A shift to openness: open consent and open science in AI health research in South Africa

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Artificial Intelligence (AI) is an invaluable tool for health research and product development in South Africa – however it requires a vast amount of health and genomic data – which is tricky to access! In South Africa, open science has become a focus in the country, as reflected in the Department of Science and Innovation (DSI) *Draft National Open Science Policy* (2022), which aims to incorporate open science into South Africa's national strategy and foster a legal environment that is more open to innovation and data-sharing. Furthermore, given that the Academy of Science of South Africa (ASSAf) has recently published the *draft Code of Conduct for Research* in terms of the *Protection of Personal Information Act 4 of 2013* (POPIA), now is the time to examine this – Keeping with the open science framework, how can we best harness the potential of AI? Open consent may be a solution! But, is it feasible?

A central aspect of health research is consent. In South Africa, various modes of consent have been developed and utilised in the context of health research – including broad consent, specific consent, and blanket consent. Whilst the Department of Health *Ethics in Health Research: Principles, Processes and Structures* (2015) permits broad consent, it does not recommend the use of blanket consent. In contrast, POPIA (and the *draft Code of Conduct for Research*) requires consent to be *specific*, voluntary, and informed. A mode of consent that has not yet been explored in South Africa's research context, and specifically in AI health research, is open consent. Open consent – developed by the Personal Genome Project (PGP) – entails that individuals openly donate and share their data for research.[1] It recognises that privacy cannot be guaranteed, and therefore makes no assurances regarding the anonymity, privacy, or confidentiality of data.[2] Further, to ensure that consent is informed, open consent requires potential participants to take (and pass) an examination to test their understanding of the research and its processes. Thus, open consent can be perceived as an attempt to marry *open science* – and the benefits associated with it – with *informed consent*. Not only does open consent pose potential solutions to the provision of samples and data for health research, and the uptake of AI in this area, but it also promotes open science.

This presentation will consider whether open consent aligns with POPIA (and *draft Code of Conduct for Research*) and the type of consent that it proposes, namely specific consent, as well as whether open consent aligns with the *Ethics in Health Research: Principles, Processes and Structures* recommendation of broad (but not blanket) consent for health research – thereby determining whether open consent may be a viable (and unexplored) solution to consent for AI health research in South Africa. This presentation will also contemplate how the *Draft National Open Science Policy* promotes open science in terms of AI health research (and other applications of AI).

References

1. Fida K Dankar, Marton Gergely & Samar K Dankar 'Informed consent in biomedical research' (2019) 17 *Computational and Structural Biotechnology Journal* 470.
2. Jeantine E Lunshof, Ruth Chadwick, Daniel B Vorhaus et al 'From genetic privacy to open consent' (2008) *Nature Reviews Genetics* 5.

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