

## The Protection of Personal Information Act No 4 of 2013: A Code of Conduct for Research

### Background

In South Africa (SA) the use of personal information for research is regulated by the National Health Act No 61 of 2003 and its 2012 regulations, the Department of Health *Ethics in Health Research: Principles, Processes and Structures* Guidelines and the Promotion of Access to Information Act (PAIA) No 2 of 2000.

This changes with the coming into force of the Protection of Personal Information Act (POPIA) No 4 of 2013 on 1 July 2020 [<https://www.justice.gov.za/infoereg/docs/InfoRegSA-POPIA-act2013-004.pdf>]. All public and private bodies that are processing personal information have until 1 July 2021 to ensure that they are compliant with the law.

POPIA seeks to give effect to the constitutional right to privacy. In so doing, it balances the right to privacy with other rights and interests, including the free flow of information within SA and across its borders. POPIA adopts a principle-based approach to the processing of personal information. It sets out eight conditions for the lawful processing of personal information: accountability, processing limitation, purpose specification, further processing limitation, information quality, openness, security safeguards, and data subject participation. These principles apply equally to all sectors that processes personal information.

### A POPIA Code of Conduct for Research

Overall POPIA is to be welcomed as it gives greater guidance to researchers regarding the use and protection of personal information for research. This should serve to improve transparency, accountability and oversight of personal information and promote public trust in the use of personal information in research. However, there is uncertainty and need for further guidance on the application of POPIA to research.

- **First**, it is unclear how some of the high-level principles will apply in practice to research.
- **Second**, although POPIA adopts a principle-based approach and not a sector-specific approach to the processing of personal information, it does provide certain exceptions for research. Many of the key concepts are undefined and further guidance as to the application of these exceptions and in particular the necessary safeguards are required.
- **Third**, it is essential that there is a comprehensive and uniform approach to the regulation of personal information for research across all government departments, academic institutions, research councils and the private sector.

Chapter 7 of POPIA makes provision for the development of codes of conduct. These codes can apply to specified information or a class of information such as health information, a specific activity such as research, or a specific industry, profession or vocation. POPIA thus foresees the need for sector-specific codes to guide the application of its principles to particular sectors. Significantly, once a Code is approved by the Information Regulator and comes into force, it is legally binding on the sector, profession or industry that is specified in it.

The Academy of Sciences of South Africa (ASSAf) considers it essential to develop a POPIA Code of Conduct for Research to ensure certainty, transparency and clarity in the use of personal information for research. ASSAf also considers that it is imperative that there is **one** Code to guide the use of personal information for research in all sectors (including health, social science, genomics, etc.). ASSAf is now embarking on a process to facilitate the development of a Code of Conduct for Research, by engaging a wide spectrum of stakeholders including researchers, ethicists and legally trained people.

As per the requirements of POPIA and the draft guidelines for the development of codes of conduct, there will be a series of engagement activities that will ensure inclusivity with multiple stakeholders prior to the submission of the Code to the Information Regulator for approval.

### **Work plan 2020**

October	Virtual forum hosted by ASSAf on POPIA, the need for a single Code of Conduct for Research and discussion of key issues to be addressed in the Code.
November	Appointment of a Steering Group to guide the development of the Code
December	Appointment of a core writing party to develop the Code Science Forum

### **2021**

March	Forum to discuss preliminary draft of the Code
May	Draft Code for comment (open for comment for 2 months)
July	Code submitted to Information Regulator for approval

Yours sincerely



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