

## A107 Bakeng Se Afrika and the Ethics of Digital Repositories of Human Remains

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**Learning Overview:** After attending this presentation, attendees will have gained knowledge on the European co-funded project, *Bakeng se Afrika*— a digital skeletal repository of South African individuals housed in South Africa. This presentation will explore the gaps in the ethics surrounding data sharing and ownership of digital copies of a human skeleton.

**Impact on the Forensic Science Community:** This presentation will impact the forensic science community by contributing to knowledge on current issues pertaining to the sharing of digital copies of a human skeleton.

The purpose of this presentation is to discuss whole-body consent and ownership of digital skeletal data in South Africa and its impact on dissemination of digital skeletal repositories. In South Africa, the use of human biological material and associated personal information for research/teaching is addressed in the National Health Act 61, 2003, Protection of Personal Information Act (POPIA) 4 2013, and material transfer agreements between institutions.<sup>1-3</sup> Whole body donations to medical schools are given under "broad consent."<sup>1</sup> Broad consent means all soft and hard tissues of that person can be used for any current and future research. Medical schools, as Higher Education Institutions, claim ownership of the human material and can grant access to it based on approval from institutional ethics review boards. The provenance of whole-body donations is from two sources: willful donated and unclaimed persons. If a person dies in a government hospital and is not claimed within 30 days of their death, the Director General donates their body to the nearest medical school. While an unclaimed body is legally donated to a medical school in South Africa, anatomists are currently debating the ethics regarding using the physical remains of unclaimed persons for research and teaching, despite upholding their anonymity.

Methods for conducting research/teaching have expanded since the creation of the current legislation for the legal and ethical use of human remains. Although human skeletal repositories are composed of donated individuals (either via themselves, their next of kin, or the government), the advancement of technology has given rise to gray areas in the associated ethics and the meaning of "consent," particularly with digital images of human bone. The digital images of a human skeleton are not legally ascribed as *symbolizing* the person, so the current ethics/issues guidelines do not necessarily apply, leaving an opening for amendment but also possible abuse. The gray areas of legislation in South Africa provide the consortium an opportunity to create ethical guidelines for the treatment of digital imaging within a diverse socio-cultural and socio-political landscape. Some areas for investigation include issues of consent, personification of "life" in bone, and ownership/Intellectual Property (IP) of 3D reconstructions and prints of a skeleton.

Digital human skeletal repositories are increasing globally. With digital imaging, researchers can easily and cost effectively obtain and collaborate on projects involving human skeletons. An example of such a project is *Bakeng se Afrika*. *Bakeng se Afrika* ("for Africa") is an Erasmus+ European Union-funded capacity building project in higher education between Europe and South Africa, with the purpose of developing a digital data repository of human skeletal remains, both living and deceased, of South Africans for research and education. The research consortium involves three South African Higher Education Institutions (HEIs), namely the University of Pretoria, Stellenbosch University and Sefako Magatho University, and the Nuclear Energy Corporation of South Africa (NECSA), along with four European HEI's, the University of Bordeaux, Centre National de la Recherche Scientifique (CNRS), University of Coimbra, and the Catholic University of Leuven.

Advancements in digital imaging technology provide an opportunity for the global application of biological anthropology as a discipline. Data sharing is aligned with building capacity in research/education in biological anthropology in developing countries, attracting high-quality and diverse postgraduate students, improving success in international research grants, validating research methodology, and applying outcomes to both medicolegal and health-related fields. Yet who stands to benefit from this advancement in data acquisition and research outcomes—the donors, the researchers, or the society in which the data are contextualized?

## Reference(s):

- <sup>1.</sup> National Health Act (63), 2003. Republic of South Africa.
- <sup>2.</sup> Protection of Personal Information Act (4), 2013. Republic of South Africa.
- <sup>3.</sup> Thaldar D.W., Botes M., Nienaber A. South Africa's new Standard Material Transfer Agreement: proposals for improvements and pointers for implementation. *BMC Medical Ethics* 21 (85) (2020)

## Micro-CT Scans, 3D Prints, Digital Data Sharing