Letter to the Editors: Data privacy and DNA data

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The manuscript titled "Data management instruments to protect the personal information of children and adolescents in sub-Saharan Africa," focuses on the challenges, complexities and strategies associated with protecting the personal information of vulnerable populations, specifically children and adolescents, within the context of recent data protection regulatory frameworks in sub-Saharan Africa (Hertzog, Chen-Charles, Wittesaele, de Graaf, Titus, Kelly, Langwenya, Baerecke, Banougnin, Saal & Southall, 2023).

Hertzog et al. (2023) highlight the recent data protection regulations, such as the Protection of Personal Information (POPI) Act (No. 4 of 2013)[3] in South Africa, in increasing the need for improved governance and protections in data management and in research and testing involving high-risk and vulnerable groups, such as children and adolescents. It is apparent that the primary objective of Hertzog et al. (2023) was to dissect and comprehend what constitutes adequate measures for safeguarding the personal information (any information that may identify a person) of these vulnerable populations and to propose strategies that align effectively with the objectives of data protection regulations.

In parallel to the POPI Act, the Access to Information Act, (No. 2 of 2000)[4] must also be considered as it deals with how a person's personnel information may be requested. Importantly, these regulations do not replace the Health Professions Council of South Africa (HSPCA) patient confidentiality and other legal policies (Smith, 2023).

Moreover, Hertzog et al. (2023) correctly emphasise the significance of adhering to transnational governance frameworks established by data protection regulations, funders, and institutions. Recognising the necessity, we concur that regulatory alignment is required throughout the entire life cycle process, from data acquisition and storage to analysis and dissemination of the results in research and testing frameworks. Thus, in order to establish a balance between ethical research and testing practices, and compliance with data protection laws, it is essential to interpret these regulatory frameworks.

We welcome the fact that Hertzog et al. (2023) shared their experiences and strategies thus seeking to ignite a broader dialogue about enhancing the protection of sensitive personal information for children, and adolescents, in sub-Saharan Africa. It has the potential to serve as a guide for scientists, community policymakers, and stakeholders engaged in research and testing initiatives with vulnerable populations. It promotes a proactive approach to data protection that complies with regulatory frameworks and advances social and health policies that benefit these populations.

We intend to capitalise on the insights presented in the article by focusing on augmenting the data protection measures that are applied to the information contained in the National Forensic DNA database of South Africa (NFDD). The Criminal Law (Forensic Procedure) Amendment Act, (No. 37 of

2013)[5], also known as the "DNA Act," provided the regulatory framework and established the NFDD. The NFDD contains numerous forensic DNA profiles derived from specific categories of persons and crime scene samples organised in distinct indexes, which can be used for comparison searches. These comparison searches are conducted to provide detectives with forensic DNA investigative leads and aid in resolving criminal cases (Smith, 2022; Smith & Horne, 2023). Notably, the legislators of the DNA Act's considered the right to privacy guaranteed by section 14 of the South African Constitution (1996)[6] and alignment to POPI. Their primary goal was to have an effective NFDD, whilst safeguarding the data of individuals whose buccal samples were collected and whose forensic DNA profiles are stored in the NFDD.

The DNA Act establishes explicit restrictions and definitions regarding the permissible purpose for which the NFDD may be used. These purposes include criminal investigations, early exoneration of the innocent during investigations, and identification of missing persons and unidentified bodies. In addition, the DNA Act is aligned with the regulations of the National Health Professions Act, (No. 56 of 1974)[7], which stipulates that individuals must be adequately informed and provide consent, using a signed document acknowledging the reason a buccal sample was collected (Smith, 2023). The DNA Act requirements are consistent with the POPI Act, which regulates data protection in South Africa. The DNA Act mandates the destruction of buccal samples within 90 days after a forensic DNA profile is uploaded to the NFDD to prevent the potential misuse of buccal samples containing an individual's genetic information for purposes other than those authorised by the DNA Act, such as research.

The DNA Act also prohibits the storage of any personally identifiable information associated with the forensic DNA profile within the NFDD, except metadata such as the unique sample identifier, index code, station and reference numbers, date of profile upload, and a minor indicator, excluding any personal information such as the identity number, name and surnames, and information about a person's predisposition, physical, or medical conditions. The DNA Act specifies the length of time that each individual's forensic DNA profile is stored. For example, the minor indicator is essential for distinguishing forensic DNA profiles derived from minors, which cannot be retained on the Arrestee Index for over 12 months. If a criminal case is dismissed or the defendant is acquitted, these profiles must be promptly deleted.

By the POPI Act's data management requirements, the DNA Act mandates specific measures to ensure the data integrity and security of the NFDD's information. In addition, it criminalises the misuse or compromise of the data's integrity within the NFDD. The Act also established the National Forensic Oversight and Ethical Board (NFOEB), which is responsible for overseeing ethical compliance, implementing the Act, and preserving data integrity within the NFDD. The NFOEB is also responsible for investigating any complaints regarding DNA forensics and the management of the NFDD.

The rapid advancement of technology in forensic DNA research and testing is unavoidably creating new challenges that threaten the security of personal information. In DNA typing, the emergence of multiple parallel sequencing technologies is introducing new markers, including STR loci, Y-STR, X-STR, and SNPs. These developments can potentially integrate DNA phenotyping, which would add a layer of complexity (Meintjes-van der Walt & Olaborede, 2023).

It is strongly suggested that various stakeholders, such as forensic DNA practitioners, public representatives, academia, legal experts, and ethicists convene to discuss the extensive implications these new DNA technologies may have for the privacy of individuals. In addition, it is necessary to consider whether and under what conditions these novel technologies should be implemented. To safeguard individuals' privacy and constitutional rights in the face of these technological advancements, it is essential to establish a comprehensive regulatory framework and effective oversight mechanisms.

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Endnotes

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[4] https://www.gov.za/documents/promotion-access-information-act

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