

1. Introduction

NEWS | AFRICA

Major U.K. genetics lab accused of misusing African DNA

Sanger Institute's aborted effort to develop gene chip could set back research in Africa

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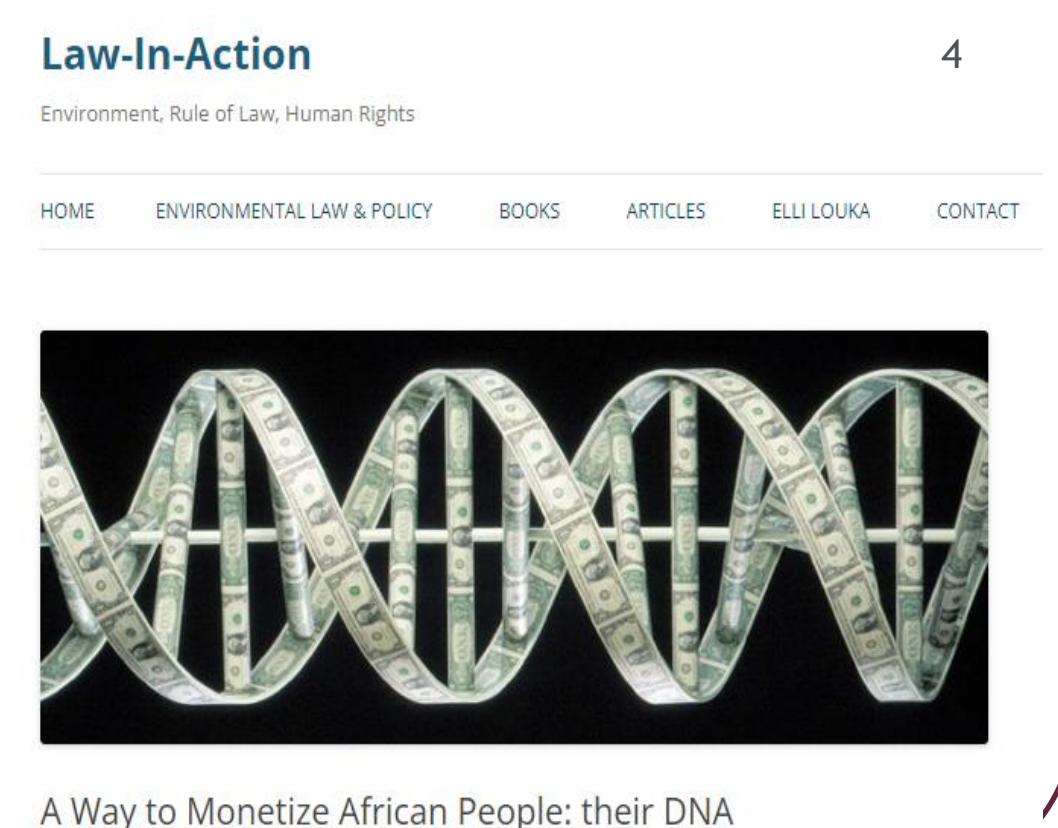
Stellenbosch University (SU) received unfortunate global attention when it became apparent through a whistleblower that human tissue collected from an indigenous population for research purposes only, was used for commercialisation purposes by an external organization (Sanger), during an international collaboration¹.

2. Initial evaluation

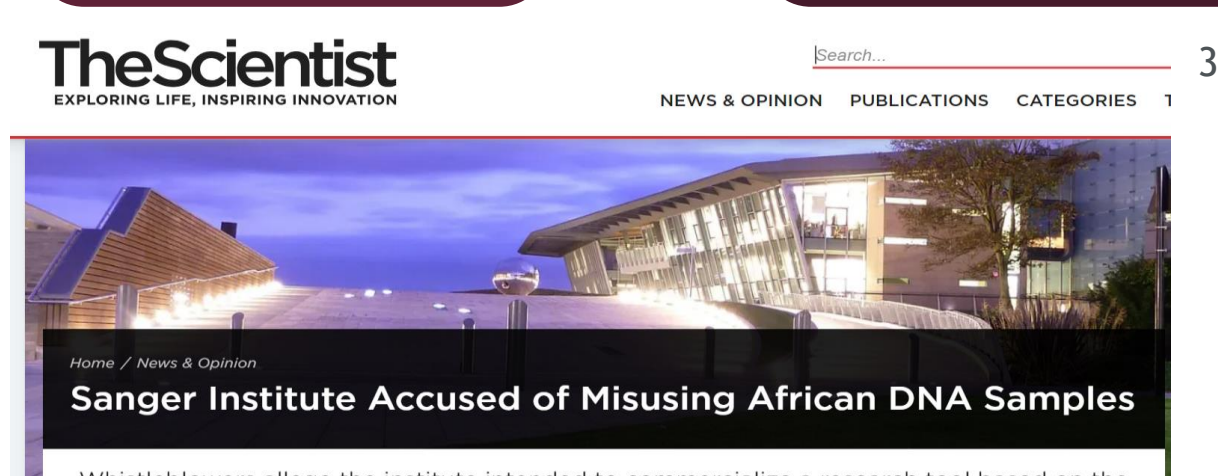
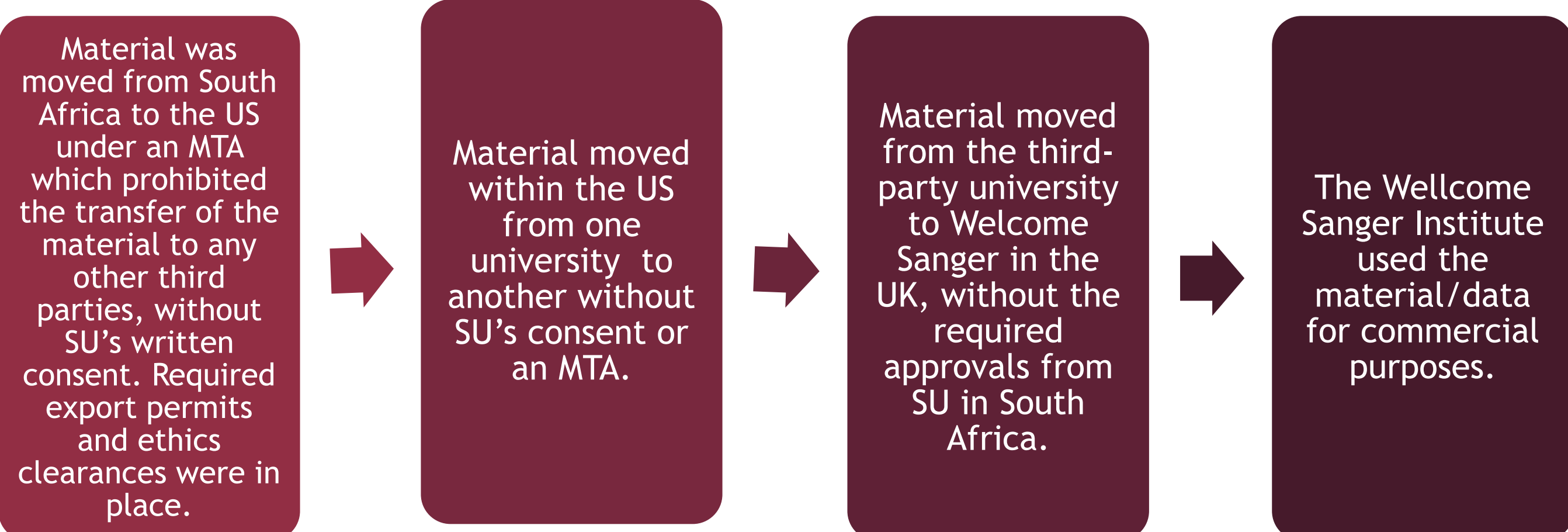
- Legal stance – violation of rights, halt further commercialisation.
- Research Integrity – is there a case of misconduct?
- Ethics: Social justice – what about the indigenous community?
- Scope of Informed consent from the participants: research, commercialisation?
- Movement of material and data by collaborators to the implicated external party – How did this happen?
- What has gone wrong and where?
- Contracts governing the transfer of material, collaboration and agreed jurisdiction
- Roles and responsibilities of all involved
- How to approach the collaborators who were involved in the movement of material?

3. Subsequent considerations

- Patient consent was limited to research purposes only – key to this matter
- Movement of material from South Africa to the US to the UK
- Difference in Human Tissue Act – USA law doesn't regard extracted DNA as human tissue, whereas SA law does. Jurisdiction is SA as agreed in contracts.
- SU, as custodians of material and data, handed over that role to a collaborator – lost control
- Appropriate actions against collaborator
- Appropriate legal actions against Sanger
- Equitable international partnerships in research



4. What went wrong?



5. And why?

- Ignorance/negligence by the US partner in ensuring that the terms of the MTA were upheld when a researcher leaves – poor management and lack of understanding of legal application of Human Tissue Act & transfer of genetic material between different countries.
- The Wellcome Sanger Institute did not conduct thorough due diligence prior to commercialisation.
- Poor operational control in the lab.
- Stellenbosch University was only approached by Sanger to discuss benefit-sharing after whistle-blowing.
- As the original patient consent was not obtained for any commercial purposes, SU could not enter into a benefit-sharing agreement and instead requested that all commercial actions be terminated and all material be returned.



6. Outcomes & Lessons learned

Outcomes

- SU reclaimed custodianship of material and data and requested the return of DNA samples.^{5,6}
- SU initiated transparent communication with the indigenous community.

Lessons learned

- Value of human genomic data
- Governance in the Operational sphere – tracking of tissue/DNA
- Differences in legislation – especially with regards to DNA – highlight to collaborators
- Emphasis of importance of informed consent especially related to research vs commercialisation
- Emphasis to collaborators to honour the Code of Conduct of Indigenous peoples⁷ – equitable partnership



7. References:

1. <https://www.science.org/content/article/major-uk-genetics-lab-accused-misusing-african-dna>
2. https://www.timeslive.co.za/news/south-africa/2019-10-16-stellenbosch-university-demands-return-of-dna-samples-but-uk-lab-hits-back/#google_vignette
3. <https://www.the-scientist.com/sanger-institute-accused-of-misusing-african-dna-samples-66573>
4. Anonymous, "A Way to Monetize African People: their DNATitle," *Law-In-Action: Environment, Rule of Law, Human Rights*, Nov. 2019.
5. <https://www.researchprofessionalnews.com/rr-news-africa-partnerships-2019-10-dna-samples-being-returned-to-africa-after-consent-row/>
6. R. Blakely, "Genetics lab told to hand back African tribes' DNA," *Times London*, London, pp. 1-3, Oct. 14, 2019.
7. South Africa San Institute, "South African San Institute 2017," 2017.