise their rights and prevent or allow the sharing of the data with others. South African literature indicates that single data instances of health data can be owned privately. This topic

⁷⁴ According to Thaldar, public interest is a broad and varied concept that should not be restricted in scope and applicability. The idea should be evaluated individually as it is defined differently in different jurisdictions. In its most basic form, public interest refers to the notion that a course of action, procedure or result will significantly benefit the public. Therefore, it should be embraced in the spirit of justice and equality. (D Thaldar 'Research and the meaning of 'public interest' in POPIA' (2022) 118(3-4) *S Afr J Sci* 1.)

⁷⁵ The Protection of Personal Information Act, s 27(1)(d)(i) and (ii).

⁷⁶ Ibid.

⁷⁷ Protection of Personal Information Act Summary, available at <https://www.michalsons.com/focus-areas/privacy-and-data-protection/protection-of-personal-information-act-popia>, accessed on 01 August 2024.

⁷⁸ Protection of Personal Information Act Summary op cit 78.

⁷⁹ 'What are public goods?', available at <https://www.khanacademy.org/economics-finance-domain/microeconomics/market-failure-and-the-role-of-government/externalities-topic/a/public-goods-cnx>, accessed on 01 October 2024.

must be addressed because it will clarify who the owner is and what the owner's rights are regarding data sharing and restriction.

III RESEARCH QUESTIONS

This dissertation aims to answer the following research question: *Should health data be publicly owned?*

To answer this research question, the following sub-questions are posed:

- a) What is health data, and why must it be shared for precision medicine?
- b) What are the different regimes of property ownership?
- c) Is Thaldar's argument for private ownership of health data valid? Or does the Academy of Science (ASSAF) make a better argument for custodianship?
- d) Does the data subject, research institution, community, or state have the most substantial claim for health data ownership?
- e) Should health data ownership follow genomic sovereignty, which is a public ownership approach or a human rights approach?

IV RATIONALE

The primary motivation for this study is South Africa's high disease burden. Precision medicine can address this, but we need to know who can claim ownership of the health data and whether it will be publicly or privately owned, as this will affect data sharing.

The HIV/AIDS crisis, the significant prevalence of tuberculosis cases, high mortality rates in mothers and infants, and the ever-increasing rates of non-communicable diseases are four main ailments that South Africa is faced with.⁸⁰ A 2016 report showed that tuberculosis had caused 6.5% of deaths in the population, and it was the highest cause of mortality.⁸¹ At the same time, HIV caused about 4.8% of deaths.⁸²

South Africa needs medical advances to resolve these issues. This is where health data and precision medicine come in. However, we still do not have a data governance framework, which makes it challenging to identify how data sharing will occur. Will the state make data

⁸⁰ D Basu 'Diseases of public health importance in South Africa' (2018) 2(3) *South Afr J Pub Health* 48.

⁸¹ Basu op cit note 80 at 48.

⁸² Ibid.

open access, or will private owners restrict access? These questions must be addressed because they affect health research and the population's health.

Furthermore, there is a gap in knowledge on whether health data should be private or publicly owned and who should claim ownership of it. Very little information is available about the concept of health data ownership, even though most countries have extensive regulations on health data.⁸³ The debate on health data ownership is ongoing. Many parties, such as research participants, researchers, sponsors, and the public, are interested in health data.⁸⁴ Therefore, a health data governance framework that balances these interests and addresses emerging challenges, such as technological, ethical, legal, and economic, is needed.⁸⁵

Health data ownership is poorly researched. Therefore, there is no consensus on the legal rules and policy decisions.⁸⁶ More studies must be undertaken to develop new ethically compliant legal frameworks and policies.⁸⁷ This is where this dissertation comes in.

V METHODOLOGY

To answer the research inquiry, this dissertation includes a desktop-based investigation that analyses primary and secondary sources in print and electronic formats. Although there would be advantages to concentrating on South African sources and academic studies, such material is scarce on health data ownership. Therefore, it was necessary to explore the literature and data from international sources to compare it to the South African perspectives on health data ownership.

Primary sources include national statutes and regulations, South African case law, recommendations from various organisations and professional bodies, statistical and empirical research data, and research reports.

Secondary sources include medical academic textbooks, legal textbooks, journal articles, dissertations, theses, internet articles, books, and reports.

⁸³ M Mirchev et al. 'The academic viewpoint on patient data ownership in the context of big data: Scoping review' (2020) 22 *Journal of Medical Internet Research* available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7463395/>, accessed on 01 May 2024.

⁸⁴ Piasecki & Cheah op cit note 12 at 1.

⁸⁵ Ibid.

⁸⁶ Mirchev op cit note 83 at 1.

⁸⁷ Ibid.

VI LITERATURE REVIEW

(a) Introduction

According to Thaldar, ownership is a bundle of rights over a thing or property.⁸⁸ Furthermore, these rights are enforceable against others. If one owns something, one can enjoy its benefits and dispose of it.⁸⁹ Ownership sets clear boundaries about what can be done with the property and what others cannot do.⁹⁰ For example, if someone takes property without the owner's permission, there will be civil and criminal consequences. Ownership provides a safety net.

(b) South African perspectives on whether data can be owned?

Ownership requires that a thing must be capable of being controlled.⁹¹ This is not an issue because single data instances of health data can be controlled. For example, gas cannot be owned, but filling a cylinder with gas makes it susceptible to ownership. Data can be brought under control by recording it in a computer file, which results in a single data instance.⁹²

Thaldar et al. also found that genomic data instances, a type of health data, could be considered objects that can be privately owned in South Africa because they comply with the general requirements of being an object.⁹³ The requirements are that the object must have use, be valuable, not be part of another object, not be part of the body of a human, and must be something that can be controlled.⁹⁴ Therefore, the literature strongly suggests that genomic/health data instances can be privately owned.

(c) Who should claim ownership of health data?

Thaldar has established that human genomic data instances can be owned privately. Now, the question arises as to who should own them. Firstly, if an object is made or produced by another

⁸⁸ Thaldar op cit note 18 at 17.

⁸⁹ Ibid.

⁹⁰ Ibid.

⁹¹ For a 'thing' to be considered property that can be owned, it must be something a human can control. This means that a person should be capable of enforcing and protecting his rights to the thing in question. If the 'thing' cannot be appropriated, it will not be considered property that can be owned. An example of this is the sun, which is impossible to control. However, some things are capable of being brought under human control. The air we breathe seems impossible to control, but if we store it in a cylinder, it becomes something we can control. H Mostert et al *Principles of the Law of Property in South Africa* (2021)23-24.

⁹¹ A McGuire et al 'Who Owns the Data in a Medical Information Commons?' (2019) 47(1) *The J Law Med Ethics* 1.

⁹² Thaldar op cit note 18 at 17.

⁹³ DW Thaldar et al. 'The Multidimensional Legal Nature of Personal Genomic Sequence Data: A South African perspective' 2022 *Frontiers in Genetics* 8.

⁹⁴ DW Thaldar et al op cit note 93 at 8.

object (object b), the object's owner will acquire ownership of this new object.⁹⁵ However, genomic data instances are not made from deoxyribonucleic acid (DNA).⁹⁶ Genomic data instances are simply a description of that DNA.⁹⁷ South African property law has no laws on genomic data instances or who should own them.⁹⁸ Therefore, these newly generated genomic data instances fall into the *res nullius* category, meaning that *they have* no owner.⁹⁹ To acquire ownership of a *res nullius* object, one needs to control that object and effectively intend to become its owner.¹⁰⁰ According to Thaldar, the research institution should claim ownership of the human genomic data instances and maintain that data when it runs its sequencing.¹⁰¹ Thaldar also argues that research institutions should claim ownership of the data they generate, as this will provide them with legal protection for the data.¹⁰²

However, the Academy of Science of South Africa (ASSAf) suggested that ownership of genomic data is not the way to go, and this idea should be discarded.¹⁰³ ASSAf suggested that custodianship of genomic data should be a better option than ownership.¹⁰⁴ ASSAf views biological samples and genomic data as natural resources.¹⁰⁵ They contend that the government should manage this 'natural resource' because it will be in the public's interest to do so.¹⁰⁶ Thus, ASSAf is calling for custodianship by the state.

⁹⁵ When two properties with different owners are joined, it falls under accession. Accession is one method used to acquire ownership of a thing. Under this concept, the two separate properties must be joined naturally or artificially. This joining of the two things makes a new composite thing. Under South African property law, the owner of the principal thing will now become the owner of the thing attached to his property. In other words, he will also become the owner of the accessory. The accessory loses its legal identity when it joins another thing and forms a new composite thing. The person who owned the accessory item will now lose ownership of it. The principal owner will have ownership of both the joined things. H Mostert et al. 'Principles of the Law of Property in South Africa' (2021)164.

⁹⁶ Thaldar op cit note 18 at 19

⁹⁷ Ibid.

⁹⁸ Ibid.

⁹⁹ *Res nullius* refers to property that has no owner. This is a property that has never had an owner at all. Examples of *res nullius* property include wild animals and sea creatures. *Res nullius* property are property that is capable of being appropriated. To become the owner of *res nullius* property, one must have sufficient and effective physical control over the property and have the mental intention of becoming the owner of that property.

¹⁰⁰ Thaldar op cit note 18 at 19.

¹⁰¹ Ibid.

¹⁰² Ibid.

¹⁰³ Academy of Science of South Africa (ASSAf) *Human Genetics and Genomics in South Africa: Ethical, Legal and Social Implications* (2018) available at

<https://research.assaf.org.za/assafserver/api/core/bitstreams/0aa91e00-396f-40d7-b3b1-27c73ea04232/content>, accessed 01 October 2024.

¹⁰⁴ Thaldar op cit note 18 at 22.

¹⁰⁵ Ibid.

¹⁰⁶ Ibid.

(d) Arguments in favour of state ownership using genomic sovereignty

According to Slabbers and Pepper, genomic sovereignty, which is a concept that came from Mexico and falls under public ownership, means that human genes are owned by the state, nation, or people, and they control its access, use, and knowledge.¹⁰⁷ Advocates of genomic sovereignty contend that a nation can control natural resources just like it can control human genomes, which are viewed as new natural resources, as long as both resources fall within its borders. They also argue that human genomes have symbolic and financial significance.¹⁰⁸ Thus, they can bring in economic income and act as a nation's pride.¹⁰⁹

(e) Arguments against genomic sovereignty

Two arguments challenge genomic sovereignty and its control claims regarding genomic data.¹¹⁰ Firstly, in science, free dissemination of genetic data is standard in state practice.¹¹¹ Schwartz argues that Mexico is a member of the global open-access network and contributes to it.¹¹² Therefore, its sovereign policy needs to be more practical because the state is not supposed to control and restrict access to genetic data, which it will do under this model.¹¹³ South Africa also has open science policies. Genomic sovereignty would go against these objectives. Secondly, research datasets are more favourable to genomic researchers when they are shared globally and not bound to one nation.¹¹⁴ Accordingly, national data has little benefit.

Furthermore, according to Thaldar et al., genomic sovereignty literature and discussions ignore human rights.¹¹⁵ He also states that it is disrespectful to consider genetic material to be natural resources, as this goes against individuals' dignity.¹¹⁶ Also, genomic sovereignty does not address the right to freedom of scientific research, a human right safeguarded in multiple

¹⁰⁷ M Slabbert and M Pepper 'A Room of Our Own?' Legal Lacunae Regarding Genomic Sovereignty in South Africa' (2010) 73(1) *Journal of Contemporary Roman-Dutch Law* 435.

¹⁰⁸ F Kabata and D Thaldar 'Regulating human genomic research in Africa: Why a human rights approach is a more promising conceptual framework than genomic sovereignty' 2023 *Frontiers in genetics* 3.

¹⁰⁹ J de Vries & M Pepper 'Genomic sovereignty and the African promise: Mining the African genome for the benefit of Africa' (2012) 38(8) *Journal of Medical Ethics* 474.

¹¹⁰ Kabata & Thaldar op cit note 108 at 4.

¹¹¹ JL Contreras & BM Knoppers 'The genomic commons' (2018) 19(1) *Annu. Rev. Genomics Hum. Genet* 432.

¹¹² M Ernesto Schwartz *Genomic Sovereignty and the "Mexican Genome"* (unpublished Doctor of Philosophy thesis, University of Exeter, 2011).

¹¹³ Ernesto Schwartz op cit note 112 at 156.

¹¹⁴ Ibid.

¹¹⁵ D Thaldar et al. 'An optimistic vision for biosciences in South Africa: A response to the ASSAf report on human genetics and genomics' (2019) 115(7/8) *S. Afr. J. Sci.* 1.

¹¹⁶ Thaldar et al. op cit note 115 at 1.

African nations.¹¹⁷ If genomic sovereignty ignores human rights, how will it pass constitutional scrutiny?¹¹⁸ Its policies and legislation would be unconstitutional.¹¹⁹

(f) conclusion

The above literature shows that instances of health data can be owned. South African common law allows for this. However, even though our law indicates that data instances can be owned, it has not progressed to accommodate this. Entities have to use other methods to claim ownership, such as research institutions using policies to claim data that they generate and own privately.

Thaldar states that the research institution is best suited to claim data ownership, as the newly generated data instances have no owner. Therefore, to gain ownership, one must intend to become an owner and have control of the asset. The research institute will have control over the genomic data instances because they will be sequencing them and can store them in computer files. Thus, they meet both requirements. What was evident was that these data instances could be owned privately. Hence, private health data ownership is justified by common law property rights. The state has not enacted legislation to claim health data ownership. It will, therefore, remain privately owned unless the state expropriates it.

ASSAf and the genomic sovereignty argument of treating health data as a natural resource also have flaws. Thaldar et al. notes that these approaches do not consider human dignity and disrespect humans. Genomic sovereignty also ignores the human right to scientific research and therefore goes against the Constitution. Lastly, Thaldar has shown that genetic data instances can be privately owned. Therefore, the only way the state can get ownership of this data is by expropriation, which is a procedure that requires excessive resources. It is, therefore, inappropriate, and more straightforward means should be adopted. The state should rather focus on encouraging open data policies in private institutions.

¹¹⁷ DW Thaldar and M Steytler 'Time for Cinderella to go to the ball: Reflections on the right to freedom of scientific research' (2021) 138(2) *S. Afr. Law J* 260.

¹¹⁸ Kabata & Thaldar op cit note 108 at 5.

¹¹⁹ Ibid.

VII CHAPTER OUTLINE

Chapter 1 – Introduction and Background

Chapter 1 introduces the topic. It reviews health data ownership and the dissertation's focus. It includes the statement of purpose, rationale, research questions, a review of literature, and research methodology. Providing a backdrop for health data ownership is necessary to prepare for the forthcoming analyses, which divide the numerous facets into chapters related to my primary research topic.

Chapter 2 – Exploring Health Data Ownership: A Legal Perspective

This chapter explores South Africa's property law system to identify how Thaldar concluded that health data instances could be privately owned. The common law property rights' argument is mainly analysed, as it is the current legal position for health data.

Chapter 3 – Claiming Ownership: Who Holds the Keys?

This chapter analyses the relevant property law theories and how they relate to private, public, and community health data ownership. It also considers the ethical and policy justifications for state health data ownership.

Chapter 4 – The Intersection of Genomic Sovereignty and Human Rights

This chapter analyses the arguments for and against the state or group having public ownership of health data through genomic sovereignty. It also explores the arguments for and against health data being considered a natural resource. Lastly, the chapter examines whether raw data should follow a similar ownership model to the Intellectual Property Rights from the Publicly Financed Research Act 51 of 2008.

Chapter 5 – Conclusion and Recommendations

This chapter concludes and summarises the main points discussed. It reviews the analyses presented in this dissertation in order to answer the main research question.

CHAPTER TWO: EXPLORING HEALTH DATA OWNERSHIP: A LEGAL PERSPECTIVE

I INTRODUCTION AND CHAPTER OVERVIEW

This chapter focuses on determining whether health data can be considered property that can be owned according to the principles of South African property law, specifically the common law property rights system. Thaldar's arguments are the heart of this discussion, as no other writer has approached this subject from a legal point of view.

II OWNERSHIP

If a person owns an object, he has a complete set of rights over that object.¹²⁰ Furthermore, ownership is enforceable by law.¹²¹ Ownership gives the owner the right to use the object as he wishes, to receive benefits from goods created by his object, and to abandon or get rid of the object.¹²² These rights are also referred to as a bundle of rights that ownership brings.¹²³ However, ownership does not give the owner absolute power.¹²⁴ The object's nature and context could make the ownership rights not absolute.¹²⁵ Ownership rights can be limited and do not trump the country's existing laws.¹²⁶ For example, an individual who owns a car without a valid licence cannot drive it on a public road.¹²⁷ If he has a licence, he can drive on the public road but must abide by the rules.¹²⁸ The car owner can also dispose of his car, but he cannot do so in a manner that is against the law, such as burning the car in his backyard.¹²⁹ This is because municipal waste disposal laws and fire hazard ordinances do not allow this.¹³⁰ Therefore, ownership is restricted by the law. However, ownership does provide the owner with legal protection for his object. The law protects the owner if a friend takes his car for a drive without his consent or destroys it.¹³¹ Those who break the law, such as the friend above, face civil or criminal consequences. Apart from legal limitations, ownership has comprehensive legal rules that allow the owner to use his property in whatever legal way he wishes and prevent others

¹²⁰ A Pope, E Du Plessis & PJ Badenhorst *The Principles of the Law of Property in South Africa: Private Law* 2 ed (2020) 28.

¹²¹ Pope op cit note 120 at 28.

¹²² *Pearly Beach Trust v Registrar of Deeds* 1990 (4) SA 614 (C).

¹²³ Ibid.

¹²⁴ *Daniels v Scribante* 2017 (4) SA 341 (CC).

¹²⁵ Thaldar op cit note 18 at 17.

¹²⁶ Ibid.

¹²⁷ National Road Traffic Act 93 of 1996, s 13.

¹²⁸ National Road Traffic Act 93 of 1996, s 58 and 59.

¹²⁹ Thaldar op cit note 18 at 17.

¹³⁰ Ibid.

¹³¹ Ibid.

from using the property without the owner's consent.¹³² Therefore, ownership is a legal 'safety net'.¹³³

III CAN DATA BE OWNED?

The most critical condition regarding whether an object can be owned is whether the data can be controlled.¹³⁴ Something that appears everywhere, such as the air around us or seawater, is commonly not considered to be an object that can be owned because it seems impossible to control it, and this is how data is viewed.¹³⁵ However, this does not mean that these examples cannot be controlled. When gas companies fill a cylinder with air or a person fills a bottle with seawater, the air or water become part of a cylinder or bottle that can then be controlled and owned. Data can follow a similar route. If the data is recorded in a computer file, that single instance in that computer file can be controlled.¹³⁶ Therefore, it can be owned. Some authors have argued that data is intangible, unlike air or seawater, and can be reproduced indefinitely.¹³⁷ It is important to note that ownership, in this case, refers to ownership of a single data instance, and not all data. Therefore, the same rules apply whether the object is tangible or intangible. When someone fills a bottle with seawater, he controls that single bottle of water, and not the whole ocean.¹³⁸ The same applies to health data. When person A records the health data of person B on a computer file, person A has control over that single data instance on the computer file, and not person B's health data generally or broadly; other persons will also have their single data instance of person B's health data if he tests his blood with their organisation. Therefore, they have control of the single data instance in their computer file. This is acceptable because data is non-rivalrous, which means that the data or object will not be depleted if one person uses it, and it does not prevent the data from being used by others.¹³⁹ Therefore, ownership of health data is possible over a single data instance. This is the focus, and not the data in general.

¹³² MC Dade, EM Bennett & BE Robinson 'Property rights play a pivotal role in the distribution of ecosystem services among beneficiaries' (2022) 18(1) *Ecosystems and People* 131.

¹³³ Ibid.

¹³⁴ J Toomey 'Property's Boundaries' (2023) 109(1) *Virginia Law Review* 168.

¹³⁵ Thaldar op cit note 18 at 17.

¹³⁶ Ibid.

¹³⁷ Ibid.

¹³⁸ Ibid.

¹³⁹ P Vassilakopoulou, E Skorve & M Aanestad 'A Commons Perspective on Genetic Data Governance: The Case of BRCA Data' 2016 *Research Papers* 11.

IV DATA OWNERSHIP IN SOUTH AFRICAN CASE LAW AND THE LITERATURE

South African law permits one to have ownership of confidential information.¹⁴⁰ To qualify as confidential information, the information must have the following qualities: (a) it must be useful and can be used in trade or industry,¹⁴¹ (b) it must have value economically that requires protection;¹⁴² and (c) the information must be something that only a few or a restricted number of people know.¹⁴³ Information that is known by the public or is the property of the public does not count as confidential information.¹⁴⁴ For example, when a medical scheme broker collects information from its clients, that information can be the property of the medical scheme broker.¹⁴⁵ Again, the focus is on single instances and not the information generally. Therefore, the medical scheme broker owns the single instance of client information collected. He generally does not have ownership of the client's information. Therefore, the client is free to share their information with other firms.¹⁴⁶

Questions arise about whether a person or organisation can own information that has been distributed or sold to outside parties.¹⁴⁷ The answer is found in an electronic point-of-sale data case. In this case, it was found that electronic point-of-sale data is valid and has value economically.¹⁴⁸ The court held that this data is private property.¹⁴⁹ Therefore, the electronic point-of-sale data could be purchased and sold. The court did not consider whether the electronic point-of-sale data would be confidential. Still, suppose the sale agreement prevents the purchaser from sharing the data with others or the public. In that case, the data will fulfil the last requirement of confidential information: only a restricted number of individuals must know it.¹⁵⁰

This case proves that if information is helpful, valuable, and is known by a few, it can be owned.¹⁵¹ Also, non-confidential information could be owned because caselaw has never spoken about non-confidential information being disallowed regarding ownership.¹⁵²

¹⁴⁰ *Curemed CC v Van Onselen* [2015] ZAGPPHC 176.

¹⁴¹ *Curemed* supra note 140.

¹⁴² *Ibid.*

¹⁴³ *Ibid.*

¹⁴⁴ *Experian SA v Haynes* 2013 (1) SA 135 GSJ.

¹⁴⁵ *Curemed* supra note 140.

¹⁴⁶ *Ibid.*

¹⁴⁷ *Competition Commission v British American Tobacco South Africa (Pty) Ltd* (2009) ZACT 46.

¹⁴⁸ *Ibid.*

¹⁴⁹ *Ibid.*

¹⁵⁰ *Competition Commission* supra note 147.

¹⁵¹ Thaldar op cit note 18 at 18.

¹⁵² *Ibid.*

According to the South African literature based on our property law system, information can be owned, which applies to general and confidential information.¹⁵³ An analysis of the concept of 'object' was undertaken by Njotini, who found that information should be considered an object under property rights.¹⁵⁴ Furthermore, it was also suggested that digital objects be regarded as objects capable of being owned by extant law.¹⁵⁵ This would include websites, email addresses, digital music, and more.¹⁵⁶ Thaldar et al. also found that genomic data instances could be considered objects that can be privately owned in South Africa because they comply with the general requirements of being an object.¹⁵⁷ The requirements are that the object must be useful and valuable, not be part of another object, must not be part of the body of a human, and must be something that can be controlled.¹⁵⁸ Therefore, the literature indicates that genomic/ health data instances can be privately owned. Thus, like other digital assets, data instances can be sold or licensed.¹⁵⁹ However, this will depend on additional rights that apply, such as rights related to data protection.

V OWNERSHIP OF INTELLECTUAL PROPERTY RIGHTS

Intellectual property rights, such as patents or copyrights, are different from owning data.¹⁶⁰ Both legal notions entail different objects of rights in terms of human genomic data. In data ownership, the object of ownership is the genomic sequence data, which is stored in a computer file.¹⁶¹ However, the object of copyright is a genomic dataset, which is a collection of several individuals' genomic sequence data.¹⁶² In patent rights, the object is an invention, such as a gene sequence with demonstratable functional use.¹⁶³

It is preferable to consider data ownership and intellectual property rights as different layers of data-related rights that interact rather than replace each other.¹⁶⁴ Therefore, a patent does not grant one ownership of the gene sequence.¹⁶⁵ Data ownership and intellectual

¹⁵³ Ibid.

¹⁵⁴ M Njotini 'Examining the 'objects of property rights' - lessons from the Roman, Germanic and Dutch legal history' (2017) 50(1) *De Jure* 136–155.

¹⁵⁵ W Erlank 'Introduction to Virtual Property: Lex Virtualis Ipsa Loquitur' (2015) 18(7) *Potchefstroom Electronic Law Journal* 2526.

¹⁵⁶ Erlank op cit note 155 at 2526.

¹⁵⁷ Thaldar op cit note 93 at 8.

¹⁵⁸ Ibid.

¹⁵⁹ Thaldar op cit note 18 at 18.

¹⁶⁰ Ibid.

¹⁶¹ Ibid.

¹⁶² Copyright Act 98 of 1978.

¹⁶³ Patents Act 57 of 1978.

¹⁶⁴ Thaldar op cit note 18 at 18.

¹⁶⁵ Ibid.

property rights have different regulations and are distinct. A patent only provides one with patent rights and cannot change the ownership of the gene sequence.¹⁶⁶ Similarly, ownership of a thing is not needed to acquire a patent for an invention related to that thing.¹⁶⁷ Therefore, it is still essential to focus on ownership of genomic data, even if the data is included in datasets or has demonstrable functional use that qualifies it for patent protection.

VI CONCLUSION

The leading issue that scholars have faced is whether health data can be brought under human control. From the above analysis, Thaldar has illustrated that single data instances can be controlled. This can be done by storing them on a computer file. Therefore, single instances of health data can be owned, and not health data generally.

Secondly, it has also been demonstrated that health data meets the requirements of being an object, which means that it can be privately owned. The requirements are that health data must be useful, have value, be capable of control, and be separate from other objects or humans. Health data has use and value for medical and scientific research. It can also be controlled by storing it on a computer file. In addition, health data is a separate entity and is not part of another object or human. Therefore, Thaldar's analysis is correct. Health data instances do meet the requirements of our common law property rights system and should be capable of being owned privately. Furthermore, no other author has criticised his legal analysis and no alternative legal arguments were found. Accordingly, health data instances remain privately owned unless the state expropriates them.

¹⁶⁶ Ibid.

¹⁶⁷ Ibid.

CHAPTER THREE: CLAIMING OWNERSHIP: WHO HOLDS THE KEYS?

I INTRODUCTION AND CHAPTER OVERVIEW

This chapter explores ethical and policy justifications for private and public health data ownership. Property law theories will also be analysed and assessed to identify which entity can claim ownership of health data. ASSAf's open science policy in favour of public ownership will also be briefly mentioned.

II ETHICAL ARGUMENTS

Ethical principles must be considered when discussing health data ownership because they safeguard individuals' rights, welfare, and dignity. Health research also involves data subjects; therefore, their rights and that of the public must be considered. The following are the ethical arguments for and against private and public health data ownership:

III ETHICAL JUSTIFICATIONS FOR HEALTH DATA PRIVATISATION

Two arguments are presented in support of private ownership of health data. The first examines the valuable model and the benefits that private property can bring to most individuals. The second uses the principle of autonomy to support privatisation.¹⁶⁸

The first argument states that if health data is privately owned, individuals and organisations will use it more efficiently.¹⁶⁹ Humans and organisations are profit-driven.¹⁷⁰ They will use the data for profit if it can deliver a profit.¹⁷¹ A market for health data will emerge, producing more health data to advance scientific and medical knowledge.¹⁷² The more profit one seeks, the more data will be made available. Privatisation is vital because if people cannot make money from the data, the data will decrease production, and so will its use.¹⁷³ Health data is the by-product of patients' encounters with medical facilities and those of data subjects with researchers. Both parties in this interaction have an interest in the data created.¹⁷⁴ Databanks

¹⁶⁸ Piasecki op cit note 12 at 4.

¹⁶⁹ MA Hall 'Property, privacy, and the pursuit of interconnected electronic medical records' 2009 *Iowa L. Rev* 631.

¹⁷⁰ P Ritala et al 'Selling and monetizing data in B2B markets: Four data-driven value propositions' (2024) 130(1) *Technovation* 1-2.

¹⁷¹ Ibid.

¹⁷² Hall op cit note 169 at 631.

¹⁷³ Ibid.

¹⁷⁴ EF Haislmaier 'Health Care Information Technology: Getting the Policy Right' 16 June 2006, available at <https://www.heritage.org/health-care-reform/report/health-care-information-technology-getting-the-policy-right>, accessed on 01 October 2024.

can also enter the relationship and act as an intermediary.¹⁷⁵ Databank tasks consist of collecting data and ensuring that the data was obtained after informed consent and that all privacy regulations were followed.¹⁷⁶ Databanks can use the data to benefit patients and the public. The databank could sell access to the health data and make a profit. The sale would help the blood bank, the patients, and the research institution. This method would also control access to health data.¹⁷⁷

The second argument refers to data subjects' and institutions' autonomy and states that entities can better practise their autonomy over property and ensure that their privacy is safeguarded.¹⁷⁸ Therefore, the data will only be sold or shared with those that the entity approves.¹⁷⁹ Furthermore, nobody can force an entity to sell their data. The entity has rights that enable it not to sell if it does not wish to.

IV JUSTICE AND THE PRIVATISATION OF HEALTH DATA

Under the private ownership model, there is a lack of balance regarding the interests of individuals and public health.¹⁸⁰ Privatisation supporters have argued that privatisation of health data will create a supply and demand for it, thus increasing its production.¹⁸¹ However, market demands do not consider the needs of public health or justice.¹⁸² Therefore, market demands are not a beneficial tool.¹⁸³ Privatisation of health data could also affect data sharing because of the cost of sourcing the data.¹⁸⁴ It will create obstacles instead of incentives.¹⁸⁵ Research institutions and other secondary data users will be disadvantaged because they must pay additional fees to access the data.¹⁸⁶ It is also argued that when scientific and medical research receives data that enables it to come up with developments for science and healthcare, it constitutes a public good.¹⁸⁷ Therefore, those who benefit from scientific advancements

¹⁷⁵ Haislmaier op cit note 174.

¹⁷⁶ Ibid.

¹⁷⁷ MA Hall & KA Schulman 'Ownership of medical information' (2009) 301(12) *JAMA* 1283.

¹⁷⁸ Piasecki op cit note 12 at 4.

¹⁷⁹ Ibid.

¹⁸⁰ B Goodair & A Reeves 'The effect of health-care privatisation on the quality of care' (2024) 9(3) *The Lancet. Public Health* 201.

¹⁸¹ Piasecki op cit note 12 at 4.

¹⁸² J Cohen 'COVID-19 Capitalism: The Profit Motive versus Public Health' (2020) 13(2) *Public Health Ethics* 176-178.

¹⁸³ Piasecki op cit note 12 at 4.

¹⁸⁴ D Mascalzoni et al. 'Rare diseases and now rare data?' 2013 *Nat Rev Genet* 372.

¹⁸⁵ Mascalzoni op cit note 184 at 372.

¹⁸⁶ Ibid.

¹⁸⁷ DMJ Delnoij 'Scientific research and the public good' (2017) 27(1-2) *The European Journal of Public Health* 2.

should ensure that others also benefit from them if they have not already done so.¹⁸⁸ This shows solidarity and reciprocity. This can be done by making data available for research and development.¹⁸⁹ Therefore, some may use the justice principle in favour of making data available as long as it is de-identified.¹⁹⁰ For this reason, privatisation of health data may be seen as going against the principle of justice. However, it can also be claimed that the justice principle creates a moral obligation for data accessibility and does not undermine the privatisation of health data.¹⁹¹

V AUTONOMY AND PRIVATISATION

According to Evans,¹⁹² Some individuals wrongly believe that their property rights over the data are absolute and that they can refuse to grant access to the data in all instances.¹⁹³ The state has the authority to access property, even if it is privately owned, and can even take the property away.¹⁹⁴ For example, suppose an individual has data that could benefit the public's interests but refuses access to it for research. In that case, the state can legally take the data away.¹⁹⁵

VI ETHICAL ARGUMENTS IN FAVOUR OF PUBLIC OWNERSHIP OF HEALTH DATA

Arguments that favour public health data ownership are based on the moral benefits the healthcare community will receive and the economic view that knowledge is a unique type of good and everyone should access it.¹⁹⁶

Science plays a vital role in the activities of humans.¹⁹⁷ Science provides multiple benefits, such as improving education systems, stimulating innovative ideas, assisting society with progress, providing information to guide policy creation, and safeguarding individuals' overall health.¹⁹⁸ However, these substantial benefits only arise if knowledge or health data is

¹⁸⁸ Haislmaier op cit note 174.

¹⁸⁹ Ibid.

¹⁹⁰ Piasecki op cit note 12 at 4.

¹⁹¹ Ibid.

¹⁹² BJ Evans 'Much ado about data ownership' (2011) 25(1) *Harv. JL & Tech* 69.

¹⁹³ Evans op cit note 192 at 69.

¹⁹⁴ Ibid.

¹⁹⁵ Ibid.

¹⁹⁶ C Hess & H Ostrom *A Framework for Analyzing the Knowledge Commons: A chapter from Understanding Knowledge as a Commons: from Theory to Practice* (2007) 8-9.

¹⁹⁷ International Science Council 'Open Science for the 21st Century Draft ISC Working Paper' 04 June 2020, available at https://council.science/wp-content/uploads/2020/06/International-Science-Council_Open-Science-for-the-21st-Century_Working-Paper-2020_compressed.pdf, accessed on 01 October 2024.

¹⁹⁸ International Science Council op cit note 197.

accessible without restriction. The issue is that health research is too restricted and difficult to access, and so advancing society's common good is an issue.¹⁹⁹ Therefore, the philosophical idea of open science can be used to resolve this obstacle and connect health research and society by making health data information accessible.²⁰⁰ Open science will use the internet to share knowledge widely, thus allowing everyone to engage in science.²⁰¹ Open science seeks to remove restrictions to research, in this case, health research, by ensuring that the principle of free sharing is upheld in research.²⁰² Barriers like article paywalls will be eliminated.²⁰³

Relevant scientific knowledge, in this case, is human genetic data. According to the International Declaration on Human Genetic Data, genetic data is knowledge that results from nucleic acid or other research.²⁰⁴ Examples of this knowledge include data on individuals' inheritable characteristics.²⁰⁵

The Declaration also states that genetic data has unique significance for the following reasons: (1) the data can reveal what medical condition the person is susceptible to;²⁰⁶ (2) it will have consequences for the offspring and spanning generations of the family;²⁰⁷ (3) the data may include information that was unforeseen in importance at the collection stage;²⁰⁸ and (4) the data can be culturally relevant to persons.²⁰⁹ Therefore, the Declaration acknowledges that this sensitive data needs safeguarding, but it also recognises that scientific and medical advancements require it for research to benefit the public.²¹⁰

The Constitution of the Republic of South Africa, 1996, includes the right to freedom of scientific research.²¹¹ This right justifies scientific research and the need for data to be open

¹⁹⁹ Ibid.

²⁰⁰ JB Holbrook 'Philosopher's Corner: Open Science, Open Access, and the Democratization of Knowledge' (2019) 35(3) *Issues in Science and Technology* 26-28.

²⁰¹ C Heise & JM Pearce 'From Open Access to Open Science: The Path from Scientific Reality to Open Scientific Communication' (2020) 10(2) *Sage Open* 1-14.

²⁰² A Steger and E Hantho 'Open Science: Removing Barriers to Knowledge' 15 April 2019, available at <https://healthlawmatters.squarespace.com/home/2019/4/27/open-science-removing-barriers-to-knowledge>, accessed on 01 October 2024.

²⁰³ MM Crow & G Tananbaum 'We Must Tear Down the Barriers That Impede Scientific Progress' 18 December 2020, available at <https://www.scientificamerican.com/article/we-must-tear-down-the-barriers-that-impede-scientific-progress/>, accessed on 01 October 2024.

²⁰⁴ UNESCO International Declaration on Human Genetic Data op cit note 54.

²⁰⁵ Ibid.

²⁰⁶ Clayton et al. op cit note 56.

²⁰⁷ Branje et al. op cit note 57.

²⁰⁸ Ibid.

²⁰⁹ Rahnasto op cit note 59.

²¹⁰ Ibid.

²¹¹ The Constitution of the Republic of South Africa, 1996, s 16(1)(d).

and freely accessible.²¹² This right also supports individual autonomy, the search for truth, and democracy.²¹³ It therefore upholds our constitutional value system.

VII ASSAF'S OPEN SCIENCE POLICY

ASSAf favours open science, but it still argues that the state should be the custodian of health data. It has not commented on private entities engaging in open science. According to ASSAf, open science has fundamental worth and multiple benefits for research and science, which the ASSAf recognises and supports.²¹⁴ Furthermore, open science is a critical component of continuous transformation in research and science.²¹⁵

The ASSAf open science policy followed the approach of the United Nations Educational, Scientific and Cultural Organisation when it formed its definition of open science.²¹⁶ Therefore, open science comprises several initiatives and methods to ensure that the research findings are accessible without restriction, can be reused, and available in different languages.²¹⁷ The policy also aligns with the FAIR principle: data must be findable, accessible, interoperable, and reusable.²¹⁸ The FAIR principles also stress that research findings should be made accessible without restriction unless there is a legal, ethical, intellectual property, or other risk to the data subject.²¹⁹

Open science includes data from Academic papers, research, collaboration, and other relevant documents.²²⁰ All this data should be accessible to the public using an open licence. ASSAf's policy applies to research made possible through public funds and to ASSAf-generated data that was also publicly financed.²²¹

²¹² Thaldar and Steytler op cit note 117 at 260.

²¹³ Ibid.

²¹⁴ Academy of Science of South Africa *Open Science Policy* (2024) available at <https://www.assaf.org.za/wp-content/uploads/2024/02/ASSAf-Open-Science-Policy.pdf>, accessed on 01 October 2024.

²¹⁵ ASSAf op cit note 214 at 5.

²¹⁶ ASSAf op cit note 214 at 6.

²¹⁷ Ibid.

²¹⁸ RG Soltero et al. 'FAIR data management: a framework for fostering data literacy in biomedical sciences education' (2024) (24(1) *BMC medical research methodology* 1.

²¹⁹ Ibid.

²²⁰ ASSAf op cit note 214 at 6.

²²¹ Ibid.

In South Africa, we have laws, organisations, and projects that support the open access of data. These include:

The draft DSI National Open Science policy

Which advocates that publications and research findings be made available to the public without restriction if public monies were used for the research or publication.²²²

The Protection of Personal Information Act 4 of 2013

The Act upholds democracy, openness, the right to privacy, and the requirement for transformation in an information society system's economic and social setting.²²³ POPIA acknowledges that this requires data to be accessible without restriction, and this data will include personal information.²²⁴ Therefore, researchers, scientists, and other relevant persons must comply with POPIA when using or collecting personal information and adopt an open science approach to sharing their findings.²²⁵

Promotion of Access to Information Act 2 of 2000 (PAIA)

Information is contained in private and public organisations, and this act deals with accessibility.²²⁶ PAIA also supports openness and information access, which comply with open science.²²⁷

The Intellectual Property Rights from Publicly Financed Research and Development Act 51 of 2008 (IPR-PFRD Act)

According to this Act, if public monies were used to cover the cost of research and development, then intellectual property produced from that research would be safeguarded, identified, used, and commercialised in a way that betters the public.²²⁸ Databases and datasets may be classified as intellectual property because the Intellectual Property Act protects them.²²⁹ Publication of research findings can take place after an evaluation of disclosure is done.²³⁰ If the review goes well, research findings will be accessible to the public and for their benefit.²³¹

²²² ASSAf op cit note 214 at 8.

²²³ Protection of Personal Information Act, s 2.

²²⁴ Ibid.

²²⁵ ASSAf op cit note 214 at 8.

²²⁶ Promotion of Access to Information Act, s 3.

²²⁷ Promotion of Access to Information Act, s 9.

²²⁸ The Intellectual Property Rights from Publicly Financed Research and Development Act, s 3.

²²⁹ ASSAf op cit note 214 at 9.

²³⁰ The Intellectual Property Rights from Publicly Financed Research and Development Act, s 2.

²³¹ Ibid.

Recipients of the intellectual property rights (IPR) are the individuals or organisations that conducted the research and development.²³² These would include universities, state research bodies like the Human Science Research Council, and other relevant bodies.²³³

The receivers of the IPR can keep their ownership and IPR safeguards, or they can abandon them.²³⁴ Whatever they choose must be communicated to the Intellectual Management Office (NIPMO). If one chooses to keep ownership, one must put one's research either in the public domain or commercialise it for public benefit. If one gives up ownership, then NIPMO can decide to take ownership of it and work to safeguard it. If NIPMO does not want to be the owner, then ownership can be proposed to a private entity that has assisted the research by providing funds.²³⁵ If no funds were given, the ownership proposal should be made to intellectual property creators, such as scientists or postgraduate scholars.²³⁶

VIII JUSTICE AND PUBLIC OWNERSHIP OF HEALTH DATA

Data supply is still an issue that public ownership does not fix.²³⁷ Unequal distribution of power between different groups and inequalities are two ethical issues with data accessibility.²³⁸ However, they are not addressed by the framework of commons.²³⁹ Vulnerable and marginalised groups are usually left out of the research.²⁴⁰ Therefore, they do not benefit from the study, as it does not relate to their issues or conditions. Equitable inclusion can be achieved only if populations are included in decision-making, data governance, and benefit sharing.²⁴¹ The framework of commons neglects these issues. This is why some scholars believe that public and private health data ownership lacks the tools or procedures to address the ethical problems of underprivileged groups being left out of research.²⁴² Therefore, individual and public interests are not being balanced.

²³² P Chetty 'Review of IPR Act and regulations : Intellectual Property Rights from Publicly Financed Research and Development Act, Act no 51 of 2008, Republic of South Africa' (2020) 10 *The African Journal of Information and Communication* available at <https://journals.co.za/doi/epdf/10.10520/EJC-15ef4f5f29>, accessed on 01 October 2024.

²³³ Chetty op cit note 232 at 79.

²³⁴ The Intellectual Property Rights from Publicly Financed Research and Development Act, s 4.

²³⁵ Ibid.

²³⁶ Ibid.

²³⁷ B Prainsack 'Logged out: Ownership, exclusion and public value in the digital data and information commons' (2019) 6(1) *Big Data & Society* 1-3.

²³⁸ Prainsack op cit note 237 at 1-3.

²³⁹ Ibid.

²⁴⁰ Piasecki op cit note 12 at 6.

²⁴¹ Ibid.

²⁴² Ibid.

IX AUTONOMY AND PUBLIC OWNERSHIP OF HEALTH DATA

Before health data can be collected or processed, an agreement must be made between the researcher, the data subject, the healthcare facility, and the patient.²⁴³ This agreement is essential because it includes the extent of the data that must be collected, how it will be processed, what protection is provided, how long the data will be kept, the reason for the processing, and how it will be shared.²⁴⁴ This agreement is ethical and sometimes legally enforceable, depending on whether the jurisdiction considers it binding.²⁴⁵ The contract will also be legally enforceable if it includes de-identified data.²⁴⁶ For example, suppose A agrees to have her health data used in a diabetes study but not for other research, such as fertility studies. In that case, the researcher cannot use her data for any other research, even if her data was de-identified.²⁴⁷ A big issue with public ownership of health data is that it does not recognise this agreement and does not follow it.²⁴⁸ Under public ownership, A's health data will still be shared as a public good.²⁴⁹ Public ownership of health data is too lenient about allowing access to the data, which will cause individuals to lose trust in the system.²⁵⁰ The trust that researchers and health facilities work so hard to build with patients and data subjects will become meaningless.²⁵¹ Patients already fear that their data will be used to identify them. Therefore, they omit certain information from healthcare staff.²⁵²

X WHO OWNS GENOMIC DATA?

Chapter 2 demonstrated that data instances can be owned privately. The next question is: Who owns these genomic data instances? The answer is found in property law.²⁵³ According to property law, if a person owns object A and if that object were used to make or produce object B, then the owner of object A will also be the owner of object B.²⁵⁴ If DNA were used to produce newly generated human genomic data instances, then the owner of the DNA would

²⁴³ CM Angst & R Agarwal 'Adoption of electronic health records in the presence of privacy concerns: The elaboration likelihood model and individual persuasion' (2009) 33(2) *MIS Quarterly* 348.

²⁴⁴ MN Laryeafio & OC Ogbewe 'Ethical consideration dilemma: systematic review of ethics in qualitative data collection through interviews' (2023) 3(2) *Journal of Ethics in Entrepreneurship and Technology* 100-104.

²⁴⁵ Angst op cit note 243 at 348.

²⁴⁶ Ibid.

²⁴⁷ Laryeafio & Ogbewe op cit note 244 at 102.

²⁴⁸ Angst op cit note 243 at 348.

²⁴⁹ Ibid.

²⁵⁰ Ibid.

²⁵¹ MJ Drolet et al. 'Ethical Issues in Research: Perceptions of Researchers, Research Ethics Board Members and Research Ethics Experts' (2023) 21(2) *Journal of Academic Ethics* 276.

²⁵² Ibid.

²⁵³ Thaldar op cit note 18 at 18.

²⁵⁴ Ibid.

also become the owner of the newly generated data instances.²⁵⁵ South African law states that when biological material is donated to a research facility, that facility has exclusive rights over it.²⁵⁶ Therefore, the research facility will own the new data instances because it owns the DNA from which it derived.²⁵⁷ However, DNA does not produce or make the newly generated data instances from itself. Human genomic data instances are not part of DNA but are just descriptions.²⁵⁸ This is the same as an entomologist making notes on the description of a new insect she discovered. The only difference is that the entomologist will have intellectual property rights over her notes. In contrast, newly generated data instances do not have intellectual property protection, as machines produce them.²⁵⁹ Therefore, no law on ownership exists to determine the ownership of newly generated data instances. It is an entirely new object that was not made from another object. Therefore, Thaldar et al. find that newly generated data instances are *res nullius*, meaning that they belong to nobody.²⁶⁰

This conclusion is important because it highlights that *res nullius* property has no owner.²⁶¹ To become a property owner, a person must intend to become the owner and effectively control the property before anyone else.²⁶² The research institution will already have control over the genomic data because they will be sequencing it.²⁶³ Therefore, they have a solid case to claim ownership of the newly generated data instances.²⁶⁴ Swales et al. state that it would greatly benefit South African research institutions to claim ownership of the new data instances because they would have a legal mechanism to protect their generated data.²⁶⁵

XI CLAIMING OWNERSHIP - THE LOKEAN THEORY

Generating human genomic data is not a simple task.²⁶⁶ It requires the input of much effort and resources to enable its production.²⁶⁷ According to the Lockean property theory, if one uses his labour and freely available or standard resources to generate a product or property, one is

²⁵⁵ Ibid.

²⁵⁶ DW Thaldar & B Shozi 'The Legal Status of Human Biological Material Used for Research' (2021) 138(4) *South African Law Journal* 893; National Health Act, s 1.

²⁵⁷ Thaldar op cit note 18 at 19.

²⁵⁸ Ibid.

²⁵⁹ Ibid.

²⁶⁰ Thaldar op cit note 93 at 16.

²⁶¹ Thaldar op cit note 18 at 4.

²⁶² *Reck v Mills* [1990] 1 All SA 560 (A).

²⁶³ Thaldar op cit note 93 at 16.

²⁶⁴ Ibid.

²⁶⁵ L Swales et al. 'Towards a data transfer agreement for the South African research community: The empowerment approach' (2023) 16(1) *S Afr J Bioethics Law* 15.

²⁶⁶ Thaldar op cit note 18 at 19.

²⁶⁷ Ibid.

entitled to hold or claim ownership of that property.²⁶⁸ Since the research institution invested effort and resources, it has a moral right to claim ownership of the newly generated data instances.²⁶⁹

Research institutions are concerned with conducting research.²⁷⁰ They face obstacles like unnecessary costs and interruptions. Therefore, to combat these obstacles, they should seek a comprehensive set of rights over the newly generated data instances they created.²⁷¹ The research institution must also remember that it has legal and ethical obligations to those who provide data.²⁷² Moral entitlement and self-interest are good arguments for research institutions to claim ownership over newly generated data instances.²⁷³

In practice, a research institution could create a clear policy that states that all the data generated by the institution belongs to it. This policy must be available online so that employees and people outside the institution know the ownership claim. The consent forms presented to the data subject must also explicitly state that the newly generated data instance will belong to the institution.²⁷⁴ Lastly, the institution must include an ownership clause in its data transfer agreements to show that it upholds the integrity of ownership of the genomic data.²⁷⁵

XII DATA OWNERSHIP IN RESEARCH SUBJECTS

It has been argued that research subjects should own the newly generated data instances because they relate to and are connected to them.²⁷⁶ However, according to property law, personal connections with the object are not a criterion for acquiring ownership.²⁷⁷

Since genomic data includes personal information, POPIA will apply.²⁷⁸ POPIA provides data subjects with a collection of rights to use for the protection of their personal information.²⁷⁹ These rights: (1) their personal information must be processed in a manner that

²⁶⁸ PT Haaga & JG Pilla 'Locke's Legitimization and Appropriation of Property for Private Ownership' (2021) 4(2) *GNOSI: An Interdisciplinary Journal of Human Theory and Praxis* 44.

²⁶⁹ Ibid.

²⁷⁰ Thaldar op cit note 18 at 19.

²⁷¹ Ibid.

²⁷² GD Miteu 'Ethics in scientific research: a lens into its importance, history, and future' (2012) 86(5) *Annals of Medicine and Surgery* 2396.

²⁷³ Thaldar op cit note 18 at 19.

²⁷⁴ Ibid.

²⁷⁵ Swales et al. op cit note 265 at 15.

²⁷⁶ Thaldar op cit note 18 at 20.

²⁷⁷ Ibid.

²⁷⁸ The Protection of Personal Information Act.

²⁷⁹ Ibid.

complies with the eight conditions for processing found in POPIA;²⁸⁰ (2) they must be informed whether their data was retrieved or accessed without their consent;²⁸¹ (3) to be made aware if someone holds their data;²⁸² (4) to ask for changes, destruction or complete removal of their data if it is necessary;²⁸³ (5) not to allow their personal information to be processed as long as their reasons are reasonable;²⁸⁴ (6) not to allow their personal information to be processed for direct marketing;²⁸⁵ (7) not having to go through automated decision-making as a result of their personal information;²⁸⁶ (8) to complain to the information regulator if there is an alleged interference with their personal information protection;²⁸⁷ and (9) to bring a civil proceeding if there is an alleged interference with the protection of the information.²⁸⁸

Some data protection rights are similar to ownership.²⁸⁹ The first similarity includes the right to delete personal information in data protection rights and the right to destroy property found under ownership.²⁹⁰ The second similarity is the right to have their information processed as long as legal grounds exist, like consent under data protection rights and ownership rights that allow the owner to permit another person to use his object by transferring the right to use to that person.²⁹¹

Data protection rights and ownership are similar but are not the same. They have different functions and natures because their branches of law are different. Transferring ownership to different people is possible under ownership.²⁹² However, it is not possible to transfer data protection rights. Protection rights cannot be separated from one's personality. If there is a clash between ownership and data protection rights, data protection rights will be given more priority.²⁹³

The South African Material Transfer Agreement (SA MTA) of 2018²⁹⁴ confused and created the wrong assumption that data subjects' data relates to them.²⁹⁵ The controversial

²⁸⁰ Ibid, s 5(1)

²⁸¹ Ibid, s 5(1)(i) and (ii).

²⁸² Ibid, s 5 (1)(b).

²⁸³ Ibid, s 5(1)(c).

²⁸⁴ Ibid, s 5(1)(d).

²⁸⁵ Ibid, s 5(1)(e)(i).

²⁸⁶ Ibid, s 5(1)(g).

²⁸⁷ Ibid, s 5(1)(h).

²⁸⁸ Ibid, s 5(1)(i).

²⁸⁹ Thaldar op cit note 18 at 20.

²⁹⁰ Ibid.

²⁹¹ Ibid.

²⁹² Ibid.

²⁹³ Thaldar op cit note 93 at 8.

²⁹⁴ Material Transfer Agreement for Human Biological Material GN 719 GG41781 of July 2018.

²⁹⁵ Ibid.

clause was clause 3.3, which states that ownership of the material remains with the donor and will only end when the material ceases to exist or is destroyed.²⁹⁶ Biological samples and data were found to be included in the definition of material in clause 3.3. The wording of clause 3.3 does not make sense because a donor donates or freely gives away something and does not retain ownership over it.²⁹⁷ If a person provides biological samples that came from their body but still has ownership of those samples, then he is not a donor. A donor gives their ownership away.

The transaction will not count as a donation.²⁹⁸ However, the SA MTA is merely a framework, and its provisions are not binding. The SA MTA clause 3.3 would also not work because it goes against primary legislation to allow data subjects to own data produced from their biological samples. Even if they were granted data ownership, it would benefit them little.²⁹⁹ Research institutions, on the other hand, will lose out significantly.

Thaldar has stated that research participants can own data produced from biological samples if the word ‘materials’ in the SA MTA refers to data.³⁰⁰ However, this data is divided into two categories. The first is data that researchers have collected from the data subjects and would include things like surgical history. The second data type is the by-product or newly generated data from biological samples sourced research subjects.³⁰¹ The first type of data, collected from research subjects, may be owned by research subjects because clause 3.3 of the SA MTA can be used.³⁰² No law in South Africa prevents data subjects from owning this type of data. However, clause 3.3 cannot be used for the second type of newly generated data, as section 60(4) of the National Health Act 61 of 2003 (NHA) will apply to biological samples collected from research participants.³⁰³ This section does not allow donors to receive rewards for the biological samples that are donated.³⁰⁴ Therefore, the reward of ownership for the newly generated data instances will not be permitted.³⁰⁵ Arguments can also be made that the new data instance's ownership value is trivial, and so the law should not consider it essential.³⁰⁶

²⁹⁶ Ibid, clause 3.3.

²⁹⁷ Thaldar op cit note 18 at 20.

²⁹⁸ Ibid.

²⁹⁹ Thaldar op cit note 18 at 21.

³⁰⁰ Ibid.

³⁰¹ Ibid.

³⁰² Ibid.

³⁰³ National Health Act, s 60(4).

³⁰⁴ Ibid.

³⁰⁵ Thaldar op cit note 93 at 8.

³⁰⁶ Ibid.

Even if data subjects were allowed to have ownership of the newly generated data instances that resulted from biological samples that they donated and which have little to no value, it would not benefit them.³⁰⁷ They already have enough protection from POPIA.³⁰⁸ Ownership would not give them more rights than they already have with POPIA.³⁰⁹ Furthermore, research institutions will face hardship if data ownership is given to data subjects.³¹⁰ These hardships come about because of the scope that ownership provides compared to data protection laws.³¹¹ Data protection rights are effective only if personal information is involved.³¹² Ownership rights do not have this limitation. They will apply even if non-personal details are involved.³¹³ For example, a research group is conducting research on a gene related to Down Syndrome, and they have collected and sequenced alleles, which are different versions of genes.³¹⁴ This research group then decides to de-identify the data by removing identifiable information to protect the data subjects' privacy and dignity.³¹⁵ Data protection, like POPIA, does not apply to de-identified information because it does not involve personal information.³¹⁶ This is why researchers de-identify the data, as it allows for easy data sharing.³¹⁷ This makes sharing across national borders much more accessible.³¹⁸ No consent is needed for de-identified data.³¹⁹ Now, if research participants were the owners of their data, they would still have rights over their data, even if it was de-identified.³²⁰ Furthermore, de-identifying the data without the data subjects' consent would be unlawful.³²¹ Therefore, research will be affected. Consider cases where a friend borrows your car. They have consent to use it for two days, they do not become the vehicle's owners but have permission to use it. If the friend refuses to return it after two days, they will commit theft, as it is an unlawful appropriation of the car.³²² The car's ownership will not end if the friend removes the car's

³⁰⁷ Thaldar op cit note 18 at 21.

³⁰⁸ Ibid.

³⁰⁹ The Protection of Personal Information Act, s 5.

³¹⁰ Thaldar op cit note 18 at 21.

³¹¹ Ibid.

³¹² V Mbonye, M Moodley & F Nyika 'Examining the applicability of the Protection of Personal Information Act in AI-driven environments' (2024) 26(1) *South African Journal of Information Management* 2.

³¹³ Ibid.

³¹⁴ Ibid.

³¹⁵ M Kayaalp 'Modes of De-identification' (2018) 2017(1) *AMIA annual symposium proceedings* 1044-1047.

³¹⁶ The Protection of Personal Information Act.

³¹⁷ Thaldar op cit note 18 at 21.

³¹⁸ Ibid.

³¹⁹ F McKay, D Treanor & N Hallowell 'Inalienable data: Ethical imaginaries of de-identified health data ownership' (2023) 4(1) *SSM - Qualitative Research in Health* 1.

³²⁰ Thaldar op cit note 18 at 21.

³²¹ Ibid.

³²² CT Joshua 'The Constitutionality of Estoppel in the Context of Vindication' (2021) 11(1) *Constitutional Court Review* 4.

number plate or the engine number.³²³ You will still be the car's owner, and there will still be theft, even if identifiable information is removed.

Research data will follow the same rules as the case above. Therefore, data de-identification will lose its benefits for research if research subjects own data. The research will face severe limitations.

Research ethics committees will be unable to block research participants from exercising their data ownership rights over the data.³²⁴ Hence, the committee cannot grant researchers permission to create and share the de-identified data. If the committee tries to block or prevent the data subjects from using their ownership rights, it will be considered an encroachment in property law.³²⁵

Solutions to this issue would be to ask research participants who own their data to provide the research institution with consent to use the data once it is de-identified. However, research participants will still argue that their ownership is being affected. Granting ownership to research subjects for the data would be disadvantageous.

XIII DATA CUSTODIAN VERSUS DATA OWNERSHIP

In a 2018 report, ASSAf suggested that the idea of ownership of genomic data should be discarded.³²⁶ ASSAf uses the communitarian Ubuntu philosophy to examine the ethical, legal, and social implications of genomics because these implications apply not only to the individual who provided the genetic data but also to their family and the community.³²⁷ Therefore, it views genomic data as a natural resource due to its importance in research, policymaking, and improvement in public health. Acknowledging genomic data as a natural resource highlights the necessity of protecting, managing, and sharing data fairly for the public's benefit.³²⁸ It suggested that custodianship of genomic data should be a better option than ownership.³²⁹ ASSAf views biological samples and genomic data as natural resources.³³⁰ It contends that the

³²³ Thaldar op cit note 18 at 21.

³²⁴ Ibid.

³²⁵ Ibid.

³²⁶ ASSAf report op cit note 103 at 85.

³²⁷ MS Pepper et al. 'ASSAf consensus study on the ethical, legal and social implications of genetics and genomics in South Africa' (2018) 114(11-12) *South African Journal of Science* 1.

³²⁸ Ibid.

³²⁹ Thaldar op cit note 18 at 22.

³³⁰ Ibid.

government should manage this ‘natural resource’ because it will be in the public’s interest to do so.³³¹

According to ASSAf, whether genomic resources can be considered property capable of being owned is a significant and disputed issue, as is the follow-up question of who should own them.³³² The nature of the ‘right’ being argued is unclear, which leads to unclear discussions of the issue.³³³ For example, it states that we gain *findings* from DNA sequencing revelations rather than inventions; therefore, it is unclear whether property rights frameworks will consider genomic resources to be property.³³⁴ Therefore, legal rights may not be recognised. Hence, attention to this subject is lacking in South Africa. Discourse on genetic resources claims that owning genetic resources and relevant property rights would be desirable and feasible.³³⁵ These claims are unfounded. Furthermore, South African laws do not mention human body parts and biological samples as something that can be owned.³³⁶ Therefore, property claims for them are not legally recognised. Therefore, it is best to treat these genomic resources as a common good. This means they will be public property and cannot be privately owned, as they cannot be used commercially.

Adopting genomic sovereignty ideas and the common good approach means the state will set up the infrastructure to govern and manage the samples and the data's use and reuse.³³⁷ However, donors can share their input on the governance system.³³⁸ The state is a custodian of natural resources like water in South Africa.³³⁹ The terms custodianship and stewardship are similar, and they are also familiar to South Africans because the state is the custodian of our minerals and water.³⁴⁰ Resource infrastructure and governance systems protect resources by supervising their exploitation, so ensuring their long-term viability and equitable access, and providing a form of benefit sharing.³⁴¹ Therefore, there is no apparent justification for not

³³¹ Ibid.

³³² Slabbert and Pepper op cit note 107 at 435.

³³³ ASSAf report op cit note 103 at 85.

³³⁴ Ibid.

³³⁵ Ibid.

³³⁶ Ibid.

³³⁷ KP Mahesh *Genomic Sovereignty in South Africa: Ethico-Legal issues* (unpublished LLM thesis, University of the Witwatersrand, 2014) 80.

³³⁸ ASSAf report op cit note 103 at 85.

³³⁹ R Stein ‘Water Law in a Democratic South Africa: A Country Case Study Examining the Introduction of a Public Rights System’ (2006) 83(7) *SAJELP* 187.

³⁴⁰ Ibid.

³⁴¹ ASSAf report op cit note 103 at 85.

applying stewardship principles to managing genetic resources in a way that effectively acknowledges sovereignty over them.³⁴²

An example of the state having custodianship over resources is the Mineral and Petroleum Resource Development Act 28 of 2002; this Act was put in place to eradicate the racial and unequal exploitation of minerals between white and non-white populations.³⁴³ The state is now in charge of regulating the minerals.³⁴⁴ It is essential to note that the state does not own the minerals; it simply regulates them.

The view that those who use genetic resources in their works should be entitled to proprietary or other rights conflicts with the view that donors are agents of the common good. According to other perspectives, the ‘right of control’ over genetics, whether symbolic or legal, could go to the following people or institutions in research: the person who supplied the genomic resources, the populations from which the data subjects come, researchers as they create databases with samples or data, research institutions, or the state.³⁴⁵ Each one can bring an argument in support of them having control, but there are also arguments against them.

It is essential to carefully examine the importance of global ownership and custodianship concerning collaborative research since the importance may vary across cooperating partners. ASSAf recommends that ownership should be disregarded and custodian principles should be followed.³⁴⁶ Furthermore, it finds that the South African Law Reform Commission should debate this issue because it has many consequences for distributive justice, equality, benefit sharing, and if intellectual property is possible in a system where genetic resources are common goods.³⁴⁷

This natural resource suggestion has been heavily criticised.³⁴⁸ The argument could justify public ownership of data instead of private ownership.³⁴⁹ However, a research institution could already have private ownership of the newly generated genomic data instances if it claimed ownership after developing them. Then, for public ownership to occur over that data, there needs to be expropriation by the government from the research institution.³⁵⁰ The

³⁴² Ibid.

³⁴³ The Mineral and Petroleum Resource Development Act, s 2.

³⁴⁴ Ibid, s 3

³⁴⁵ Ibid.

³⁴⁶ Ibid.

³⁴⁷ Ibid.

³⁴⁸ Thaldar et al op cit note 115 at 1.

³⁴⁹ Thaldar op cit note 18 at 22.

³⁵⁰ Thaldar op cit note 115 at 1.

government will be disadvantaged because it must use excessive government resources to achieve public ownership through expropriation.³⁵¹ Policy initiatives can make data sharing more accessible and allow for fair access to the data for the public. Therefore, why should appropriation be considered when more accessible options are available?³⁵² More straightforward methods should be used instead.

XIV CONCLUSION

Thaldar has used South African property law principles to determine that newly generated data instances are *res nullius*. They are not part of another object, and no legislation governs them. Therefore, they belong to nobody. To become the owner, an entity needs to take effective control of it and intend to become its owner. The research institution will have control over the new data instances because they are sequencing the data. This argument makes perfect sense. It will also help boost health research, which is lacking in South Africa. This legal property argument should be incorporated into our legal system.

The second argument for health data ownership used the Lockean property approach, which is that the research institution uses many resources and much effort to conduct the sequencing and should claim ownership for its effort. This is another valid claim. It is very costly for research institutions to perform sequencing. Furthermore, this will also boost medical research and benefit the public.

Health data ownership must follow property law principles. Data subjects cannot rely on their personal connection with the data, and there is no property law argument that they can use to claim the data. Furthermore, they are granted multiple data protection rights under POPIA. It would be futile to grant them ownership, especially in cases of de-identification of research data. If the data subject is the owner, they can still request that their data not be used, even if it is de-identified. Thaldar is correct in finding that this would hinder research.

ASSAf disagrees with Thaldar's argument. Instead, it views genomic data and biological samples as natural resources. ASSAf also found that body parts and biological samples are not owned in South Africa and applied that argument to health data ownership. This is not the correct approach because health data needs governance. ASSAf is not engaging with South African property law to assess whether health data ownership is possible. It merely states that health data ownership is disputed, and the right being argued is unclear. Furthermore, it states

³⁵¹ Ibid.

³⁵² Thaldar op cit note 115 at 1.

that property law might not consider health data as property because findings result from DNA sequencing and not inventions. It firmly believes that genetic material is a natural resource and a common good that the government should oversee through custodianship. Their approach is dismissive as South African literature makes a strong case for health data ownership. Data ownership must not be ignored in favour of custodianship. Custodianship will not provide data owners with the legal remedies to protect their data, such as in theft cases.

However, they have correctly mentioned that the South African Law Reform Commission should enter this debate. The debate has been ongoing for years but has not progressed. Arguments have been made, but no outcome has been achieved. Therefore, the South African Law Reform Commission must decide on health data ownership. Data sharing for precision medicine depends on it.

Public ownership has many benefits for South Africa's population. It will boost health research and make research data accessible to all. This aligns with the view of open science. Open science also has the backing of the International Declaration on Human Genetic Data, the constitutional right to freedom of scientific research, the PAIA, and the IPR-PFRD Act. Therefore, public ownership objectives are essential. However, public ownership ignores agreements between the data subject and the researcher, affecting data subjects' trust in research.

Private ownership is backed by the common law and will ensure that more research is done because private entities can profit from it. This is a positive for health research. It will also give entities more autonomy and protection, as they can choose who to share their data with. If they restrict access to data too much, the state can create a policy to make them share their data. Private entities also have the funds and the infrastructure to govern data more efficiently. Publicly owned entities perform poorer than private entities due to insufficient funds and inadequate infrastructure.

Public ownership of health data aims to make it freely accessible to all without restriction. In other words, the aim is to make it a public good. This objective is important because we need more health research for medical advancements. However, it has been legally determined that health data can be privately owned, and open science can be used to combat restrictions on access. This will ensure that data is open access to assist researchers, and precision medicine will also be improved. Therefore, private entities will still carry out the state's objective. To ensure that private entities make their data accessible, the state could implement a policy for

them to share their data openly, mainly if it was publicly funded. Furthermore, entities will have safeguards for their data in cases of theft. Custodianship will not be able to provide the same legal remedies. Thus, ownership is a better option. Most importantly, private ownership has legal support, more funds, better infrastructure, and the possibility of open science. Accordingly, it seems more practical.

CHAPTER FOUR: THE INTERSECTION OF GENOMIC SOVEREIGNTY AND HUMAN RIGHTS

I INTRODUCTION AND CHAPTER OVERVIEW

This chapter analyses the arguments for and against genomic sovereignty, which is the state, nation, or group's ownership and control over genetic material and data access and use. Furthermore, the natural resource argument for health data and genomic sovereignty will be compared with the human rights approach to ownership. An open-science mechanism is also proposed to combat access restrictions in private entities. Lastly, raw data ownership is explored.

II GENOMIC SOVEREIGNTY

The Universal Declaration on the Human Genome and Human Rights introduced the idea of a shared ownership framework of governance when it addressed genomes and used the phrase 'heritage of humankind'.³⁵³ This resulted in nations from the Global South asserting sovereign claims over genetic material from their people to protect it from exploitation by northern countries.³⁵⁴ These claims were made because they supported the idea of genomic sovereignty, which later became a political and scientific idea.³⁵⁵ Eventually, nations started to include this in their national laws and policies.³⁵⁶ According to Slabbers and Pepper, genomic sovereignty means that human genes are owned by the state, nation, or people, and they control their access, use, and knowledge.³⁵⁷

The biopolitical concept of genomic sovereignty came from Mexico as a mechanism to preserve its national genomics.³⁵⁸ In 2008, the genomic sovereignty policy became part of Mexican law.³⁵⁹ The law also prohibited Mexican biological samples from being used in population studies in other countries.³⁶⁰ If samples left Mexico, there would be penalties or

³⁵³ General Conference of the United Nations Educational, Scientific and Cultural Organization 'Universal Declaration on the Human Genome and Human Rights' 11 November 1997, available at <https://www.ohchr.org/en/instruments-mechanisms/instruments/universal-declaration-human-genome-and-human-rights>, accessed on 01 October 2024.

³⁵⁴ Kabata & Thaldar op cit note 108 at 1.

³⁵⁵ Ibid.

³⁵⁶ Ibid.

³⁵⁷ Slabbert and Pepper op cit note 107 at 127.

³⁵⁸ Ernesto Schwartz op cit note 112 at 27.

³⁵⁹ EE Vasquez & V García Deister 'Mexican samples, Latino DNA: The Trajectory of a National Genome in Transnational Science' (2019) 5(1) *Engaging Sci. Technol. Soc.* 109.

³⁶⁰ Ernesto Schwartz op cit note 112 at 146.

imprisonment.³⁶¹ Furthermore, intellectual property claims would be disallowed if genetic material was sent to other countries without seeking permission or if Mexico could not benefit from it. Those favouring the laws stated that international research collaboration would still be possible through a permit system.³⁶² The problem with the genomic sovereignty law is that it was explicitly created for Mexican genomes that are considered easily identifiable and capable of global monitoring.³⁶³

Genomic sovereignty rests on the belief that genomes from a nation can be mapped and governed as a justification.³⁶⁴ The issue is that populations are being confused with territories. Advocates of genomic sovereignty contend that a nation can control human genomes because they are viewed as new natural resources as long as they fall within its borders.³⁶⁵ It is also argued that human genomes have symbolic and financial significance. Therefore, they can bring in economic income and act as a nation's pride.³⁶⁶

Economic profit, national legacy and patrimony, combined with natural resource and dispossession reasoning, are the bases for genomic sovereignty.³⁶⁷ Bio-value will result from the genomic revolution, which justifies claims of economic gain.³⁶⁸ Hardy explains this notion by stating that if resources like oil are shared by all in Alaska, then resources like the Indian DNA should be shared by all.³⁶⁹ However, Alaskan oil is not shared by all.³⁷⁰ This illustration shows that oil and genomes are natural resources with monetary worth and can be in danger of exploitation by foreign nations.³⁷¹

National heritage and economic gain are linked, as the former depends on the genome's symbolic and cultural worth.³⁷² National populations worldwide are different and come with differences.³⁷³ This is why they are referred to as biological units, providing a foundation for the theme.³⁷⁴ In developing countries, there is a connection between national heritage, self-

³⁶¹ Ibid at 145.

³⁶² Ibid.

³⁶³ Ibid at 102.

³⁶⁴ Ibid at 24.

³⁶⁵ Ibid.

³⁶⁶ De Vries & Pepper op cit note 109 at 474.

³⁶⁷ Kabata & Thaldar op cit note 108 at 3.

³⁶⁸ Vasquez & Garcia Deister op cit note 359 at 109.

³⁶⁹ BJ Hardy *Bridging the Genomics Gap: The role of Large-scale Genotyping Projects in the Developing World and the Importance of Genomic Sovereignty* (unpublished Doctoral thesis, University of Toronto, 2009).

³⁷⁰ Hardy op cit note 369 at 134-135.

³⁷¹ Kabata & Thaldar op cit note 108 at 3.

³⁷² Ernesto Schwartz op cit note 112 at 283.

³⁷³ E Schwartz-Marín & A Arellano Méndez 'The law of genomic sovereignty and the protection of "Mexican genetic patrimony"' (2012) 31(2) *Med Law* 238.

³⁷⁴ Schwartz-Marín & Arellano Méndez op cit note 373 at 238.

determination, and national development. The population's genetics are considered natural resources and using them is a nation-building endeavour to provide citizens with results and ensure global involvement in the knowledge economy.³⁷⁵

Patrimony focuses more on preventing bio-exploitation.³⁷⁶ The premise is that patrimonial theories can help the state claim sovereignty over the national DNA, allowing it to define and separate it from different populations.³⁷⁷ Therefore, in this scenario, genomic sovereignty entails using property concepts to safeguard the population's genomes.³⁷⁸ In this regard, genomes are considered a public good and a sovereign resource in Mexican law. This means that the state could control it globally.³⁷⁹ Furthermore, inheritance implies protective control.³⁸⁰

III DEFECTS OF GENOMIC SOVEREIGNTY

Genomic sovereignty does not explain what happens in genomic research, such as whether a claim can be made for the national unique genome and which governments can claim sovereignty.³⁸¹ The theory does not mention whether it relates to data, biological samples, or both. Furthermore, it is still being determined whether genomic sovereignty laws are binding.³⁸²

Schwartz-Marín and Arellano Méndez argue that discussions about sovereignty are theoretically possible if we consider one person's unique DNA.³⁸³ However, it is difficult to do this when the whole population's genomes are involved. Thus, it is impossible to speak about a distinct Mexican composition while discussing the fluctuating proportions of DNA pieces that humanity shares.

Marin-Schwartz also argues that monitoring Mexican samples, having control of genetic data, and eliminating property rights just so that the state can claim sovereignty is unreasonable.³⁸⁴ Firstly, it must be noted that sovereignty-based legislation applies to specific territories and will not be effective for diasporic populations. People are fluid and can move

³⁷⁵ R Benjamin 'A Lab of Their Own: Genomic Sovereignty as postcolonial science policy' (2017) 28(4) *Policy and Society* 341.

³⁷⁶ Schwartz-Marín & Arellano Méndez op cit note 373 at 238.

³⁷⁷ Ibid.

³⁷⁸ Ibid at 16.

³⁷⁹ Ibid.

³⁸⁰ Vasquez & Garcia Deister op cit note 359 at 109.

³⁸¹ Kabata & Thaldar op cit note 108 at 3.

³⁸² Ibid.

³⁸³ Schwartz-Marín and Arellano Méndez op cit note 373 at 238.

³⁸⁴ Ibid.

beyond national borders. Secondly, the nature of genomic research must be considered, as genetic data is found in transnational datasets. Therefore, data cannot be contained inside national borders. Thirdly, property and patrimonial theories will only work for population genetic regulation if individual and communal property rights aspects emerge.³⁸⁵

Vasquez and García Deister also found the sovereignty claim impractical because genomic sovereignty laws do not consider that Mexican DNA and samples were turned into cloud data after they were analysed.³⁸⁶ Therefore, the data is migrating globally and moving beyond national borders without restriction.³⁸⁷

Two arguments challenge genomic sovereignty and its control claims regarding genomic data.³⁸⁸ First, in science, free dissemination of genetic data is standard in state practice.³⁸⁹

Ernesto Schwartz argues that Mexico is a member of and contributes to the global open-access network.³⁹⁰ Therefore, its sovereign policy needs to be more practical.³⁹¹ Second, research datasets are more favourable to genomic researchers when shared globally and not bound to one nation.³⁹² Thus, national data has little benefit.

Regarding genomic sovereignty laws, it was found that the rules, guidelines, and regulations were not enforced in Mexico.³⁹³ Several legal flaws prevented enforcement.³⁹⁴ Firstly, a distinct Mexican genome does not exist. Therefore, it needs to be clarified what 'Mexican uniqueness' needs to be safeguarded.³⁹⁵ Secondly, Siqueiros-Garcia et al. found that institutional and administrative methods needed to be present, so hindering the law's implementation.³⁹⁶ Thirdly, the laws aimed to control the population's genetics, but it has been found that they are fluid because they move across borders.³⁹⁷ Articulations of state sovereignty do not govern fluid but fixed things.³⁹⁸

³⁸⁵ Ibid.

³⁸⁶ Vasquez & Garcia Deister op cit note 359 at 109.

³⁸⁷ Ibid.

³⁸⁸ Kabata & Thaldar op cit note 108 at 4.

³⁸⁹ Contreras & Knoppers op cit note 111 at 432.

³⁹⁰ Ernesto Schwartz op cit note 112 at 156.

³⁹¹ Ibid.

³⁹² Ibid.

³⁹³ Kabata & Thaldar op cit note 108 at 4.

³⁹⁴ Ernesto Schwartz op cit note 112 at 14.

³⁹⁵ Ibid.

³⁹⁶ JM Siqueiros-García et al. 'Genomic sovereignty or the enemy within' (2013) 19(2) *Acta Bioethica* 272.

³⁹⁷ Ernesto Schwartz op cit note 112 at 155.

³⁹⁸ Ibid.

IV ACADEMIC SUPPORT OF GENOMIC SOVEREIGNTY IN SOUTH AFRICA

In South Africa, Pepper and his collaborators wrote about genomic sovereignty as the primary authors.³⁹⁹ Therefore, African literature on the subject is highly influenced by Pepper's views.⁴⁰⁰

In South Africa, Slabbert and Pepper found that the South's data must be protected from northern exploitation and that a connection exists between genomic sovereignty and benefit sharing when the genomic material is of South African origin.⁴⁰¹ Slabbert and Pepper also found that individual data and South African-origin exports of biological samples should have legislation governing them.⁴⁰²

De Vries and Pepper then explored whether genomic sovereignty could safeguard the exploitation of the global south's genetics.⁴⁰³ It must be noted that, by 2012, Mexico's genomic sovereignty policy was found to be unsuccessful. Therefore, De Vries and Pepper took a more critical approach.⁴⁰⁴ It was found that genomic sovereignty is attractive to the African setting, even if it has conceptual limits. Some of the limitations are that it was not mentioned who has authority to regulate the genetic material's access and use; donors' roles were also not clarified; the interest of the populations was not equally reflected by the state in the territorial boundaries; indigenous people did not know how to voice their concerns; ethnic groups were not contained within state borders and were fluid; wrongly assuming that state populations are distinct biological entities; and the fact that genomic data is transnational.⁴⁰⁵ The authors contend that genomic sovereignty has limitations and that the sovereignty idea alone cannot address inequality and unequal benefits for genomic research in South Africa.⁴⁰⁶

Furthermore, Pepper stated that a balance between preventing exploitation and encouraging innovation for DNA exporting is needed.⁴⁰⁷ He also linked DNA ownership with genomic sovereignty and said that human genetic resource ownership needs to be regulated.⁴⁰⁸

³⁹⁹ Kabata & Thaldar op cit note 108 at 4.

⁴⁰⁰ Ibid.

⁴⁰¹ Slabbert & Pepper op cit note 107 at 436.

⁴⁰² Ibid.

⁴⁰³ De Vries & Pepper op cit note 109 at 475.

⁴⁰⁴ Ibid.

⁴⁰⁵ Ibid.

⁴⁰⁶ Ibid.

⁴⁰⁷ MS Pepper 'Exporting DNA - striking a balance between preventing exploitation and promoting innovation' (2017) 107(2) *S Afr Med J* 106.

⁴⁰⁸ Pepper op cit note 407 at 106.

Pepper has also contributed to policy recommendations regarding genetic sovereignty and was a member of the National Biotechnology Advisory Committee, that urged discussions on genetic material regulation and surveillance.⁴⁰⁹ In 2018, ASSAf released a report on genomics in South Africa, which Pepper headed.⁴¹⁰ The report stated that DNA and genetic data from individuals are ‘natural resources’ that the government should own and control, just like it does with water or minerals.⁴¹¹ An example of this is shown below:

The Mineral and Petroleum Resource Development Act established a new legal regime for minerals and petroleum in South Africa.⁴¹² The concept of state custodianship was introduced, allowing the state to exercise its sovereignty rights.⁴¹³ However, state custodianship is still unclear because a definition is missing from the Act and the courts.⁴¹⁴

Previously, racial practices made it impossible for non-white South Africans to participate in the mineral distribution and exploitation.⁴¹⁵ Now, the state is the custodian of mineral and petroleum regulation. The state’s regulation will be made in compliance with the objectives of the Act.⁴¹⁶ The state now has more power over mining activities.⁴¹⁷ However, this power must be used to enhance the act's objectives and consider that these minerals can result in economic growth.

The South African Constitution also requires the state to guarantee that the public will gain from mineral exploitation, but this must be done without harming the environment. In addition, the state has a fiduciary obligation to its people regarding those minerals.⁴¹⁸ Custodianship is not the same as ownership; therefore, the state does not own the minerals. It regulates them, especially concerning mineral access.⁴¹⁹

ASSAf supports the idea of custodianship, but it did not comment on the drastic expropriation problems; it only suggested a policy to eliminate the notion of ownership.⁴²⁰

⁴⁰⁹ National Biotechnology Advisory Council ‘Position statement on Genomic Sovereignty in South Africa’ 2011, available at <https://www.naci.org.za/wp-content/uploads/NBAC-position-statement-on-Genomic-Sovereignty-in-South-Africa.pdf>, accessed on 01 October 2024.

⁴¹⁰ ASSAf report op cit note 103 at 85.

⁴¹¹ Ibid.

⁴¹² Mineral and Petroleum Resources Development Act 28 of 2002.

⁴¹³ H Schmidt *The legal meaning of state custodianship in the context of the Mineral and Petroleum Resources Development Act 28 of 2002* (unpublished Doctoral Thesis, University of Cape Town, 2023).

⁴¹⁴ Schmidt op cit note 413 at 2.

⁴¹⁵ Ibid at 18.

⁴¹⁶ Ibid at 1.

⁴¹⁷ Ibid at 5

⁴¹⁸ Ibid at 2.

⁴¹⁹ Ibid at 160.

⁴²⁰ ASSAf report op cit note 103 at 86.

South African law makes it possible for genomic data to be owned privately.⁴²¹ Legal facts about whether there is ownership of the newly generated data instance and who owns it can all be taken to court and proven.⁴²² Therefore, ownership cannot be discarded. Therefore, a policy to abandon ownership does not work. Also, what happens if genomic data is stolen? A research collaborator could make a copy of the computer file containing the data and then delete the original file found at the research institute. The data collaborator could declare that he/she owns the genomic data as it is stored in his/her computer or memory stick. The research institution can only bring a case of theft against the research collaborator if they own the data file. Section 12 of the Cybercrimes Act 19 of 2020 includes the theft of incorporeal property.⁴²³ Accordingly, the remedy is available.⁴²⁴ Ownership would also provide the research institution with civil remedies.⁴²⁵ The *Rei Vindicatio* remedy could have been used to claim that the file be returned.⁴²⁶ However, no remedies are available to the research institution if they do not claim ownership.⁴²⁷ Contractual remedies may be used if they exist, but they come with limitations.⁴²⁸ Furthermore, the research collaborator could become the owner of the newly generated data instance on the computer file because it had no owner. All the collaborator needs to do to get ownership is to take effective control of the data and intend to become its owner. Ownership will go to them via appropriation. Therefore, the effectiveness of ownership is seen. Custodianship does not come with these legal remedies and rights. Contracts could be used to ensure that data collaborators, students, and others do not try to claim the data as their own.⁴²⁹ However, this offers only civil and weak protection compared to ownership.

As a result, research institutions need to claim ownership of their research data, as this will provide them with legal protection and remedies, especially with theft cases. However, ownership is not absolute.⁴³⁰ Research institutions will also face limitations to their ownership.⁴³¹ The first limitation for research institutions is ethics supervision.⁴³² A health research ethics committee must approve the purposes for which the genomic data will be used.

⁴²¹ Thaldar op cit note 18 at 22.

⁴²² Ibid.

⁴²³ Cybercrimes Act 19 of 2020, s 12.

⁴²⁴ Thaldar op cit note 18 at 22.

⁴²⁵ Ibid.

⁴²⁶ Joshua op cit note 322 at 4.

⁴²⁷ Thaldar op cit note 18 at 22.

⁴²⁸ Ibid.

⁴²⁹ Ibid.

⁴³⁰ AJV Derwalt & P Dhliwayo 'The notion of absolute and exclusive ownership: a doctrinal analysis' (2017) 134(1) *South African Law Journal* 34.

⁴³¹ Ibid.

⁴³² Thaldar op cit note 18 at 23.

(Refer to Annexure 1 for an example of an ethical clearance letter used in research). The committee has the authority to uphold the interests of the research subjects.⁴³³ The second limitation is that POPIA compliance is non-negotiable for research institutions.⁴³⁴ POPIA applies to all personal information that can be used to identify people/research subjects.⁴³⁵ The research institution and the principal investigator will be considered to be the responsible parties mentioned in POPIA for carrying out the legal duties to protect research subjects.⁴³⁶ Even though ownership is not absolute, research institutions must claim ownership of the data.

Thaldar et al. analysed the South African common law property rights and found that genetic data can be brought under human control by storing it on a computer file; therefore, it can be considered property that can be owned privately.⁴³⁷ This is important because private ownership can promote or prevent access to genomic data relevant to forming open science policies.⁴³⁸ For open science principles to be implemented, the scope of the legal rights regarding human genetic data must be clear.⁴³⁹

V AN EVALUATION OF GENOMIC SOVEREIGNTY

Public ownership, which encompasses genomic sovereignty and the ASSAf's view of the state as the health data custodian, is severely criticised by arguments concerning the state's administrative inefficiency, risk of political interference, conflict with global collaboration due to data sharing restrictions, overreliance on expropriation, and data privacy rights.

(a) State administrative inefficiency

Section 195 of the Constitution relates to public administration and requires the following:

Professional ethics must be upheld, resources must be used in an economically friendly manner, there must be impartiality and fairness in its function, it must have strategies that have a growth mindset, and there should be the aim of upholding honesty, accountability and inclusivity.⁴⁴⁰

⁴³³ S Mahomed & M Labuschaigne 'The role of research ethics committees in South Africa when human biological materials are transferred between institutions' (2019) 12(2) *SAJBL* 79-80.

⁴³⁴ Thaldar op cit note 18 at 23.

⁴³⁵ Ibid.

⁴³⁶ Ibid.

⁴³⁷ D Thaldar et al. 'Open science and human genetic data: Recommendations on South Africa's Draft National Open Science Policy' (2023) 14(1) *Frontiers in Genetics* 3.

⁴³⁸ Thaldar et al. op cit note 437 at 3.

⁴³⁹ Ibid.

⁴⁴⁰ The Constitution, s 195.

However, evidence indicates that these constitutional principles have not been accomplished in public service.⁴⁴¹

(b) Lack of professional ethics

Corruption, bribery, and fraud cases have been rife in our country.⁴⁴² State capture has become quite common in discussions about the state and refers to entrenched corruption. In 2018, the judicial commission on state corruption investigated state capture, and the investigation revealed that it was promoted by individuals who work inside and outside the state and operate illegally.⁴⁴³

(c) Poor economic use of resources

Public resources are not being used in an economically friendly manner, and this has raised questions about maladministration.⁴⁴⁴ Furthermore, the State Capture Commission reported that public money was illegally obtained from the state through procurement.⁴⁴⁵ Procurement cases were exceptionally high in state-owned companies like Eskom.⁴⁴⁶ In addition, it was found that a large amount of state money was being used without authorisation.⁴⁴⁷ Poor resource use occurs because of inadequate skills, failing governance methods, lack of accountability or consequence control, incorrect financial management, and lack of oversight.⁴⁴⁸

(d) Lack of impartial and fair operation

Section 191 of the Constitution clearly states that a public servant's support for a political party should not be used against them in a discriminatory or preferential way.⁴⁴⁹ However, this has, in fact, been happening.⁴⁵⁰ Public servants are supposed to conduct themselves fairly and unbiasedly and consider the public's interests when performing their duties.⁴⁵¹ However, the African National Congress (ANC) policy of cadre employment conflicts with the

⁴⁴¹ M Nagar 'South Africa's public service is dysfunctional – the five main reasons why' 09 May 2024, available at <https://theconversation.com/south-africas-public-service-is-dysfunctional-the-5-main-reasons-why-228915>, accessed on 01 October 2024.

⁴⁴² Nagar op cit note 441.

⁴⁴³ Ibid.

⁴⁴⁴ Ibid.

⁴⁴⁵ L Kohn 'The National Prosecuting Authority as Part of South Africa's Integrity and Accountability Branch and the Related Case for an Anti-Corruption Redress System' (2022) 12(1) *Constitutional Court Review* 8.

⁴⁴⁶ Ibid.

⁴⁴⁷ Nagar op cit note 441.

⁴⁴⁸ Ibid.

⁴⁴⁹ The Constitution, s 191.

⁴⁵⁰ Nagar op cit note 441.

⁴⁵¹ Ibid.

Constitution.⁴⁵² The policy allows individuals to be given senior positions in the civil service if they support the ANC. This will also lead to unqualified persons taking up complex and important positions.⁴⁵³

(e) Lacking a vision of growth

The South African state struggles to provide essential services such as infrastructure, healthcare, and access to housing for its people.⁴⁵⁴ This means that equitable economic growth is not being achieved. For example, the electricity provider Eskom, has been unable to provide electricity, and there have been consistent power outages since 2007.⁴⁵⁵ Furthermore, basic human rights like water are still not accessible to specific areas in our country.⁴⁵⁶

(f) Discussions about privatisation

State-owned enterprises in South Africa have been failing in their public obligations, which indicates that the state's capacity is declining.⁴⁵⁷ Some of the failures include Transnet's inability to operate the rail networks, Eskom's inability to provide the public with electricity, and municipality failures to provide water and sanitation.⁴⁵⁸ These are but a few examples of how the state has failed in its duties. Given these issues, there have been discussions about involving the private sector.⁴⁵⁹

The private sector would increase competition, which would cause organisations to improve themselves.⁴⁶⁰ This is very much needed in a country that is failing economically due to its state-owned enterprises.⁴⁶¹ For example, if we had competition, Eskom would improve its operations, or people would look elsewhere for electricity supply. The private sector will also bring in more funds unrelated to the state.⁴⁶² This will improve infrastructure, energy, ports, and more.⁴⁶³ The South African government is already low on funds due to providing

⁴⁵² CF Swanepoel 'The slippery slope to State capture: cadre deployment as an enabler of corruption and a contributor to blurred party-State lines' (2021) 25(1) *Law democrat. Dev* 450.

⁴⁵³ Ibid.

⁴⁵⁴ Nagar op cit note 441.

⁴⁵⁵ Ibid.

⁴⁵⁶ Ibid.

⁴⁵⁷ 'Unlocking South Africa's potential: The case for privatisation' 06 February 2024, available at <https://focusontransport.co.za/unlocking-south-africas-potential-the-case-for-privatisation/>, accessed on 01 October 2024.

⁴⁵⁸ 'Unlocking South Africa's Potential' op cit note 457.

⁴⁵⁹ Ibid.

⁴⁶⁰ NA Makhaye, The benefits of privatisation of Eskom, the stakeholders' perspective (unpublished master's in business administration thesis, Technikon Witwatersrand, 2004), 1-2.

⁴⁶¹ Ibid.

⁴⁶² 'Unlocking South Africa's Potential' op cit note 457.

⁴⁶³ Ibid.

enormous amounts of bailouts for its enterprises. This means it needs funding from elsewhere, such as the private sector.⁴⁶⁴

(g) Risk of political interference

A case approach was conducted in the Umlazi municipal to investigate political interference. It was found that the municipal manager was forced to make decisions that were beneficial to the ANC.⁴⁶⁵ The manager confessed that his actions were unconstitutional.⁴⁶⁶ De Visser (2008) also found many corruption and fraud cases in municipalities due to inappropriate political interference.⁴⁶⁷ Political interference has resulted in poor service delivery as a result of hiring incompetent or unqualified individuals. ANC cadre deployment is to blame for unqualified staff, who mainly focus on their loyalty to the ANC.⁴⁶⁸ The individual's skills are not assessed. This will affect health data ownership frameworks because poorly skilled staff members will manage them, and this could lead to data misuse and breaches. Furthermore, political interference could affect data use and access, as state parties only want to share data with entities supporting their political party.

(h) Overreliance on expropriation

Genomic sovereignty involves the state's ownership of genetic material and data.⁴⁶⁹ This means that the state must expropriate and nationalise private property for it to become public property.⁴⁷⁰ Expropriation is quite a complex process and consists of the following steps:

Investigation and valuation

The expropriating authority (EA) will first investigate the property to determine whether it can be expropriated.⁴⁷¹ The EA is also responsible for assessing the registered and unregistered rights involved in the property.⁴⁷² Furthermore, the property will be inspected and valued.

⁴⁶⁴ Ibid.

⁴⁶⁵ S Mngomezulu 'Political Interference in the Administration of Service Delivery in UMLALAZI Local Municipality of KwaZulu-Natal, South Africa' (2020) 12(1) *Journal of Economics and Behavioural Studies* 42.

⁴⁶⁶ Mngomezulu op cit note 465 at 42.

⁴⁶⁷ J de Visser 'The political-administrative interface in South African municipalities assessing the quality of local democracies' 2010 *Commonwealth Journal of Local Governance* 87.

⁴⁶⁸ Ibid.

⁴⁶⁹ D Thaldar & B Shoji 'The legal status of human biological material used for research' (2021) 138(4) *S. Afr. J. Law* 881.

⁴⁷⁰ Thaldar and Shoji op cit note 469 at 881.

⁴⁷¹ The Expropriation Act 13 of 2024, s 5.

⁴⁷² Ibid.

Notice and consultation

The property owner must receive a notice of intention to expropriate from the EA before the process starts. The reason for the expropriation must also be included in the notice, which should be dated.⁴⁷³ The EA does not automatically become the owner, as there are still more steps in the expropriation process. Also, if the owner agrees to the expropriation, he/she can object and decide on what is an equitable and equitable amount.⁴⁷⁴ All these conditions will be included in the notice. The EA must inform the owner whether they agree to the compensation amount.⁴⁷⁵ If it does not agree, the EA must make an offer, justify the amount, and provide supporting paperwork.⁴⁷⁶

Expropriation and compensation

If the EA still needs to expropriate, it must send the owner another notice containing the agreed or offered compensation amount.⁴⁷⁷ Furthermore, the notice will inform the owner that they have 180 days to object to the compensation amount and to bring court proceedings.⁴⁷⁸ The amount of compensation granted is usually the most significant issue. Mediation or court proceedings are necessary if the parties cannot agree on an amount.⁴⁷⁹ However, the EA can obtain property ownership before the compensation matter is settled through mediation or court proceedings.⁴⁸⁰ This does not mean the compensation issue will go away. The court will still address that matter, and the state must pay the agreed-upon amount, which could be costly.

Institutions could own genetic material that data subjects donate to research institutions. Genomic data could become private property after it undergoes sequencing and is stored as a digital item, which would probably be the private property of the research institution because they sequenced it.⁴⁸¹ Therefore, if this private ownership had to be made state ownership, it would constitute expropriation and activate legislation on property rights protection.⁴⁸² Therefore, private owners must be compensated for the state's expropriation. Property law aspects of genetic material and data cannot be ignored.⁴⁸³ Furthermore, the expropriation

⁴⁷³ Ibid at s7.

⁴⁷⁴ Ibid at s 7(4).

⁴⁷⁵ Ibid at s 7(6).

⁴⁷⁶ Ibid.

⁴⁷⁷ Ibid at s 8.

⁴⁷⁸ Ibid.

⁴⁷⁹ Ibid at s 21.

⁴⁸⁰ Ibid.

⁴⁸¹ Thaldar op cit note 93 at 1.

⁴⁸² Kabata & Thaldar op note 108 at 5.

⁴⁸³ Ibid.

process is very long and requires many unique skills and resources, and the court could take a long time to resolve the compensation issue. Additionally, the agreed-upon amount could also be excessive.

(i) Conflict with global collaboration owing to data sharing restrictions

According to Thaldar et al., genomic sovereignty does not address the right to freedom of scientific research, a human right safeguarded in multiple African nations.⁴⁸⁴ Genetic sovereignty entails the state or a community owning and controlling genetic data.⁴⁸⁵ However, this will work against open science objectives, as the state or community will decide who gets access to this data and under what conditions.⁴⁸⁶ Open access is supposed to be free and open without barriers to genetic data. Kabata and Thaldar have acknowledged that genomic sovereignty may appear enticing. Still, after considering its ramifications, it is evident that it will not work in South Africa.⁴⁸⁷ They further state that genetic data needs a framework based on human rights.⁴⁸⁸ The focus should be on the right to science and using mechanisms like open science to achieve this. If genomic sovereignty ignores human rights, how will it pass constitutional scrutiny? Its policies and legislation would be unconstitutional.

(j) Information Privacy Rights

Discussions on genetic data must also include information privacy rights.⁴⁸⁹ They are essential for the protection of privacy. Multiple African countries, such as South Africa, Tanzania, Kenya, and Nigeria, have passed data protection laws that cover genomic data.⁴⁹⁰ Furthermore, there is a small chance that identifiable information can be removed (de-identification) from the genomic data to bypass these legislations.⁴⁹¹ Therefore, genetic data will still fall under informational privacy legislation.⁴⁹² Informational privacy rights are for individuals, and they protect their privacy interests.⁴⁹³ This goes against genomic sovereignty, which focuses more on state and collective /group interests.

⁴⁸⁴ Thaldar & Steytler op cit note 117 at 260.

⁴⁸⁵ Crow & Tananbaum op cit note 203.

⁴⁸⁶ Ibid.

⁴⁸⁷ Kabata & Thaldar op cit note 108 at 11.

⁴⁸⁸ Ibid.

⁴⁸⁹ Ibid.

⁴⁹⁰ C Staunton et al. 'Cross-border data sharing for research in Africa: An analysis of the data protection and research ethics requirements in 12 jurisdictions' 15 April 2024, available at <https://pmc.ncbi.nlm.nih.gov/articles/PMC11065056/>, accessed on 12 March 2025.

⁴⁹¹ Kabata & Thaldar op cit note 108 at 5.

⁴⁹² Ibid.

⁴⁹³ Ibid.

VI HUMAN RIGHTS OBLIGATIONS

The Universal Declaration on the Human Genome and Human Rights was adopted over 25 years ago, but the governance structure for human genomes still needs to be agreed to.⁴⁹⁴ The Declaration supported the standard heritage governance structure, but governments called for more consideration.⁴⁹⁵ Progress is still needed in the governance area. However, the state's behaviour has changed to reflect a variety of strategies for genomic research. Proposed international governance frameworks and the Human Genome Project's drive to be involved in the bioeconomy have changed the state's behaviour.⁴⁹⁶

One important conclusion is that genomic sovereignty, which involves the state owning genomic material, requires the appropriation of private genetic material to make it public property.⁴⁹⁷ Therefore, genomic sovereignty goes against human rights. Therefore, it should be discarded, as individuals are essential for genomic research.

As for human rights, nations have obligatory duties in genomic research according to global human rights legislation, even if governance structures are lacking. The International Covenant on Economic, Social, and Cultural Rights (ICESCR) guarantees the right to science for all, and states have enforceable responsibilities to carry out because of this international body.⁴⁹⁸ Almost all states have ratified the ICESCR, and no state has reserved the right to science.⁴⁹⁹

The state still must fulfil its obligations set out by the ICESCR, even if a definitive international governance structure for genomic research does not exist.⁵⁰⁰ Furthermore, state ownership of genomic material approaches infringes the rights of persons and researchers and goes against the ICESCR obligations.⁵⁰¹

Individual personality rights, state sovereignty, and shared heritage ideas all conflict and make it difficult to agree on genomic governance.⁵⁰² However, these conflicting approaches can be combined. The state must uphold human rights and the right to science and safeguard

⁴⁹⁴ Universal Declaration on the Human Genome and Human Rights op cit note 431.

⁴⁹⁵ Ibid.

⁴⁹⁶ Ibid.

⁴⁹⁷ Ibid.

⁴⁹⁸ General Assembly resolution 2200A (XXI) *International Covenant on Civil and Political Rights* available at <https://www.ohchr.org/en/instruments-mechanisms/instruments/international-covenant-economic-social-and-cultural-rights>, accessed on 01 October 2024.

⁴⁹⁹ International Covenant on Civil and Political Rights op cit note 498.

⁵⁰⁰ Kabata & Thaldar op cit note 108 at 10

⁵⁰¹ Ibid.

⁵⁰² Ibid.

other relevant rights.⁵⁰³ This will ensure that the state plays a part in genomic research governance.

VII A WAY FORWARD – PRIVATE ENTITIES ENGAGING IN OPEN SCIENCE

Genomic research is crucial for advancing healthcare.⁵⁰⁴ Genome sequencing is popular and expected due to declining prices and technical advancements, which have improved our understanding of how genomes work and can be used to improve health.⁵⁰⁵ With the growth of genomic research, local and international research institutions have undertaken genome research.⁵⁰⁶ However, bioethical concerns have arisen from this research.⁵⁰⁷ The main bioethical concerns involve privacy protection for data subjects and equitable data sharing.⁵⁰⁸ There is a global view that individuals of African origin are incredibly underrepresented in worldwide genomic research.⁵⁰⁹ Many countries in the Northern Hemisphere have established genomic databases. However, the global south has not been able to do the same.⁵¹⁰ In 2011, South Africa launched its human genomic programme, but it did not seem very effective as only 24 individual genomes were sequenced.⁵¹¹ This shows that more genomic data is much needed. To access databases for genomic programmes, you must apply for permission.⁵¹² For example, data access committees (DAC) oversee applications to access the Southern African Human Genomic Project databases.⁵¹³ The DAC will then decide whether to approve the application.

⁵⁰³ Ibid.

⁵⁰⁴ JS Mattick et al ‘The impact of genomics on the future of medicine and health’ (2014) 201(1) *Med. J. Aust.* 17.

⁵⁰⁵ Mattick et al op cit note 504 at 17.

⁵⁰⁶ A Gooden & D Thaldar ‘Toward an open-access genomics database of South Africans: ethical considerations’ (2023) 14(1) *Front Genet.* 1.

⁵⁰⁷ Gooden & Thaldar op cit note 506 at 1.

⁵⁰⁸ Ibid.

⁵⁰⁹ AR Bentley et al. ‘Evaluating the promise of inclusion of African ancestry populations in genomics’ (2020) 5(1) *NPJ Genom. Med.* 5.

⁵¹⁰ Gooden & Thaldar op cit note 506 at 1.

⁵¹¹ MS Pepper ‘Launch of the Southern African Human Genome Programme’ (2011) 101(5) *S. Afr. Med. J* 1-2.

⁵¹² Gooden & Thaldar op cit note 506 at 2.

⁵¹³ Ibid.

According to Gooden and Thaldar, an open-access database would solve the problem of underrepresentation of individuals of African origin in global research.⁵¹⁴ The database would include thousands of South African genomes and would be accessible globally.⁵¹⁵ According to Thaldar et al., these open-access databases can also be legally established.⁵¹⁶

VIII ADVANCEMENTS IN GENOMIC RESEARCH AND PRIVACY CONCERNS

Genomic research requires that both the duties of sharing health data and protecting the privacy of data subjects should be upheld.⁵¹⁷ Privacy risks have increased for data subjects and their genetic relatives because genomic data is sensitive, and data sharing is increasing.⁵¹⁸ This is because identifiable genomic data can be published and used to identify people and supposedly de-identified data can be shared, which may cause privacy breaches for data subjects and their genetic family members.⁵¹⁹

According to section 1 of POPIA, de-identification means deleting information that (1) can be used to identify data subjects,⁵²⁰ (2) can be used or made changes to by techniques that are reasonably foreseeable to learn the identity of the data subject,⁵²¹ (3) or can be used in conjunction with other information by some reasonably foreseeable technique to identify the data subject.⁵²² Townsend and Thaldar have found that it may be impossible to fully de-identify genomic data because genomic sequences will be used or connected to other genomic sequences, which could expose the data subject's identity.⁵²³ This is possible because we have many cases where the supposedly de-identified information underwent specific methods and processes that re-identified it.⁵²⁴ Re-identification is an issue because it brings risk to the data subject and their family, such as genetic discrimination,⁵²⁵ racial, sexual and ethnic

⁵¹⁴ Ibid.

⁵¹⁵ Ibid at 1.

⁵¹⁶ D Thaldar et al. 'Toward an open access genomics database of South Africans: Legal considerations' (2023) 119(7-8) *Forthcom. S. Afr. L. J* 1.

⁵¹⁷ National Human Genome Research Institute 'Privacy in genomics' 06 February 2024, available at <https://www.genome.gov/about-genomics/policy-issues/Privacy>, accessed on 01 October 2024.

⁵¹⁸ J Kaye 'The tension between data sharing and the protection of privacy in genomics research' 2012 *Annual Review of Genomics and Human Genetics* 13.

⁵¹⁹ L Bonomi et al. 'Privacy challenges and research opportunities for genomic data sharing' (2020) 52(7) *Nat. Genet* 646.

⁵²⁰ Protection of Personal Information Act 4 of 2013, s 1.

⁵²¹ Ibid.

⁵²² Ibid.

⁵²³ DW Thaldar & BA Townsend 'Exempting health research from the consent provisions of POPIA' (2021) 24(1) *Potchefstroom Electronic Law Journal* 10-11.

⁵²⁴ MG Hansson et al. 'The risk of re-identification versus the need to identify individuals in rare disease research' (2016) 24(11) *Eur. J. Hum. Genet* 1553.

⁵²⁵ J Lynch et al. 'Media coverage of direct-to-consumer genetic testing' (2011) 20(5) *Journal of Genetic Counselling* 486.

discrimination,⁵²⁶ exposing genetic predisposition, personal health data information,⁵²⁷ revealing genetic members,⁵²⁸ and the degradation of self-image or a person's image in society.⁵²⁹ These risks will negatively affect genomic research by giving it a poor outlook, which hinders data collection and sharing.⁵³⁰

Solutions have been identified to combat these risks.⁵³¹ Organisational techniques include access control systems, data transfer agreements, passwords, and access agreements.⁵³² Technical techniques include encryption, private networks, antimalware, and firewalls.⁵³³ However, even these techniques come with problems.⁵³⁴ For example, encryption ensures that sensitive information, like health data, is transferred and stored securely, but it is time-consuming and requires infrastructure and computers.⁵³⁵ Furthermore, researchers have to decrypt data from its encrypted form to use it, which makes it vulnerable.⁵³⁶ This vulnerable data could be disclosed or stolen, which makes encryption a poor safety mechanism.⁵³⁷

IX CLOSING THE GAP BETWEEN PRIVACY AND DEVELOPMENT IN GENOMIC RESEARCH: OPEN RESEARCH.

It is crucial to consider genomic research in the larger open science framework.⁵³⁸ The following components characterise open science: (a) publication must be done promptly, completely, and honestly; (b) it must be free from intellectual property claims; and (c) all data, deliberations, and activities of researchers must have the utmost transparency with its pre-and post-publication.⁵³⁹ Open science has many benefits, such as its efficiency and tendency to

⁵²⁶ Y Erlich et al. 'Redefining genomic privacy: Trust and empowerment' (2014) 12(11) *PLoS Biol* 1.

⁵²⁷ Z Shapiro 'Big Data, Genetics, and Re-Identification' 24 September 2015, available at <https://blog.petrieflom.law.harvard.edu/2015/09/24/big-data-genetics-and-re-identification/>, accessed on 01 October 2024.

⁵²⁸ Erlich et al. op cit note 526 at 1.

⁵²⁹ JE Lunshof et al. 'Personal genomes in progress: From the human genome project to the personal genome project' (2010) 12(1) *Dialogues in clinical neuroscience* 47.

⁵³⁰ Bonomi et al. op cit note 519 at 646.

⁵³¹ Gooden & Thaldar op cit note 506 at 2.

⁵³² C Stouffer 'What is encryption? How it works + types of encryptions' 18 July 2023, available at <https://us.norton.com/blog/privacy/what-is-encryption>, accessed on 01 October 2024.

⁵³³ Stouffer op cit note 532.

⁵³⁴ Ibid.

⁵³⁵ AB Carter 'Considerations for Genomic Data Privacy and Security when Working in the Cloud' (2019) 21(4) *Journal of Molecular Diagnostics* 542.

⁵³⁶ D Gil 'How to Preserve the Privacy of Your Genomic Data' 09 November 2020, available at <https://www.scientificamerican.com/article/how-to-preserve-the-privacy-of-your-genomic-data/>, accessed on 01 October 2024.

⁵³⁷ Gil op cit note 536.

⁵³⁸ R Caso & R Ducato 'Intellectual Property, Open Science and Research Biobanks' (2014) 22 *Trento Law Technol. Res. Group Res. Pap.*, available at <file:///C:/Users/juwer/Downloads/ssrn-2511602.pdf>, accessed on 01 October 2024.

⁵³⁹ Caso & Ducato op cit note 538 at 15.

prevent duplications and high costs associated with working, collecting, creating, transferring, and reusing data;⁵⁴⁰ it promotes scrutiny and broad assessment of research findings; it boosts data quality; helps boost reproduction of research; ensures disclosure, participation, collaboration, and faith in science are upheld; ensures that access to data leads to the new creation of inventions; and stimulates the production of research and findings that advance science, medicine, and public health.⁵⁴¹

The Human Genomic Project (HGP) is a prime example of an open science approach.⁵⁴² It featured international cooperation and collaboration by multiple disciplines to map and sequence the human genome.⁵⁴³ HGP allowed DNA sequencing information to be shared openly, and the software that carried out the analysis could be accessed publicly and freely.⁵⁴⁴ HGP encouraged more projects to traverse the open science route.⁵⁴⁵ This led to the International HapMap Project (HapMap) and the Encyclopaedia of DNA Elements (ENCODE) Project embracing open science.⁵⁴⁶ These projects prove that open science leads to meaningful collaboration and purposeful data sharing that advances health research and population health.⁵⁴⁷

X AUTONOMY SERVES AS THE CORNERSTONE OF INFORMED CONSENT.

According to the Ubuntu ethic, we all have mutual responsibilities to other human beings to establish a positive environment in society because humans are social and depend on one another to live a fulfilling life.⁵⁴⁸ Ubuntu recognises that human beings are relational, but it also recognises and appreciates the individuality of persons because it stimulates positive relationships with individuals and the community.⁵⁴⁹ This means that we should not prioritise the community's interests over a person's or vice versa.⁵⁵⁰ Instead, we must balance both

⁵⁴⁰ Gooden & Thaldar op cit note 506 at 2

⁵⁴¹ Ibid.

⁵⁴² L Hood & L Rowen 'The Human Genome Project: Big Science transforms biology and medicine' (2013) 5(9) *Genome medicine* 1.

⁵⁴³ Ibid.

⁵⁴⁴ Ibid.

⁵⁴⁵ Gooden & Thaldar op cit note 506 at 2.

⁵⁴⁶ Ibid at 3.

⁵⁴⁷ Ibid.

⁵⁴⁸ M Munyaka & M Mothlabi 'Ubuntu and its socio-moral significance,' in African ethics: An anthology of comparative and applied ethics' (2009) 3(2) *Black Theology An International Journal* 215.

⁵⁴⁹ B Shoji *An Afrocentric approach to CRISPR-Cas9: Analysing the use of genetic technologies in human reproduction through the lens of human rights and African values* (unpublished Doctoral thesis, University of KwaZulu-Natal, 2021).

⁵⁵⁰ Gooden & Thaldar op cit note 506 at 3.

interests. Therefore, if the research involves a community, researchers should engage with it first before discussing it with individuals, as this is ethically and legally necessary.⁵⁵¹

XI AUTONOMY AND PRIVACY

Privacy may take many forms.⁵⁵² However, we are concerned with informational privacy because it relates to genomic data. Informational privacy indicates that individuals can decide when, how, and how much of their data they want to share.⁵⁵³

Autonomous choice, which is people deciding what personal information they want to share, when this sharing can take place, and under what circumstances the sharing will be done, is the foundation of safeguarding information privacy.⁵⁵⁴ This means that research subjects have a choice, and it must not be assumed that their data must be protected in all cases, even if that is the default ethical position.⁵⁵⁵ Research subjects can choose to have their data openly accessible and waive their protection. According to Gooden and Thaldar, it is incorrect to assume that data subjects' data must never be made public or identified.⁵⁵⁶ Furthermore, they found that always believing that all data subjects want to use their right to privacy for their data is excessively paternalistic. However, research subjects who elect to waive their privacy rights in the informed consent stage become vulnerable to the risks mentioned above concerning identified genomic data since their data will be open and freely accessible.⁵⁵⁷

XII OPEN CONSENT

The Personal Genomic Project (PGP) aimed to generate open-access health data but did not actively de-identify the data.⁵⁵⁸ PGP instead chose to 'truly inform' research subjects of the research's nature, but this did not include signing logs or consent forms.⁵⁵⁹ Some viewed this approach as honest and transparent.⁵⁶⁰ This is where the form of open consent derived.⁵⁶¹ This means that when data subjects donate their genomic health data, they do so knowing their

⁵⁵¹ Ibid.

⁵⁵² H Leino-Kilpi et al. 'Privacy: A review of the literature' (2001) 38(6) *International journal of nursing studies* 663.

⁵⁵³ Leino-Kilpi et al. op cit note 552 at 663.

⁵⁵⁴ Gooden & Thaldar op cit note 506 at 3.

⁵⁵⁵ Ibid.

⁵⁵⁶ Ibid.

⁵⁵⁷ Ibid.

⁵⁵⁸ M Angrist 'Eyes wide open: The personal genome project, citizen science and veracity in informed consent' (2009) 6(6) *Personalized Medicine* 691.

⁵⁵⁹ Angrist op cit note 558 at 691.

⁵⁶⁰ MP Ball et al. 'Harvard Personal Genome Project: Lessons from participatory public research' (2014) 6(10) *Genome Med* 10.

⁵⁶¹ JE Lunshof et al. 'From genetic privacy to open consent' (2008) 9(5) *Nat. Rev. Genet* 406.

privacy will not be guaranteed.⁵⁶² Therefore, open consent involves informing data subjects about the research benefits and risks and that their identity may be discovered when their data becomes open.⁵⁶³ Harvard also conducted its own personal genomic project using the open consent model. Potential participants were required to undergo an online examination to determine whether they understood the study's benefits and risks.⁵⁶⁴

XIII BRINGING OPEN CONSENT TO SOUTH AFRICA

The values of Ubuntu and its relational understanding of personhood are deeply ingrained in South African Society.⁵⁶⁵ Therefore, researchers must ensure that they communicate with the communities of their research subjects.⁵⁶⁶ Unique perspectives can be gained from the community, so guaranteeing that the community is considered before and throughout the study.⁵⁶⁷ In research, the following actions fall under the umbrella of community engagement: information sharing, discussions, empowerment, making collaborative decisions, stakeholder alliances, and receiving direction from community leaders.⁵⁶⁸ Community engagement helps communities by increasing their knowledge of the study, making the informed consent process more effortless due to their increased understanding, and shielding them from exploitation.⁵⁶⁹ Community engagement also helps researchers gain insight into community preferences, which allows them to tailor their communication and research approaches to each community.⁵⁷⁰ Therefore, community interaction techniques should be added to the study's planning, implementation, monitoring, and viability.⁵⁷¹

There are three critical aspects to community engagement.⁵⁷² The first is exchanging information, which significantly benefits genomic research, especially since terms and

⁵⁶² Lunshof et al op cit note 561 at 406.

⁵⁶³ I Budin-Ljosne et al. 'Dynamic consent: A potential solution to some of the challenges of modern biomedical research' (2017) 18(4) *BMC Med. Ethics* 4.

⁵⁶⁴ Thaldar et al. op cit note 516 at 1.

⁵⁶⁵ R Musesengwa & MJ Chimbari 'Community engagement practices in Southern Africa: Review and thematic synthesis of studies done in Botswana, Zimbabwe and South Africa' 2017 *Acta Trop* 20.

⁵⁶⁶ Musesengwa & Chimbari op cit note 565 at 20.

⁵⁶⁷ Ibid.

⁵⁶⁸ C Akondeng et al. 'Community engagement in research in sub-Saharan Africa: approaches, barriers, facilitators, ethical considerations and the role of gender – a systematic review protocol' (2022) 12(5) *BMJ Open* 2.

⁵⁶⁹ S Ahmed & AGS Palermo 'Community Engagement in Research: Frameworks for Education and Peer Review' (2010) 100(8) *American Journal of Public Health* 2.

⁵⁷⁰ GF Black & P Sykes 'Steps Toward Engagement Integrity: Learning from participatory visual methods in marginalized South African Communities' 2022 *Frontiers in Public Health* 2.

⁵⁷¹ Akondeng et al. op cit 568 at 2.

⁵⁷² P Tindana et al. 'Community engagement strategies for genomic studies in Africa: A review of the literature' (2015) 16(24) *BMC Medical Ethics* 6.

procedures are difficult to understand.⁵⁷³ The second is discussions with the community to receive feedback on their interests.⁵⁷⁴ The third involves the community in creating a mutual relationship where the researcher and community respect each other.⁵⁷⁵

XIV WHAT ABOUT RAW HEALTH DATA

This dissertation has focused on the ownership of research data, which is data in processed form. However, raw data is unprocessed and comes directly from research trials and data subjects.⁵⁷⁶ Examples include laboratory notes and records compiled by the researcher that concern patients or data subjects.⁵⁷⁷ According to the Promotion of Access to Information Act, patients must be granted access to their medical records, which means they only have access privileges. The medical records are not the patient's or data subject's property; they are owned by the entity that created them. Therefore, they are privately owned by these entities. As for access to the raw data, the Intellectual Property Rights from Publicly Financed Research and Development Act can act as a guide. The Act stipulates that if a public body has provided funding for research and intellectual property resulting from it, that intellectual property should be safeguarded and used to benefit the public. This can apply to raw health data. If public funds were used to create the raw data records, they should be used to benefit the public. This could be done by making the records available for research purposes subject to confidentiality and privacy legislation.

XV CONCLUSION

Genomic sovereignty entails the state owning genetic material and regulating its access and use. The concept was developed to prevent northern countries from exploiting genetic material from the South, so it seemed reasonable. However, the relevant literature on it has exposed its many flaws.

Firstly, in Mexico, the state did not allow the genetic material of its people to be used in outside studies. A permit and authorisation were needed. This goes against the public good objectives of open science. Data is supposed to be freely accessible and without restriction. The state should not hinder scientific research. In South Africa, this would negate the

⁵⁷³ Tindana et al. op cit note 572 at 6.

⁵⁷⁴ Ibid.

⁵⁷⁵ Ibid.

⁵⁷⁶ O Chukwuma 'The dilemma of raw data in healthcare' 21 July 2022, available at <https://www.linkedin.com/pulse/dilemma-raw-data-healthcare-chukwuma-okoroafor#:~:text=Raw%20data%20is%20the%20unprocessed,of%20data%20is%20quite%20objective.> , accessed on 01 October 2024.

⁵⁷⁷ Chukwuma op cit note 576.

constitutional right to freedom of scientific research and PAIA. It also means that genomic sovereign states will ignore their obligation to the ICESCR for genomic research. Schwartz-Marin and Arellano Mendez have highlighted the many flaws of genomic sovereignty. For example, it does not specify who will regulate the access and use of genetic material; donors did not understand what their roles were; the interests of the people in the territories were not equally considered; indigenous groups were not given any guidance on whom to voice their complaints to, ethnic groups move in and out of borders and are fluid, groups' genetics cannot be considered unique or distinct, and genetic data does not stay within a state's borders. Genomic sovereignty did not work well for Mexico; therefore, it would have presented the same problems for South Africa.

A big issue for South Africa is that genomic sovereignty opposes open science. The state or community decides to use and access genetic material and data. South Africa has a very high burden of disease issues. In addition, African genomes are underrepresented in genetic studies. This means that South Africa needs health research to develop its treatment and care, but the data is not being shared enough. Open science would be a mechanism to combat this issue, but genomic sovereignty goes against open science because it requires that the state control the access and use of the data. To get access, permission is needed from the state. Genomic sovereignty focuses more on preventing the exploitation of genetics by northern countries rather than on data access. Public goods are meant to be freely accessible. This shows that a public ownership model of genomic sovereignty hinders the right to scientific research and open science. This could be catastrophic in a country that needs access to health data.

South Africa is also failing in its requirements for public administration, which are covered by section 195 of the Constitution. Firstly, corruption and bribery exist in almost every state department. Because of this, state capture, which refers to entrenched corruption, has become prevalent in the country. To make matters worse, governmental officials are engaging in corruption. Secondly, resources are not being used in an economically friendly way. Public monies are disappearing from the state via procurement. There are no accountability or consequences for this action. Furthermore, individuals are employed without the required skills, and no financial oversight exists. The ANC has also been guilty of hiring individuals based on their loyalty to the party instead of their abilities. This places unskilled workers into critical positions. In addition, essential services like infrastructure, water, and healthcare are still unavailable for many South Africans. The state is struggling to cope with its duties.

Granting the state health data ownership would be foolish, as it requires high-level skills and protection.

Public interference is another issue. State officials could use their power to make sensitive health data available to entities of their choice based on political loyalty, and the data could be misused for illegal purposes.

Moreover, for genomic sovereignty to work in South Africa, the state would have to expropriate privately owned data to make it publicly owned, and the private data owners would also have to be compensated. The agreement on the amount of compensation is another issue for the state. The owner would try to get the most profit for their property, and court proceedings to resolve the matter could be lengthy. This would be a waste of resources, and the expropriation process is also complex and time-consuming. Instead, the state should look at alternative options.

We know that genetic data can be owned privately. Therefore, an open science policy is more effective. ASSAf's open science policy, which requires publicly funded research to publicise its results, is a good example. Private entities using state money to fund their research should also make their data accessible to the public, thus providing a public good. It seems more reasonable that health data should be privately owned but performing a public function.

The public ownership objective of open science has been explored to facilitate the sharing of health data and to improve precision medicine. This mechanism would work well in South Africa, mainly because we have such a high disease burden, our African genomes are underrepresented in medical research, and it is a strategy to combat restricted access in private entities. The open consent model would also work well for our country. The risks and benefits of the research could be explained to data subjects, and they would have to undergo an examination, just like the Harvard project above. This will ensure that they fully understand what the research comprises, especially the risk of identification. If data subjects voluntarily share their data for open science, it will boost research. Informed consent will be complied with.

CHAPTER FIVE: CONCLUSION AND RECOMMENDATIONS

I SUMMARY AND KEY FINDINGS

(a) Why is it argued that health data can be privately owned?

This study aimed to analyse whether health data should be publicly owned. Thaldar is the only author who has analysed whether health data meets the requirements of being considered a ‘thing’ that can be owned. According to the common law property rights system, a thing is capable of ownership if it has use, is of value, is not part of something else or a human, and can be controlled. Therefore, Thaldar found that newly generated data instances can be owned because they have use and value for health research and precision medicine, are not part of humans or other objects, and can be controlled by storing them on computer files. Thaldar emphasises that this relates to data instances and not data generally. Thus, data instances can be owned privately.

(b) Who can claim ownership of health data?

It has been noted that intellectual property and data ownership entail different rights. In data ownership, the object of ownership is the genomic sequence data stored in a computer file. The object of a copyright is a genomic dataset. In patent rights, the object is an invention. Furthermore, data ownership and intellectual property rights have different regulations and are distinct. Patent rights cannot change ownership of a gene sequence. Therefore, ownership must still be focused on.

Regarding whom should own the data, it was found that the research institution has the most substantial claim because the newly generated data instances are *res nullius*, which means they have no owner. To gain control, an entity needs to intend to become its owner and have effective control over it. The research institution will already have control over the data instances because they are sequencing the data. The institution must save the data instance on a computer file and have the required intention. The second method that can be used for the research institution is the Lockean property theory, which states that a person or entity that uses their own labour to produce a property has a right to claim ownership. The research institution uses effort and resources to conduct the sequencing of genetic material; therefore, this is counted as labour and effort. Ownership by the research institution benefits scientific and medical research, leading to advancements in precision medicine.

The research subjects claim that they had a personal connection with the data and should own it. However, property law determines who becomes the owner of property. Personal connection is not a property law requirement. Therefore, data subjects will fail in their claims. Secondly, data subjects have been given several data protection rights, and it would be futile to grant them ownership. Furthermore, if the data subjects own the data, it would mean that even their de-identified data would still be owned by them. If the data subject does not want their de-identified data to be used in research, it will not be used. This will severely affect medical research and precision medicine. Therefore, it would not serve the public to grant data ownership to data subjects.

Since health data instances can be owned privately, the state can only acquire them through expropriation, which is very resource-heavy and should be avoided. More straightforward approaches can be taken, such as creating a policy requiring private institutions to open their data to the public if a public source funds their research. This is precisely what the ASSAf's open science policy requires.

(c) Should health data adopt the genomic sovereignty approach and make health data publicly owned?

Genomic sovereignty entails the state, nation, or people owning genetic material and regulating its use and access. However, it was found to have too many flaws to work in South Africa. Firstly, the state or nation decides who can access and use the data. This means that there are restrictions on its use and access. This is not fulfilling a public good function, which is to be accessible to all. This also goes against the right to scientific research, which includes open science. Open science requires data to be made freely accessible to all. Genomic sovereignty restricts this access. Other problems include the fact that it is unclear who will be regulating the data use and access, the donors did not have clarification on their roles, the interests of the people from that nation were not being considered equally, indigenous people were not guided on whom they should take their complaints to, ethnic groups do not stay in one territory and are fluid, and genetic material cannot be kept within borders, as data is transnational. The disadvantages of state public ownership with genomic sovereignty outweigh the advantages.

Furthermore, the state is not capable of owning a health data framework. Essential services like water, healthcare, and housing are still not accessible to a large portion of the population. The state does not have the funds or infrastructure to take on more duties like health data governance. It has already been proven that bribery and corruption are rife in the public

sector, and state officials are involved. Public monies are also being obtained illegally by procurement. Therefore, the state is short on public funds. Public funds that go towards the health data framework could also be stolen. There is also the issue of the state hiring unskilled labour because of its loyalty to the governing party. Again, health data governance frameworks are complex and require highly skilled individuals. If poorly skilled individuals manage the data, it could result in misuse and privacy breaches. It is also important to note that certain public services like electricity production were looking to the private sector for help, as it could thrive in the public sector. This suggests that private entities can manage health data ownership more efficiently.

Lastly, legal arguments are available for private ownership of health data, which means that the state will have to expropriate the data for it to become public property. This will include using many resources, which is a drastic move. A more straightforward approach should be taken, such as creating a data policy for publicly funded research to be made public in private entities. This will ensure that the public good objective is reached. Furthermore, private entities have better infrastructure and more funds to govern health data more efficiently than public entities. Therefore, health data should not be publicly owned.

II RECOMMENDATION AND IMPLICATIONS

(a) The South African Law Reform Commission should enter this debate.

South African literature has provided compelling evidence that a single instance of health data meets the requirements of a thing capable of being owned. The Commission must consider these findings, as they are compatible with our South African law. The commission should implement legislation that defines health data ownership, as it is crucial to health research and access to data. The debate has been ongoing without progress. The Commission needs to enact legislation to provide clarity. Furthermore, legislation on data ownership will bring about trust and ethical data use. It will also protect the researchers against theft. This protection will encourage researchers to engage in more health research for the public, as they have legislation to protect their data.

(b) Health data should be privately owned

Private entities increase competition, meaning the health data framework will be better managed because private entities will profit from it. Suppose the data is not maintained correctly and is of poor quality. In that case, users will go to other private entities to gain access

to data, which will decrease the private entity's profits. Furthermore, the private sector will drive a surge in health research since it involves a profit gain. Increasing research will lead to better treatment and care in precision medicine. The public will also have more trust in private entities since they function more effectively than public institutions due to higher funds and less corruption.

(c) Open science policies can be used to combat access restrictions in private entities

The legal position is that health data can be privately owned, which raises questions about whether access to the data will be restricted. To combat this issue, the state should implement a policy similar to ASSAf's open science policy. This would mean that research that has been publicly funded should make its data accessible to the public. This ensures that the research institution gives back to the public that supported it. This will also enhance health research because more data will be easily accessible to the public.

The Harvard open consent model could be used in South African private entities to protect data subjects' privacy and to boost research. Those who choose to share their data voluntarily in the public domain will be informed of all the risks and benefits of the research, especially the risk of being identified. The data subjects must then write an online examination to test whether they understand the study's implications. This also complies with informed consent. Therefore, this model will benefit individuals who want to share their data, exercising their autonomy, and it provides higher protection by making participants undergo an examination.

III CONCLUSION

This dissertation, which consisted of a legal analysis of South African legislation and literature, as well as international literature, made it clear that health data instances are capable of being considered property that can be privately owned according to common law. Therefore, the state would have to use immense resources to expropriate the private property and convert it into public property. This would be a waste of money and resources, as more practical solutions are available. For example, the state could implement a similar policy to the ASSAf's open science policy, which entails that research entities would have to make their data accessible to the public if they used public funds to conduct their research. This means that if private entities use public funds to conduct their research, which many do, they will have to make their data more accessible to the public. Therefore, legal and practical arguments exist to support the privatisation of health data.

Furthermore, arguments favouring genomic sovereignty oppose the right to scientific research, as the state will restrict access to health data. This will negatively affect health research, which is very much needed in South Africa. Additionally, the state is not equipped to manage a health data framework due to administrative inefficiencies, political interference risks, conflict with global collaboration, and limited funds.

Therefore, it is recommended that the state should not own health data. Instead, research institutions should own it privately, as they will process genomic data and generate new data instances. South African literature has provided evidence that newly generated human genomic data instances meet the South African law requirements of an object that can be owned privately, as it is useful, valuable, separate from another object, separate from the human body, and capable of being controlled. The control requirement is satisfied when data instances are stored on computer files. South African literature also provides evidence that newly generated data instances are *res nullius* property (without owner). Therefore, the requirements to gain ownership of this property are to take possession of it and intend to become the owner. Research institutions will already be in possession of the data since it processed the genomic material. Furthermore, research institutions use a lot of effort and resources to process the data. Thus, according to the South African property law examined, they are best suited to own the data. Additionally, research institutions should own health data to ensure the data subjects' personal information is confidential. This also builds trust between the researcher and the subject. This ownership will also encourage innovation as the researchers will have protection of the law for their data. This will also ensure that data is used ethically and that academic or commercial benefits are appropriately attributed to the relevant individuals.

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APPENDIX 1: ETHICAL CLEARANCE



Miss Juweriya Khan (213526939)
School Of Law
Howard College

Dear Miss Juweriya Khan,

Original application number: 00026143 **Project title:**
Health data as a public good

Exemption from Ethics Review

In response to your application received on 2 August 2024, your school has indicated that the protocol has been granted **EXEMPTION FROM ETHICS REVIEW**.

Any alteration/s to the exempted research protocol, e.g., Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through an amendment/modification prior to its implementation. The original exemption number must be cited.

For any changes that could result in potential risk, an ethics application including the proposed amendments must be submitted to the relevant UKZN Research Ethics Committee. The original exemption number must be cited.

In case you have further queries, please quote the above reference number.

PLEASE NOTE:

Research data should be securely stored in the discipline/department for a period of 5 years.

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

Yours sincerely,

Dr Jacintha Deleane Toohey
PP Academic Leader Research
School Of Law

UKZN Research Ethics Office
Westville Campus, Govan Mbeki Building
Postal Address: Private Bag X54001, Durban 4000
Website: <http://research.ukzn.ac.za/Research-Ethics/>

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