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Human Rights Implications of Stroke Biobanking and Genomics Research in Sub-Saharan Africa

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Abstract

Stroke is a major cause of death in Sub-Saharan Africa (SSA) and genetic factors appear to play a part in its pathogenesis. This led to the development of stroke biobanking and genomics research in SSA. Existing stroke studies have focused on causes, incidence rates, fatalities and effects. However, scant attention has been paid to the legal issues about stroke biobanking and genomics research in the sub-region. Therefore, this article examines the legal implications of stroke biobanking and genomics research in Sub-Saharan Africa from a human rights perspective. The study argues that the right to dignity of the human person, the right to privacy, the right to freedom of information, the right to freedom from discrimination, the right to own property, the right to self-determination and the right to health may be implicated. The study concludes that the court may have to be involved in balancing one right against the other which may prove somewhat herculean depending on the circumstances of each case.

Keywords

human rights – stroke – biobanking – genomics research – Sub-Saharan Africa – dignity – inhuman or degrading treatment– privacy – freedom of information – discrimination – right to property – right to self-determination – right to health

1 Introduction

Stroke affects 62 million people worldwide.[1] Out of this figure, 87% live in low- and middle-income countries.[2] In these countries, stroke fatality rates are as high as 35%.[3] The mortality rate is as high as 84% three years after stroke.[4] Stroke is a major cause of dementia, depression, disability and death in Sub-Saharan Africa (SSA).[5] Compared to high-income countries, stroke incidence rates in SSA are surging, outcomes are worse and relatively younger people are affected.[6] It is noteworthy that most of the world's low-and middle-income

1 DAMOCLES Study Group 'A Proposed Charter for Clinical Trial Data Monitoring Committees: Helping Them to do Their Job Well' (2005) 365 *Lancet* 711–722; K Strong, C Mathers and R Bonita, 'Preventing Stroke: Saving Lives Around the World' (2007) 6 *The Lancet Neurology* 182–187; LLYan and others 'Prevention, Management, and Rehabilitation of Stroke in Low- and Middle-Income Countries' (2016) 2 *eNeurologicalSci* 21–30.

2 *Ibid*.

3 VL Feigin and others 'Global and Regional Burden of Stroke during 1990–2010: Findings from the Global Burden of Disease Study 2010' (2014) 383 *Lancet* 245–254; VL Feigin and others 'Worldwide Stroke Incidence and Early Case Fatality Reported in 56 Population-Based Studies: A Systematic Review' (2009) 8 *The Lancet Neurology* 355–369.

4 MO Owolabi and others 'The Burden of Stroke in Africa: A Glance at the Present and a Glimpse into the Future' (2015) 26 *Cardiovascular Journal of Africa* 527–538.

5 RO Akinyemi and others 'Unravelling the Ethical, Legal, and Social Implications of Neurobiobanking and Stroke Genomic Research in Africa: A Study Protocol of the African Neurobiobank for Precision Stroke Medicine ELSI Project' (2020) 19 *International Journal of Qualitative Methods* 1; MO Owolabi and others 'The Burden of Stroke in Africa: A Glance at the Present and a Glimpse into the Future' (2015) 26 *Cardiovascular Journal of Africa* 527–538; RO Akinyemi and others 'Stroke, Cerebrovascular Diseases and Vascular Cognitive Impairment in Africa' (2019) 145 *Brain Res Bull* 97–108; H Bronnum-Hansen and others 'Long-Term Survival and Cause of Death after Stroke' (2001) 32 *Stroke* 2131–2136; WN Kernan and others 'The Stroke Prognosis Instrument II (SPI-II): A Clinical Prediction Instrument for Patients with Transient Ischemic and Non-Disabling Ischemic Stroke' (2000) 31 *Stroke* 456–462; GW Petty and others 'Survival and Recurrence after First Cerebral Infarction: A Population-Based Study in Rochester, Minnesota 1975 through 1989' (1989) 50 *Neurology* 208–216; CM Viscoli and others 'A Clinical Trial of Estrogen-Replacement Therapy after Ischemic Stroke' (2001) 345 *The New England Journal of Medicine* 1243–1249; S Vernino and others 'Cause-Specific Mortality after Cerebral Infarction: A Population-Based Study' (2003) 34 *Stroke* 1828–1832.

6 MC Ezejimofor and others 'Stroke Survivors in Nigeria: A Door-to-Door Prevalence Survey from the Niger Delta Region' (2017) 372 *Journal of the Neurological Sciences* 262–269; MJ Hall and others 'Hospitalization for Stroke in U.S. Hospitals, 1989–2009 (2012) *NCHS Data Brief* 1–8; A Rosengren and others 'Twenty-Four-Year Trends in the Incidence of Ischemic Stroke in Sweden from 1987 to 2010' (2013) 44 *Stroke* 2388–2393; Y Wang, AG Rudd & CDA Wolfe 'Trends and Survival between Ethnic Groups after Stroke: The South London Stroke Register' (2013) 44 *Stroke* 380–387; B Ovbiagele 'National Sex-Specific Trends in Hospital-Based Stroke Rates' (2011) 20 *Journal of Stroke and Cerebrovascular Diseases* 537–540.

countries are located in SSA. In family-oriented societies, most people cannot afford health expenditures.[7] In these societies that are largely found in SSA, stroke changes the life of its survivors and family members who are caregivers. Apart from the negative impact on the individual, the costs in terms of direct expenditures and lost productivity related to stroke are prohibitive.[8] Additionally, stroke is a prototypical disease where racial differences in burden, severity and outcomes are quite striking, suggesting that genetic factors could explain part of these racial differences.[9]

Since the incidence of stroke continues to escalate in SSA and genetic factors appear to play a part, genetic and genomics stroke research need to be developed. Thus, to reduce the high and escalating burden of stroke in the sub-region through genomics research, the collection of human biological samples becomes inevitable. As human biological samples are collected and kept, and research conducted on those samples yield results that may sometimes be required to be returned to the donors or their relatives, many ethical, legal and social issues (ELSI) related to genetic and genomics stroke research become imperative to be addressed.

In this article, the legal implications of stroke biobanking and genomics research from a human rights perspective in SSA are examined. The thesis is that the right to dignity of the human person, the right to privacy, the right to freedom of information, the right to freedom from discrimination, the right to own property, the right to self-determination and the right to health are likely to be implicated as human rights and that the court may have to be involved in balancing one right against the other which may prove somewhat herculean depending on the circumstances of each case. It is worth mentioning that while these human rights are likely to be implicated in other health related activities and/or research, the subject of focus here is stroke biobanking and genomics research and it is within this context that this work is situated. Having stated thus, each of these rights and some of the circumstances under which they can be implicated will now be examined.

2 Freedom from Torture, Inhuman or Degrading Treatment

As previously noted, genomics research to probe into the mechanisms of stroke causation involves banking human tissues and preserving data on those

7 W Rosamond and others 'Heart Disease and Stroke Statistics-2008 Update: A Report from the American Heart Association Statistics Committee and Stroke Statistics Subcommittee' (2008) 117 *Circulation* e25-e146.

8 Rosamond and others (n 7).

9 On the role of genetic factors on diseases, see M Claussnitzer and others 'A Brief History of Human Disease Genetics' (2020) 577 *Nature* 179.

who develop a stroke. In obtaining data from those with stroke, questions may have to be asked of them or their family members who take care of them. In doing this, the researcher has to be careful and tactical so as not to subject them to cruel, inhuman or degrading treatment.[10] At the point at which questionnaires are being administered on them, the researcher must make clear to them that they are free to withdraw at any stage, that their decision will be respected and that withdrawal from the study will not affect the health care the individual receives. Where oral interviews are being conducted, the decision of the participants to withdraw must be respected at any stage. On no account must information be forcefully obtained and on no account must they be treated with disdain just because they choose to withdraw. Where the genomics researcher fails to do this, it may give rise to 'inhuman' or 'degrading' treatment.

Art 5 of the Universal Declaration of Human Rights (UDHR or Universal Declaration) stipulates that no one shall be subjected to torture, inhuman and degrading treatment. It has been argued that customary international law forbids violation of any of the rights set forth in the Universal Declaration.[11] This implies that a State violates international law if, as a matter of State policy, it practices, encourages, or condones violations of human rights declared in the UDHR including freedom form torture or other cruel, inhuman or degrading treatment or punishment. For conduct to amount to cruel, inhuman or degrading treatment, it does not need to involve physical pain.[12] It suffices once the treatment humiliates or debases a person, causes fear, anguish or a sense of inferiority, or is capable of breaking moral or physical resistance or driving a person to act against their will or conscience.[13] Art 7 of the International Covenant on Civil and Political Rights (ICCPR)[14] provides that no one shall be subjected to torture or cruel, inhuman and degrading treatment or punishment. It is categorically stated that 'no one shall be subjected without his free

10 On human rights approach to medical law and ethics, see A Plomer *The law and ethics of medical research: international bioethics and human rights* (2005).

11 *Filartiga v Pena-Irala* 630 F. 2d 876 (1980); (1980) 19 ILM 966; US Circuit Court of Appeals, 2nd Circuit; A Lowe 'Customary International Law and International Human Rights Law: A Proposal for the Expansion of the Alien Tort Statute' (2013) 23 *Indiana International and Comparative Law Review* at 544–546.

12 Acts that cause both physical and mental suffering are also included.

13 *Keenan v United Kingdom* (2001) 33 EHRR 38 [109]; *Pretty v United Kingdom* (2002) 35 EHRR 1 [52].

14 The International Covenant on Civil and Political Rights was adopted by the United Nations General Assembly Resolution 2200A(XXI) on 16 December 1966 and entered into force on 23 March 1976. As of September 2019, the treaty had been ratified by 173 parties and had six signatories without ratification.

consent to medical or scientific experimentation.' As of September 2021, there were 173 state parties to the Covenant including several African States.

Art 5 of the African Charter on Human and Peoples' Rights[15] (African Charter) provides that every individual shall have the right to the respect of the dignity inherent in a human being and to the recognition of his legal status. It adds that 'All forms of exploitation and degradation of man particularly slavery, slave trade, torture, cruel, inhuman or degrading punishment and treatment shall be prohibited.' As of 15 June 2017, all States in Africa had ratified the Charter except Morocco.[16] Thus, it has been contended that the African Charter has become a local or regional custom[17] because of the universal ratification that the Charter has enjoyed in Africa, and its *sui generis* nature. Nonetheless, it is worth mentioning that States with a dualist tradition inherited from the English common law, where treaties must be enacted into law before they can have effect in domestic jurisdictions, would have to enact the rights protected in the Charter into law in their respective domains.[18] In Nigeria where the dualist tradition applies, the Charter has been enacted into law through the African Charter on Human and Peoples' Rights (Ratification and Enforcement) Act.[19] On the other hand, the Charter takes effect upon ratification in States with monist tradition inherited from the civil law tradition where treaties automatically take effect in domestic jurisdictions.[20]

15 African Charter on Human and Peoples' Rights, OAU Doc. CAB/LEG/67/3 rev. 5, 21 I.L.M. 58 (1982) entered into force 2 October 1986.

16 See African Union, 'List of Countries which have Signed, Ratified/Acceded to the African Charter on Human and Peoples' Rights.'

17 See NJ Udombana, 'Shifting institutional paradigms to advance socio-economic rights in Africa' LLD thesis, University of South Africa, 2007 at 208. See also WA Schabas *The customary international law of human rights* (2021) 83-91. In the Asylum Case 1950 ICJ Rep 266, the International Court of Justice (ICJ) recognised the possibility of the existence of a local custom or regional customs amongst a group of states in their relations *inter se*, in addition to a general custom binding on the international community as a whole. Local customs could also exist between two states, as was held to exist between India and Portugal in the Right of Passage Case 1960 ICJ Rep 6. See also *Trendtex Trading Corp v Central Bank of Nigeria* [1977] QB 529 (English CA); [2004] All FWLR (Pt 238) 776.

18 Examples are African Commonwealth States such as Nigeria, South Africa and Ghana.

19 Cap (A9) Laws of the Federation of Nigeria (LFN) 2004.

20 Examples are French Speaking African States such as Benin Republic and Senegal. On monism and dualism, see MN Shaw *International law* 9 ed (2021) 110–144; N Ndeunyema 'The Namibian Constitution, International Law and the Courts: A Critique' (2020) 9 *Global Journal of Comparative Law* at 271–296; M Adigun 'The Process of Giving Domestic Effect to Treaties in Nigeria and the United States' (2019) 6(1) *Journal of Comparative Law in Africa* at 85–114; G von Glahn & JL Taulbee *Law among nations: an introduction to public international law* (2017) 168-191; M Dixon, R McCorquodale & S Williams *Cases and*

Art 1 of the Convention against Torture and other Cruel, Inhuman and Degrading Treatment[21] defines torture in a narrow sense. However, under art 16 the Convention also applies to ill-treatment.[22] The difference between torture and other forms of cruel, inhuman and degrading treatment is in terms of pain and severity.[23]

Apart from the Universal Declaration and the treaties considered above, the right not to be subjected to torture, inhuman and degrading treatment can be found in various constitutions of States in SSA.[24] However, they vary in scope and extent. In some instances, it is categorically stated that no one can be made to submit to a medical or scientific experiment without the person's consent.[25] It is noteworthy that fundamental rights including the right not to be subjected to torture, inhuman or degrading treatment whenever it is violated by an individual as well as the state, can be enforced against that individual. In Nigeria, for example, it can be enforced through Fundamental Rights (Enforcement Procedure) Rules 2009 which does not require the applicant to have a locus. Similarly, in South Africa, sec 33 of its Constitution empowers

materials on international law 6 ed (OUP, 2016) 103–105; A Abass *International law: text, cases, and materials* 2 ed (OUP, 2014) 304–306.

21 Convention against Torture, Cruel, Inhuman and Degrading Treatment or Punishment, Adopted and opened for signature, ratification and accession by General Assembly Resolution 39/46 of 10 December 1984, entry into force 26 June 1987, in accordance with art 27(1). As of September 2021, the convention has 170 state parties.

22 See also Committee against Torture, General Comment 2, Implementation of article 2 by States Parties, U.N. Doc. CAT/C/GC/2/CRP.1/Rev.4 (2007).

23 Redress, *The Convention against Torture and other Cruel, Inhuman and Degrading Treatment or Punishment: a guide to reporting to the Committee against Torture* (2018) 10; Y Arai-Yokoi, 'Grading Scale of Degradation: Identifying the Threshold of Degrading Treatment or Punishment under Article 3 ECHR' (2003) 21(3) *Netherlands Quarterly of Human Rights* at 385–421.

24 For example, see Constitution of the Republic of Angola 2010, art 36; Constitution of the Federal Republic of Nigeria 1999, sec 34; Constitution of South Sudan 2011, art 18; Constitution of the Federal Democratic Republic of Ethiopia 1995, art 18(1); Constitution of Cape Verde 1992, art 26(2); Constitution of Guinea-Bissau 1984, art 37(2); Constitution of Madagascar 2010, art 8; Constitution of Mozambique 2004, art 40(1); Constitution of Eritrea 1997, art 18; Constitution of Namibia 1990, art 8; Constitution of Rwanda 2003, art 15; Constitution of Swaziland 2005, sec 38; Constitution of Uganda 2006, sec 24; The Constitution of the Republic of Ghana 1996, art 15(2); Constitution of the United Republic of Tanzania 1977, art 13(6); Constitution of Botswana 1966, sec 7; Constitution of the Republic of the Gambia 1997, sec 21; Constitution of the Republic of Malawi 1994, sec 19(3); Constitution of the Republic of Sudan 1998, art 20; Constitution of the Republic of South Africa 1996, sec 12; The Constitution of Kenya 2010, art 29(f). See also Constitution of Algeria 1963, art 34; Constitution of Tunisia 2014, art 23.

25 For example, see Constitution of the Republic of Angola 2010, art 36; Constitution of Madagascar 2010, art 8; Constitution of Rwanda 2003, art 15; Constitution of Somalia 2012, art 15(3); Constitution of the Republic of South Africa 1996, sec 12(2)(c).

anyone to file a public interest litigation without the need to have an interest that has suffered. In *Onwo v Oko*,[26] the Nigerian Court of Appeal allowed a fundamental right action filed by an individual against other individuals as opposed to the state. This position contrasts sharply with what obtains in England where human rights action can only be maintained against the government and public officials.[27]

While a person suffering from stroke or his or her family may have a right of action against a genomics researcher with respect to inhuman and degrading treatment, one may be tempted to inquire what defence, if any, is available to the researcher. It can be argued that there is no defence available to the genomics researcher. The reason is that the right not to be subjected to inhuman or degrading treatment permits no derogation.[28] It constitutes a norm of *jus cogens* for which no derogation is permitted.[29] Therefore, what can avail the researcher is if a finding of inhumane or degrading treatment is not made. Once it is made, the researcher is likely to be held liable. Also, the state may be held liable for its failure to put mechanisms in place for the protection of the right.

3 The Right to Privacy

Since biological samples will be collected and banked, the first likely issue of legal purport concerning banking is the right to privacy. This arises from questions which are asked of those who develop strokes or from their family members who are taking care of them. These questions, without a doubt, are very personal. The questions will be personal as they will be directed towards

26 *Onwo v Oko* [1996] 6 NWLR (Pt 456) 584.

27 Human Rights Act 1998, secs 6 & 7.

28 Convention against Torture and other Cruel, Inhuman and Degrading Treatment or Punishment, art 2(2); UN Human Rights Committee, General Comment 20, para 5.

29 UN Human Rights Committee, General Comment 29, para 11. On the norm of *jus cogens*, see Vienna Convention on the Law of Treaties, art 53. See also D Shelton *Jus cogens* (OUP, 2021); U Linderfalk (ed) *Understanding jus cogens in international law and international legal discourse* (Edward Elgar, 2020); T Weatherall *Jus cogens: international law and social contract* (CUP, 2015); R Kolb *Peremptory international law-jus cogens: a general inventory* (2015); E Cannizzaro (ed) *The present and future of jus cogens* (Sapienza Università Editrice, 2015); M den Heijer & H van der Wilt (eds) 'Jus Cogens: Quo Vadis' (2015) 46 *Netherlands Yearbook of International Law* at 3-451; L Yarwood, *State accountability under international law: holding states accountable for a breach of jus cogens norms* (Routledge, 2011); T Tomuschat & J Thouvenin (eds) *The fundamental rules of the international legal order: jus cogens and obligations erga omnes* (Brill, 2006).

probing the medical history of the person in question and those of members of his or her family. Since information obtained is likely to be voluntarily surrendered by those from whom they are obtained, it is unlikely that any privacy right can be violated at the point of extraction. However, this right can be violated if information obtained is misused or not carefully protected and thus leaked to the outside world. Stroke is often viewed with disdain in SSA and those who are suffering from it and their family are stigmatised.[30] Also, if information obtained is not carefully protected and a third person who has access to it makes use of it in a nefarious way, the researcher to whom the information is supplied may be held liable for having violated the right to privacy of those who supplied the information.

Apart from the information obtained from participants, to the extent that genes contain information, and tissues contain genes, the right to privacy may also be implicated. Thus, where tissues are not handled properly and stray into the hand of a third party who may make use of them and extract information from them by way of sequencing, the right to privacy of the participant donor may be violated. Where the tissue is not the one that is carelessly handled but the information already extracted, the human right to privacy may also be implicated as well.

Art 12 of the Universal Declaration stipulates that no one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks. To the extent that the Universal Declaration is customary international law, it can be argued that this provision binds all States including those in SSA. Art 17 of the ICCPR is also similarly worded and ratified by most States in SSA. The Convention on the Rights of the Child,[31] the European Convention on Human Rights[32] and the American Convention on Human Rights[33] also provide for the right to privacy. These treaties are widely ratified. This reinforces the position that the right to privacy is widely accepted in legally binding treaties.[34] However, the African Charter does not explicitly contain a provision on the right to privacy. It may be that the collectivist view of human rights as embedded in the Charter as

30 FS Sarfo and others, 'Stroke-related Stigma among West Africans: Patterns and Predictors' (2017) 375 *Journal of the Neurological Sciences* at 270–274.

31 Art 16.

32 Art 8.

33 Art 11.

34 A Pillai & R Kohli 'A Case for a Customary Right to Privacy of an Individual: A Comparative Study on Indian and other State Practice' (2017) *Oxford University Comparative Law Forum* 3.

opposed to the individualistic Western conception of human rights gave rise to this.[35] Although, the African Charter does not provide for the right to privacy, nonetheless the right to privacy is protected by domestic law in several States in SSA. The implication is that a genomics researcher is required to respect the right, failing which a remedy subsists in the person whose right is violated. Apart from the Universal Declaration and the treaties previously mentioned, nearly all States in SSA have their respective constitutions providing for the right to privacy.[36]

If fundamental right action is filed against a genomics researcher for an infraction of the right to privacy, is there any defence for such a researcher? There may be a defence under what is often termed a derogation clause. This is found in nearly all constitutions of States in SSA.[37] The provisions vary in scope and legislative approach.[38] Sec 45(1) of the Nigerian Constitution 1999 is an example of a derogation clause. It stipulates that nothing in secs 37, 38, 39, 40 and 41 of the Nigerian Constitution shall invalidate any law that is reasonably justifiable in a democratic society in the interest of defence, public safety, public order, public morality or public health. The clause is traditionally meant for the benefit of the state such that if there is the need to deny human rights in deserving situations, the state can so do.

However, it can be argued that if the interest of the state and that of the individual converge, the individual should be able to rely on it. With the Nigerian

35 IS Nwankwo 'Informational Privacy in Nigeria' in AB Makulilo (ed) *African Data Privacy Laws* (2016) at 51.

36 See Constitution of the Republic of Angola 2010, art 32; Constitution of the Federal Republic of Nigeria 1999, sec 34; Constitution of South Sudan 2011, art 22; Constitution of the Federal Democratic Republic of Ethiopia 1995, art 26; Constitution of Cape Verde 1992, art 38; Constitution of Guinea-Bissau 1984, art 44; Constitution of Madagascar 2010, art 13; Constitution of Mozambique 2004, art 41; Constitution of Eritrea 1997, art 18; Constitution of Namibia 1990, art 13; Constitution of Rwanda 2003, art 22; Constitution of the Kingdom of Swaziland 2005, sec 14; Constitution of Uganda 2006, sec 27; The Constitution of the Republic of Ghana 1992, art 18; Constitution of the United Republic of Tanzania 1977, art 16; Constitution of Botswana 1966, sec 3; Constitution of the Republic of the Gambia 1997, sec 23; Constitution of the Republic of Malawi 1994, sec 21; Constitution of Sudan 2019, sec 55; Constitution of Sierra Leone 1991, sec 22; Constitution of the Republic of South Africa 1996, sec 14; The Constitution of Kenya 2010, art 31.

37 For example, see Constitution of the Federal Republic of Nigeria 1999, sec 45; Constitution of the Federal Democratic Republic of Ethiopia 1995, art 93(4); Constitution of Angola 1992, art 52; Constitution of Cape Verde 1992, art 26; Constitution of Guinea-Bissau 1984, art 31; Constitution of Mozambique 2004, art 72; Constitution of Eritrea 1997, art 27(5)(a); Constitution of Namibia 1990, art 24(3); Constitution of Rwanda 2003, art 137; Constitution of the Kingdom of Swaziland 2005, sec 38; Constitution of Uganda 2006, sec 44; The Constitution of the Republic of Ghana 1992, art 31(10); Constitution of the United

example, it can be argued that since the right to privacy is contained in sec 37 of the Nigerian Constitution 1999 against which derogation is permitted under sec 45, the implication is that if there is a law that protects the interest of that researcher on the ground of public health[39] and that law can be said to be reasonably justifiable in a democratic society, then it could be a defence for such a researcher. Two requirements are involved here. The first one is that there must be a law. The second one is that such a law must be reasonably justifiable in a democratic society. While what qualifies as law includes statutes and possibly rules of law created in decided cases, they also include subsidiary legislation such as rules and executive orders.

In *Committee for Commonwealth of Canada v Canada*,[40] a rule made by an airport authority was held to qualify as law by the Canadian Supreme Court. Similarly, in *President of the Republic of South Africa and Another v John Phillip Hugo*,[41] an executive order was held to qualify as law by the Constitutional Court of South Africa. In *Mbanefo v Molokwu*,[42] the Supreme Court of Nigeria held that a rule made by a king banishing a recalcitrant member of his kingdom qualifies as law and is reasonably justifiable in a democratic society. The implication is that ethical rules and regulations made by a body of genomics researchers which protect the researcher may qualify as law and if the court considers it to be reasonably justifiable in a democratic society may constitute a defence.

However, this may create a somewhat absurd situation where there are 'parallel legal systems, under which doctors are judged by doctors' norms, lawyers by lawyers' norms, magicians by magicians' norms'[43] and invariably genomics researchers by genomics researchers' norms. Nonetheless, the fact that such norms are still amenable to the scrutiny of the court through the test of

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Republic of Tanzania 1977, art 31; Constitution of Botswana 1966, sec 16; Constitution of the Republic of the Gambia 1996, sec 35; Constitution of the Republic of Malawi 1994, sec 45; Constitution of the Republic of South Africa 1996, sec 37; The Constitution of Kenya 2010, art 58.

38 See AJ Ali, 'Derogation from Constitutional Rights and its Implication under the African Charter on Human and Peoples' Rights' (2013) 17 *Law, Democracy & Development* at 93–97.

39 On the privacy issues within the context of the relationship between genomics and public health, see BM Knoppers (ed) *Genomics and public health: legal and socio-ethical perspectives* (2007) 149–162.

40 *Committee for Commonwealth of Canada v Canada* (1991) 77 DLR (4th) 385.

41 *President of the Republic of South Africa and Another v John Phillip Hugo* (CCT 11/96) [1997] ZACC 4; 1997 (6) BCLR 708; 1997 (4) SA 1 (18 April 1997).

42 *Mbanefo v Molokwu* [2014] 6 NWLR (Pt 1403) 377.

43 I Brassington, 'On the Relationship between Medical Ethics and the Law' (2018) *Medical Law Review* at 14.

reasonableness within a democratic society may have obviated the somewhat absurd situation.

While the defence available to a genomics researcher under a derogation clause as exemplified in sec 45 of the Nigerian Constitution is somewhat clumsy, provision for the right to freedom of expression may be a veritable defence for the researcher. Art 19 of the Universal Declaration stipulates that everyone has the right to freedom of opinion and expression and that the right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers. Art 19 of the ICCPR is also similarly worded but with the additional provision that information and 'ideas of all kinds' can be imparted orally, in writing or in print, in the form of art, or through any other media of one's choice. However, the African Charter is less pungently worded. While art 9(1) of the Charter provides that every individual shall have the right to receive information, art 9(2) stipulates that every individual shall have the right to express and disseminate his opinion within the law. The phrase 'without interference' is conspicuously missing. Nonetheless, it can be argued that this may not be fatal to the extent that the Universal Declaration and the ICCPR constitute customary international law.

Apart from the Universal Declaration and the ICCPR, various constitutions of the States in SSA have provisions on the right to freedom of expression.[44] Using Nigerian law as an example, sec 39(1) stipulates that 'Every person shall be entitled to freedom of expression, including freedom to hold opinions and to receive and impart ideas and information without interference.' The use of the clause 'impart ideas and information without interference' may avail the genomics researcher in a situation where they release information supplied to them. This cannot be ruled out since genomics research often involves collaborations nationally and internationally. In addition, since the word 'including' is used, the implication is that circumstances for freedom of expression are

44 See, for example, Constitution of the Republic of Angola 2010, art 40; Constitution of the Federal Republic of Nigeria 1999, sec 34; Constitution of the Republic of South Sudan 2011, art 24; Constitution of the Federal Republic of Ethiopia 1995, art 29; Constitution of Cape Verde 1992, art 45; Constitution of Guinea-Bissau 1984, art 51; Constitution of Madagascar 2010, art 10; Constitution of Mozambique 2004, art 48; Constitution of Eritrea 1997, art 19; Constitution of Namibia 1990, art 21; Constitution of Rwanda 2003, art 33; Constitution of the Kingdom of Swaziland 2005, sec 24; Constitution of Uganda 2006, sec 29; The Constitution of the Republic of Ghana 1992, art 21; Constitution of the United Republic of Tanzania 1977, art 18; Constitution of Botswana 1966, sec 12; Constitution of the Republic of the Gambia 1997, sec 25; The Constitution of Kenya 2010, art 33; Constitution of the Republic of Malawi 1994, secs 34–35; Constitution of Sudan 2019, sec 57; Constitution of Sierra Leone, sec 25; Constitution of the Republic of South Africa 1996, sec 16.

not limited to imparting ideas alone. However, while this defence appears to be broad, it may have to be balanced with the right to privacy of the person who supplied the information. In doing this, the principle of proportionality[45] may have to be applied and each case may have to be decided on its merit by the court.

As previously noted, the right to privacy is not explicitly protected in the African Charter. Thus, it can be argued that an individual who supplied information to a genomics researcher and whose right is later violated may not have a right of action under the African Charter. On the other hand, art 27 of the Charter may serve as a defence for a genomics researcher. Art 27 of the Charter stipulates that 'the rights and freedoms of each individual shall be exercised with due regard to the rights of others, collective security, morality and common interest.' The defence of 'common interest' may be invoked by the researcher and it may be argued that the common interest in genomics research should not be made to suffer and that if the grievance of the person who supplied the information is allowed to be remedied, the conduct of genomics research will be made more difficult. For the defence of common interest to avail the researcher, the exercise of due diligence in line with international best practices may have to be considered by the court. Also, each case will be decided on its merit. Therefore, while international best practices will be considered, the peculiarities of local circumstances will be the context.

It may be argued that the reliance on this provision as a defence is predicated on the fact that any person who intends to rely on it to make a claim must have had a right under the Charter. The way the article is couched makes this argument plausible since it stipulates that 'the rights and freedoms of each individual shall be exercised with due regard to the rights of others…' Although the Charter does not protect the right to privacy explicitly, the right may be read into some other rights protected by the Charter. For example, it can be argued that the rights to life and liberty recognised under arts 4 and 6 of the Charter have the right to privacy implicit in them since privacy is essential to securing a full and dignified life. Thus, the implication is that the 'common interest' provision of the Charter can be invoked as a defence.

From another perspective, if one considers art 27 of the Charter to the extent that it constitutes law in each of the States in SSA, it can be argued that the provision constitutes law and that it is reasonably justifiable in a democratic

45 On the principle of proportionality, see G Huscroft, BW Miller & G Webber (eds) *Proportionality and the rule of law: rights, justification, reasoning* (2014) 2; S Tsakyrakis, 'Proportionality: An Assault on Human Rights?' (2009) 7 *International Journal of Constitutional Law* at 468; AS Sweet & J Mathews *Proportionality, balancing and constitutional governance: a comparative and global approach* (2019).

society. Thus, if a person who supplied information to a genomics researcher seeks to file an action by relying on the constitutional provision on the right to privacy, the researcher can rely on the defence of 'common interest' under the Charter as a law reasonably justifiable in a democratic society.

4 The Right to Freedom of Information

The question of whether research results should be returned is one of the most intractable problems in genomics research. This question relates to an instance when a participant dies. Thus, should the outcome of the research which may violate the privacy and the dignity of the deceased participant be released to the family which may need the information where a potential risk to them is involved? It can be argued that a deceased person is no longer human and cannot claim the human right to privacy or dignity. The implication is that the right to freedom of information of the family is the only human right at stake in this instance.

The right to freedom of information is subsumed under the right to freedom of expression. Thus, it is contained in art 19 of the Universal Declaration, art 19 of the ICCPR and art 9 of the African Charter, all of which provide for the right to freedom of expression. To the extent that the Universal Declaration and some rights protected in the ICCPR constitute customary international law, they are binding on all States. In the same vein, various constitutions of States in SSA provide for the right to freedom of expression and in these provisions, the right to freedom of information is also subsumed.[46] While the right to freedom of information is subsumed under the right to freedom of expression under the constitution, however, various States in SSA have sought to give the

46 Constitution of the Republic of Angola 2010, art 40; Constitution of the Federal Republic of Nigeria 1999, sec 34; Constitution of the Republic of South Sudan 2011, art 24; Constitution of the Federal Republic of Ethiopia 1995, art 29; Constitution of Cape Verde 1992, art 45; Constitution of Guinea-Bissau 1984, art 51; Constitution of Madagascar 2010, art 10; Constitution of Mozambique 2004, art 48; Constitution of Eritrea 1997, art 19; Constitution of Namibia 1990, art 21; Constitution of Rwanda 2003, art 33; Constitution of the Kingdom of Kingdom of Swaziland 2005, sec 24; Constitution of Uganda 2006, sec 29; The Constitution of the Republic of Ghana 1992, art 21; Constitution of the United Republic of Tanzania 1977, art 18; Constitution of Botswana 1966, sec 12; Constitution of the Republic of the Gambia 1997, sec 25; The Constitution of Kenya 2010, art 33; Constitution of the Republic of Malawi 1994, secs 34–35; Constitution of Sudan 2019, sec 57; Constitution of Sierra Leone, sec 25; Constitution of the Republic of South Africa 1996, sec 16.

right its distinct expression through statutory enactment.[47] However, the right recognised in the statute appears somewhat narrower than what it is under the right to freedom of expression. Under the statute, it tends to apply to public officials whereas, under the constitution, it applies to all persons.

While it appears that the right to freedom of information of the family is the only human right at stake, however, in WHO's *Genetic Databases: Assessing the Benefits and the Impact on Human and Patients' Rights* 2003, it is stipulated that the death of a participant who supplied genetic information does not represent the end of ethical responsibilities owed in respect of the information. This tends to imply that the dead have rights even though it may not necessarily be human rights. However, in the Kenyan case of *Joan Akoth Ajuang and Another v Chief Ukwala Location*,[48] the court held that the dead have human rights. What was in issue was the hurried manner in which the deceased suspected of having Covid-19 was buried by public officials without coffin, without the presence of the deceased's family and in the night in contravention of the deceased's custom and religious beliefs, to prevent the spread of Covid-19. The court held that the dead have rights and that the defendants violated the deceased's right to human dignity. However, on the application that the deceased's body be exhumed, an autopsy performed on it and buried again in a more dignifying manner, the court invoked precautionary principle and refused the application invariably stating that the public health risks involved outweighed the deceased's right to dignity. Since the dead have rights, the implication is that the right of the family to freedom of information may have to be balanced with the right of the deceased to dignity and privacy.

In balancing the right of the deceased to privacy with the right of the family to freedom of information, what the deceased would have done if he/she were alive may have to be inquired into. At this point, the UNESCO *Universal Declaration on the Genome and Human Rights* (1997) becomes apposite. The

47 For example, see Freedom of Information Law 2002 (Angola); Freedom of Mass Media and Access to Information 2008 (Ethiopia); Right to Information Act 2019 (Ghana); Access to Information Act 2016 (Kenya); Freedom of Information Act 2010 (Liberia); Access to Information Act 2017 (Malawi); Access to Information Act 2014 (Mozambique); Law on Access to Administrative Documents 2011 (Niger); Freedom of Information Act 2011 (Nigeria); Access to Information Law 2013 (Rwanda); Access to Information Act 2018 (Seychelles); Access to Information Act 2013 (Sierra Leone); The Promotion of Access to Information Act 2000 (South Africa); Right to Access to Information Act 2013 (South Sudan); Freedom of Information Law 2015 (Sudan); Access to Information Act 2016 (Tanzania); Access to Information Act 2005 (Uganda); Freedom of Information Act 2020 (Zimbabwe).

48 *Joan Akoth Ajuang and Another v Chief Ukwala Location* Constitutional Petition No. 1 of 2020 [2020] eKLR.

Declaration provides for instances where a research participant cannot give consent. This applies to minors and incapacitated adults. It requires the consent to be obtained in a manner prescribed by law and in accordance with the best interest of the person.[49] If this is adapted to a deceased participant, the implication is that since the deceased is incapacitated by death, whether to return the outcome of the research and how to return it must be in the best interest of the deceased. In practical terms, determining this is likely to be herculean.

5 The Right to Freedom from Discrimination

The Universal Declaration stipulates in art 7 that all are equal before the law and are entitled without any discrimination to equal protection of the law. It is further stipulated that all are entitled to equal protection against any discrimination in violation of the Declaration and any incitement to such discrimination. This constitutes the right to freedom from discrimination. Art 26 of the ICCPR stipulates that all persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

Art 2 of the African Charter is worded similarly to that of art 26 of the ICCPR. However, it does not prohibit discrimination *per se*. What it does is that it guarantees the rights recognised under the Charter to every individual without distinction of any kind such as race, ethnic group, colour, sex, language, religion, political or any other opinion, national and social origin, fortune, birth or other status. However, since the Charter guarantees the right to life under art 4 and the right to human dignity under art 5, it can be argued that since discrimination impacts negatively on these rights, it is indirectly prohibited under art 2. While art 2 can be argued not to have directly prohibited discrimination, art 18 stipulates that the state shall ensure the elimination of every discrimination against women and also ensure the protection of the rights of women and children as stipulated in international declarations and conventions. The purport of art 18 is that it places a duty on the state which invariably implies a right for the individual against the state. The individuals in this instance are women and children.

49 Art 5(b).

Apart from these treaties, various constitutions of States in SSA have provisions on the right to freedom from discrimination. They are couched in different forms and vary in scope.[50] The issue now is: how can the right to freedom from discrimination be implicated in genomics research and bio-banking? At this point, the case of *Havasupai Tribe v The Arizona Board of Regents* is most illustrative.[51] In 2005, the members of the Native American Havasupai Tribe sued Arizona State University for using their tissue samples for a purpose different from that for which they were donated. The tissues were donated for diabetes research whereas they were used to investigate schizophrenia, inbreeding, alcoholism and the origin and migration of the tribe. This was found unacceptable to members of the group. The case was eventually negotiated out of court with payment made to them. The samples were also withdrawn and returned. Within the context of the right to freedom from discrimination, it can be argued that schizophrenia is a form of mental disorder and that mental disorders are stigmatising in Africa. Therefore, publications linking them to schizophrenia might be considered discriminatory, not because it is incorrect, but because of its stigmatising effect. However, it can be questioned if other people are not supposed to know about it to guide them in their choice of spouse. In this respect, the right to freedom from discrimination may have to be balanced with the right to information. Since the effect of other people getting to know may have the consequence of discrimination against them, the right to freedom from discrimination may be sustained at the expense of the right to information.

50 Constitution of the Republic of Angola 2010, arts 21 & 80; Constitution of the Federal Republic of Nigeria 1999, sec 42; Constitution of the Republic of South Sudan 2011, art 14; Constitution of the Federal Republic of Ethiopia 1995, art 25; Constitution of Cape Verde 1992, arts 81, 85 & 87; Constitution of Guinea-Bissau 1984, arts 24 & 25; Constitution of Madagascar 2010, art 6; Constitution of Mozambique 2004, art 44; Constitution of Eritrea 1997, art 14; Constitution of Namibia 1990, art 10; Constitution of Rwanda 2003, art 11; Constitution of the Kingdom of Kingdom of Swaziland 2005, sec 20; Constitution of Uganda 2006, sec 21; The Constitution of the Republic of Ghana 1992, art 17; Constitution of the United Republic of Tanzania 1977, arts 12 & 13; Constitution of Botswana 1966, sec 15; Constitution of the Republic of the Gambia 1997, sec 33; The Constitution of Kenya 2010, art 40; Constitution of the Republic of Malawi 1994, sec 20; Constitution of Sudan 2019, secs 43 & 48; Constitution of Sierra Leone, sec 27; Constitution of the Republic of South Africa 1996, sec 9.

51 See RL Sterling 'Genetic Research among the Havasupai: A Cautionary Tale' (2011) 13(2) A*merican Medical Association Journal of Ethics* at 113–117.

6 The Right to Property

The Universal Declaration stipulates in art 17 that 'everyone has the right to own property alone as well as in association with others' and that 'no one shall be arbitrarily deprived of his property'. It is noteworthy that the ICCPR and the International Covenant on Economic, Social and Cultural Rights (ICESCR) do not contain a provision on the right to own property. However, art 14 of the African Charter provides that the right to property shall be guaranteed and that it may only be encroached upon in the interest of public need or in the general interest of the community and in accordance with the provisions of appropriate laws. Various States in SSA have provisions on the right to property. They are expressed in different forms and vary in scope.[52]

The right to own property appears to be implicated in genomics research and biobanking when one considers the issue of whether ownership rights should exist in body parts. With respect to this issue, three cases will be examined here. In *Moore v Regents of the University of California*,[53] the plaintiff filed an action against his physician and other defendants contending that his physician did not disclose to him that there was existing medical research that was lucrative and that at the time he consented to the extraction of his cell, it was not disclosed to him. The trial court sustained the defendants' objection that the plaintiff's case did not disclose a cause of action. The Court of Appeal reversed the decision of the trial court. On appeal to the Supreme Court of California, the Court held that the plaintiff's case disclosed a cause of action but that a case of conversion was not made. Since only property could be converted, the implication is that property right does not subsist in the human biological samples. In *Washington University v Catalona*,[54] the plaintiff filed

52 Constitution of the Republic of Angola 2010, art 37; Constitution of the Federal Republic of Nigeria 1999, secs 43 & 44; Constitution of the Republic of South Sudan 2011, art 28; Constitution of the Federal Republic of Ethiopia 1995, arts 35(7) & 40; Constitution of Cape Verde 1992, art 66; Constitution of Guinea-Bissau 1984, art 12; Constitution of Madagascar 2010, art 34; Constitution of Mozambique 2004, art 82; Constitution of Eritrea 1997, art 23; Constitution of Namibia 1990, art 16; Constitution of Rwanda 2003, art 29; Constitution of the Kingdom of Kingdom of Swaziland 2005, sec 19; Constitution of Uganda 2006, sec 26; The Constitution of the Republic of Ghana 1992, arts 18 & 20; Constitution of the United Republic of Tanzania 1977, art 24; Constitution of Botswana 1966, sec 8; Constitution of the Republic of the Gambia 1997, s 22; The Constitution of Kenya 2010, art 33; Constitution of the Republic of Malawi 1994, sec 28; Constitution of Sudan 2019, sec 61; Constitution of Sierra Leone, sec 21; Constitution of the Republic of South Africa 1996, sec 25.

an action, seeking for a declaratory order to the effect that it had ownership right over biological samples in its biorepository. The District Court held that it had ownership right over those biological samples and that once the donors had submitted them to the University, they had no property right in them and could not control how they would be transferred. On appeal, the decision of the District Court was affirmed by the United States Court of Appeal, 8th Circuit.

However, in the United Kingdom case of *Yearworth and Others v North Bristol NHS Trust*[55] the decision is different. In this case, the claimants were diagnosed with cancer and the treatment through chemotherapy could render them infertile. The defendant offered to store their sperm for future use. The storage system later failed which made the samples thaw and be irreversibly damaged. The claimants filed an action claiming personal injury and injury to property. While the personal injury was rejected, the court sustained that of property.

While the traditional common law position is that there is no property right in corpses,[56] some exceptions have emerged over the years that some property rights could subsist where skill has been expended on it[57] and that products from the human body are capable of being stolen.[58] In all these cases, the property rights relate to a third party who has added something of value to take the body parts from what is ordinary to something of value. With respect to self-ownership, this had never been addressed until this case was decided. A case that is closely related is *Hecht v Superior Court of LA County*[59] but it was not directly declared as it was done in *Yearworth*. In this case, a man deposited his sperm in a bank for his partner's use and stated it in his will. The California Court of Appeal distinguished the case from *Moore* and held that the man had a proprietary interest in his genetic material (sperm) and could bequeath it

53 51 Cal.3d 120 Supreme Court of California July 9, 1990. See also M Adigun and others 'Symbolic Legislation and the Regulation of Stroke Biobanking and Genomics Research in Sub-Saharan Africa' (2021) 9(3) *The Theory and Practice of Legislation* at 411–413.

54 Nos. 06-2286, 06-2301. Decided June 20, 2007.

55 [2009] 2 All ER 986 (CA).

56 *Haynes* Case (1614) 77 ER 1389; *R v Lynn* (1788) 2 TR 394; *R v Sharpe* (1857) 169 ER 959; *Foster v Dodd* (1867) LR 3 QB 67; *R v Price* (1884) 12 QBD 247; *Williams v Williams* [1881–1885] All ER 840. See also Sir Edward Coke *Institutes of the Laws of England* (1641) 3–203; PE Jackson *The law of cadavers and of burial and burial places* (1950).

57 *Doodeward v Spence* (1908) 6 CLR 408 (Australian High Court); *R v Kelly* [1998] 3 All ER 741 (CA); *AB v Leeds Teaching Hospital NHS Trust* [2005] 2 WLR 358 (QB).

58 *R v Welsh* (urine sample) [1974] RTR 478 (CA); *R v Rothery* (blood sample) [1976] RTR 550 (CA).

59 (1993) 20 Cal.R. 2d 275 (Cal CA).

to his partner under probate law. This is an indirect way of recognising it as a property.

It is worth noting that none of these cases was decided from the perspective of human rights. Nonetheless, the right to own property as a human right is implicated and the courts tend to balance the right against public need and the general interest of the community. In *Moore* and *Catalona*, the decisions tend to suggest that public need and the general interest of the community in genomics research outweigh the human right to property in biological samples. On the other hand, the human right to property appears to have been given greater weight than public need and general community interest in *Yearworth*.

7 The Right to Self-determination

A part of what is envisaged in genomics research on stroke is to develop technical know-how on how stroke can be prevented or cured. With respect to knowledge obtained from traditional sources, the question of intellectual property arising from such knowledge becomes apposite.[60] For example, the neem tree has been traditionally used in India as a pesticide and toothpaste. The pesticidal ingredient was extracted by the traditional technique. In spite of this, the US Patent and Trademark Office granted a patent to WR Grace & Co which also produced a pesticide from neem tree although through a scientific means. In contrast, a similar patent granted to WR Grace & Co by the European Patent Office was revoked in 2000 because of its prior use in India.[61]

Some medicinal plants and knowledge obtained from traditional sources have served as the foundation for drugs produced by pharmaceutical companies in States of the Global North. These drugs have yielded a lot of incomes to these companies and nothing is paid to traditional knowledge holders.[62] For example, the San people of South Africa through their traditional knowledge discovered that hoodia cactus traditionally known as Xhoba could be used to suppress hunger and thirst. They made use of it during a long hunting expedition. In 1997, the South African government laboratory derived an appetite suppressant known as P57 from hoodia cactus and without the knowledge of the San people patented it to Phytopharm PLC, a small British firm that also sub-licensed it to Pfizer. Although a royalty agreement was later reached with

60 See EC kamau & G Winter (eds) *Genetic resources, Traditional Knowledge and the Law: Solutions for Access and Benefit Sharing* (Routledge, 2009).

61 RN Nwabueze, *Biotechnology and the challenge of property* (2007) 243–244.

62 *Ibid*, 233.

the San people, this illustrates the issue in terms of exploitation involved.[63] The above developments tend to implicate the right to self-determination under the African Charter.

Art 20 of the African Charter stipulates that 'All peoples shall have the right to existence. They shall have the unquestionable and inalienable right to self-determination. They shall…pursue their economic and social development according to the policy they have freely chosen.' Art 21(1) provides that 'All peoples shall freely dispose of their wealth and natural resources.' Art 21(3) provides that 'The free disposal of wealth and natural resources shall be exercised without prejudice to the obligation of promoting international economic cooperation based on mutual respect, equitable exchange and the principles of international law.' Art 21(4) stipulates that 'State Parties to the present Charter shall individually and collectively exercise the right to free disposal of their wealth and natural resources with a view to strengthening African Unity and solidarity.' Art 21(5) states that 'State Parties to the present Charter shall undertake to eliminate all forms of foreign exploitation particularly that practised by international monopolies so as to enable their peoples to fully benefit from the advantages derived from their national resources.' Similarly, art 22(1) of the African Charter stipulates that 'All peoples shall have the right to their economic, social and cultural development with due regard to their freedom and identity and in the equal enjoyment of the common heritage of mankind.' Art 22(2) provides that 'States shall have the duty, individually or collectively, to ensure the exercise of the right to development.' Art 24 provides that 'All peoples shall have the right to a general satisfactory environment favourable to their development.' With these provisions, the actions of corporate interests and African states in exploiting the people of Africa may be difficult to sustain legally from a human rights perspective. This argument appears reinforced by the fact that the interest of the people is recognised distinctly from that of the state.[64]

However, it can be questioned if the provisions can be enforced in practical terms since African states are implicated and the justice process in their domain may not be able to hold them and corporate interests accountable. While this reservation is not without foundation, nonetheless the possibility of holding African states and complicit corporate interest accountable is not completely foreclosed. For example, the African Charter can be enforced by the ECOWAS Court. Although, it can be argued that the judgments of the Court

63 On San Hoodia issue, see R Wynberg, D Schroeder & R Chennells (eds) *Indigenous people, consent and benefit sharing: lessons from the San-Hoodia case* (Springer, 2009).

64 D Raič, *Statehood and the law of self-determination* (Brill, 2002) 247–248.

are not being enforced by the Member States, nonetheless the obstacle is not insurmountable.[65] It is worth noting that the rule of exhaustion of local remedies does not apply to ECOWAS Court.[66] The implication is that individuals and groups can have recourse to the court directly and bypass the domestic legal system.[67] Similarly, it is possible for African states to assume universal jurisdiction when the right to self-determination is implicated. In this respect, where the right is violated in one state, it can be remedied in any other state in Africa. In this respect, where the judicial system in an African state is weak, it can be compensated for by another. This will definitely involve having a treaty arrangement to achieve. But it is achievable. In addition, sub-regional courts like the ECOWAS Court, East African Court of Justice and the Southern African Development Community (SADC) Tribunal can be granted universal jurisdiction such that a violation of the right to self-determination in one region can be redressed in another. Further, the African Court of Justice and Human and Peoples' Rights can also be imbued with universal jurisdiction.[68]

65 See M Adigun, 'Enforcing the ECOWAS Judgments on Human Rights through the Fundamental Rights Enforcement Procedure in Nigeria' (2018) 8 *International Journal of Procedural Law* at 100–120; M Adigun, 'Enforcing ECOWAS Judgments in Nigeria through the Common Law Rule on the Enforcement of Foreign Judgments in Nigeria' (2019) 15(1) *Journal of Private International Law* at 130–161.

66 *Mme Hadijatou Mani Koraou v The Republic of Niger* ECW/CCJ/JUD/06/08. Read in open court to the public on 27th October 2008.

67 While the Supplementary Protocol does not recognize the rule of exhaustion of local remedies, it however recognises 'exclusion of cumulative international procedures.' According to Article 10(d)(ii) of the Supplementary Protocol, access to ECOWAS Court is open to '(b) individuals on application for relief for violation of their human rights; the submission of application for which shall…(i) not be anonymous; nor (ii) be made whilst the same matter has been instituted before another international court for adjudication.' This rule is provided for in all international investigation or settlement mechanisms for the purpose of avoiding the same case being brought before several international bodies. See art 35.2(b) of the European Convention on Human Rights, art 56.7 of the African Charter on Human and Peoples' Rights, art 46(c) of the American Convention on Human Rights, art. 5.2(a) of the first Optional Protocol to the International Covenant on Civil and Political Rights.

68 On these possibilities within the context of climate change litigation, see PK Oniemola 'A Proposal for Transnational Litigation Against Climate Change Violations in Africa' (2021) 38(2) *Wisconsin International Law Journal* at 324–328.

8 The Right to Health

The human right to health is recognised in various international instruments.[69] Art 25(1) of the Universal Declaration stipulates that 'Everyone has the right to a standard of living adequate for the health of himself and of his family, including food, clothing, housing, and medical care and necessary social services.' Art 2(1) of the ICESCR stipulates that 'State Parties to the present Covenant recognize the right of everyone to the enjoyment of highest attainable standard of physical and mental health.' This provision appears broader in scope than that of the Universal Declaration. Similarly, the right to health is recognised in article 5(e)(iv) of the International Convention on the Elimination of All Forms of Racial Discrimination 1965, articles 11(1)(f) and 12 of the Convention on the Elimination of All Forms of Discrimination against Women 1979 and article 24 of the Convention on the Rights of the Child 1989. Art 16(1) of the African Charter also recognises that 'Every individual shall have the right to enjoy the best attainable state of physical and mental health' while art 16(2) stipulates that 'State Parties shall take necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick.' This provision is identical with that of the ICESCR and could be said to be broad as well. However, art 12 of the ICESCR appears to be addressed to the states as duty bearers whereas art 16(1) of the African Charter appears to be addressed to individuals as right holders. Nonetheless, when art 16(1) is read with art 16(2), it can be argued that art 16 is addressed to both duty bearers and right holders.[70] It is worth mentioning that art 14 of the Protocol to the African Charter on the Rights of Women contains rights that are much more detailed in content.

In Nigeria, the African Charter, as previously noted, has been enacted into domestic law. Similarly, the right also applies to children in Nigeria since the Convention on the Rights of the Child has been enacted into domestic law.[71] Apart from these international instruments, various States in SSA have the

69 See O Oluduro & E Durojaye 'The Normative Framework on the Right to Health under International Human Rights Law' in E Durojaye (ed) *Litigating the right to health in Africa: challenges and prospects* (Routledge, 2016) at 13–41.

70 E Durojaye 'The Approaches of the African Commission to the Right to Health under the African Charter' (2013) 17 *Law, Democracy & Development* at 397.

71 Child Rights Act, Cap C50 Laws of the Federation of Nigeria (LFN) 2004, sec 13(1). On the implementation of the Convention on the Rights of the Child in Nigeria, see M Adigun 'The Implementation of the Convention on the Rights of the Child in Nigeria' [2019] Issue 3 *Public Law* at 476.

right to health in their respective constitutions.[72] This right is expressed in different forms and varies in scope.[73]

The right to health is not the right to be healthy since a person's lifestyle can make or mar the person's health.[74] The right is also not to guarantee the state of complete physical, mental and social well-being which is the definition of health in the preamble to the Constitution of the World Health Organisation (WHO).[75] However, the right is certainly broader than providing health care and its realisation is dependent on other determinants of health such as adequate supply of safe and potable water, food, nutrition and housing, healthy environment and access to health-related information.[76] Thus, the right to health includes availability, accessibility, and acceptability of health facilities, goods and services[77] without discrimination.[78] Acceptability implies that 'All health facilities, goods and services must be respectful of medical ethics and

72 As of 2006, these countries were about 39. See C Heyns and W Kaguongo 'Constitutional Human Rights Law in Africa' (2006) 22 *South African Journal on Human Rights* at 673; and GA Mosissa 'Ensuring the Realization of the Right to Health Through the African Union (AU) System: A Review of its Normative, Policy and Institutional Frameworks' in B Toebes and others (eds) *The right to health: a multi-country study of law, policy and practice* (2014) at 57.

73 See Constitution of the Republic of Angola 2010, arts 77 & 80(2); Constitution of the Republic of South Sudan 2011, arts 17(1) & 31; Constitution of Cape Verde 1992, art 68; Constitution of Guinea-Bissau 1984, art 15; Constitution of Madagascar 2010, art 19; Constitution of Mozambique 2004, arts 85, 89 & 116; Constitution of Namibia 1990, art 15; Constitution of Rwanda 2003, art 14; Constitution of the Kingdom of Swaziland 2005, sec 29(1); Constitution of Uganda 2006, sec 34(4); The Constitution of the Republic of Ghana 1992, art 28(2); Constitution of the Republic of the Gambia 1997, secs 29(2) & 31(2); The Constitution of Kenya 2010, art 43; Constitution of the Republic of Malawi 1994, secs 13 & 23(5); Constitution of Sudan 2019, sec 65; Constitution of the Republic of South Africa 1996, secs 27 & 28.

74 CESCR General Comment 14: The Right to the Highest Attainable Standard of Health (Art 12), Adopted at the Twenty-second Session of the Committee on Economic, Social and Cultural Rights, on 11 August 2000 (Contained in Document E/C.12/2000/4), paras 8–9.

75 CESCR General Comment 14, para 4.

76 CESCR General Comment, para 11; *Sudan Human Rights Organization and Another v Sudan* (2009) AHRLR 153 (ACHPR 2009), paras 205, 212, 216 & 223.

77 CESCR General Comment, para 12; Principles and Guidelines on the Implementation of Economic, Social and Cultural Rights in the African Charter on Human and Peoples' Rights (African Commission Principles and Guidelines), adopted in 2010 and formally launched in 2011, para 78; *Free Legal Assistance Group and others v Zambia* (2000) AHRLR 74 (ACHPR 1995).

78 CESCR General Comment, para 18–26; *Purohit and others v The Gambia* (2003) AHRLR 96 (ACHPR 2003); *Festus Odafe and another v Attorney General of the Federation and another* (2004) AHRLR 205 (NgHC 2004).

culturally appropriate', medical treatment must be consensual and that torture is prohibited.[79]

Within the context of stroke biobanking and genomics research, it can be argued that where the genomics researcher fails to inform the family of the deceased participant, the right to health of the members of that family may be implicated. A situation is where the research conducted on the deceased participant's biological sample indicates that the family of the participant may be prone to certain diseases such as cancer. In this respect, the right to health and the right to information appear conflated. Of course, the right to privacy of the deceased participant may be in conflict with the right to health of the family. Similarly, where the government's policy on stroke biobanking and genomics research is discriminatory of, say people living with disabilities, then the right to health of these people can be said to have been violated.[80]

9 Conclusion

This article examines the legal implications of stroke biobanking and genomics research in Sub-Saharan Africa from a human rights perspective. The article argues that the right to dignity of the human person, the right to privacy, the right to freedom of information, the right to freedom from discrimination, the right to own property, the right to self-determination and the right to health may be implicated. With respect to the right to dignity of the human person, the treatment that a genomics researcher gives to a participant in the course of conducting the research may violate the participant's right to dignity and the genomics researcher does not appear to have any defence in law. As regards the right to privacy, a genomics researcher may be found to have violated the participant's right where the information the participant supplied is not properly kept, where it is released to a third party or misused, or where the tissue in the custody of the genomics researcher falls into the hand of a third party. In this instance, the genomics researcher may find a defence under a derogation clause or the right to freedom of information. The right to freedom of information may be implicated when research results are to be returned to the family of a deceased participant and the results have consequences for them. The right to freedom from discrimination is implicated when research results have discriminatory consequences for participant donors while the right to own property is implicated

79 CESCR General Comment 14, paras 3, 8 & 12(c).

80 See *Minister of Health and Others v Treatment Action Campaign and Others* 2000 11 BCLR 1169 (CC).

when property rights are claimed on biological samples. As regards the right to self-determination, governments and corporate entities that collude to sidestep the interest of the people may find their actions contrary to the provisions of the right to self-determination. In addition, the right to health may be implicated where government's policy on biobanking is discriminatory. In conclusion, the court may have to be involved in balancing one right against the other which may prove somewhat herculean depending on the circumstances of each case.

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