

Unified Interpretation of POPIA in the context of Protection of Personal Information: ASSAf Compliance Framework for Research

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Setting the scene and telling the back-story

- Protection of Personal Information Act No 4 of 2013 (POPIA) came into effect 1 July 2020 with a grace period of one year to comply
- Chapter 7 of POPIA makes provision for the development of codes of conduct to provide guidance on the interpretation of POPIA in relation to a particular sector or industry, or class of information
- An industry 'best practice' guidance for researchers is critical to a uniform interpretation of POPIA

Why do we want a national 'best practice' guidance for research in the context of POPIA?

- Unclear how some of the high-level principles will apply in practice to research
- POPIA provides certain exceptions from the lawful conditions of processing personal information for research (how and where do they apply)
- Uniform approach to the regulation of personal information for research across all government departments, academic institutions, research councils and the private sector
- To establish South Africa as a safe haven for research data (and to prepare for a possible application to the European Commission for an adequacy decision)
- To ensure that research institutions and researchers are accountable for non-compliance

Scope of the Code

Applies to: industry and academia

Academic/scholarly/commercial research of **all disciplines** that uses (collects, processes and stores) personal information as part of the research.

Research: broadly, the generation, preservation, augmentation, and improvement of knowledge using investigations and methods pertinent to the scientific field or discipline, and which is mindful of the value of knowledge for the betterment of society, including open science.

Typically, such research would undergo prior independent ethics review and would be intended for publication.

Existing frameworks governing research

Bill of Rights: 'everyone has ... the right not to be subjected to medical or scientific experiments without their informed consent'

National Health Act and DoH Guidelines on Ethics in Research:

- Applies to research in a broad sense (not strictly health research)
- consent of the individual involved for research projects that involve human participants
- Health ethics committees to be registered with the NHREC

International standards: open science and data protection law in the African Union and European Union (GDPR)

Why ASSAf?

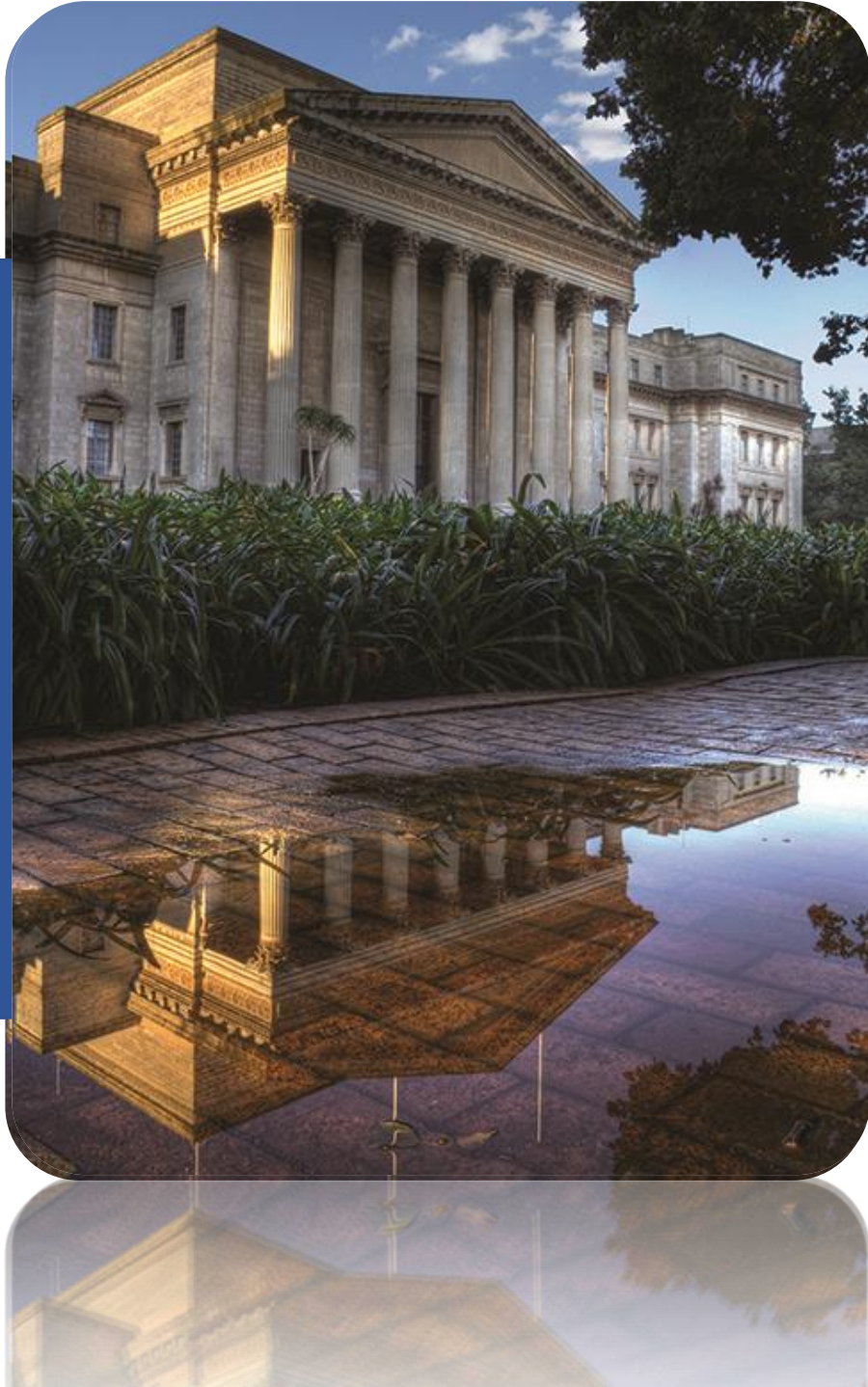
The objectives of the Academy are (amongst others)

- to promote common ground in scientific thinking across all disciplines,
- to promote the optimum development of the intellectual capacity of all people and
- to provide effective advice and facilitate appropriate action in relation to the collective needs, opportunities, and challenges of all South Africans.

ASSAf views the balancing of the right to privacy of Research Participants against the collective public interest in scientific research as an integral part of these objectives.

Progress on the POPIA Code of Conduct for Research

- **Establishment of the Steering and Drafting committees**
 - 10 Members of the Steering Committee
 - 12 Members of the Drafting Committee
 - 31 meetings held from 2021 to date
- **Public consultation held**
 - Open Science week (Sept 2020) *290 attendees
 - Science Forum (Dec 2020)
 - 2 consultation forums – general public + NHREC stakeholders (May 2021) *934 attendees
- **Publication and Comments of the Code**
 - Announcement of CoC & call for comments (Jan 2021)
 - Commentary & discussion document published (May 2021)
 - Draft CoC - Selected readers (May 2022)
 - Draft CoC - public comment (Sept 2022)
 - Draft CoC submitted to the IR (Apr 2023)
 - Feedback from the IR (Jul 2023)
- **Stakeholders involved**
 - 92% of the researchers and research institutions in South Africa



Perspectives from two research practitioners at Wits University

Michele Ramsay
Matty van Niekerk

What are the important questions for research participant protection in the light of POPIA compliance?

1. What is special personal information and what is its relationship to vulnerability in health-related research?
2. What conceptual safeguards are necessary (or sufficient) to protect research participants?
 - a. Consent that is necessary (or sufficient) to comply with protection of personal information for research purposes (including special personal information like health-related and genetic data, and data on children)
 - b. Deidentification vs Anonymisation vs Pseudonymisation
 - c. Managed access to datasets with special personal information



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Vulnerability and Special Personal Information:

Council for International Organizations of Medical Sciences (**CIOMS**)

and

Protection of Personal Information Act (**POPIA**)



Vulnerability (CIOMS 2016)

Requires judgements about

- both the probability **and** degree of physical, psychological, or social harm; **and**
- a greater susceptibility to deception or having confidentiality breached.

Involves not only the ability to provide initial consent to participate in research, but also aspects of the ongoing participation in research studies.

- People who are **relatively (or absolutely) incapable of protecting their own interests.**
 - Persons who have relative or absolute impairments in decisional capacity, education, resources, strength, or other attributes needed to protect their own interests.
- Some feature of the circumstances (temporary or permanent) in which they live **makes it less likely that others will be vigilant about, or sensitive to, their interests.**
 - People who are marginalized, stigmatized, or face social exclusion or prejudice that increases the likelihood that others place their interests at risk, whether intentionally or unintentionally.

Special personal information

POPIA lists specific categories:

- Religious or philosophical beliefs
- Race or ethnic origin
- Political persuasion
- Health
- Sex life
- Biometric information (including genetic data), or
- Criminal behaviour relating to the **alleged** commission of an offence or proceedings relating to an **alleged** offence.



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POPIA and CIOMS are aligned on the issues of vulnerability and special personal information

- Information that may make someone vulnerable to stigma, marginalisation, social exclusion or prejudice.
- Information that pertains to people who are relatively (or absolutely) unable to protect their own interests (e.g. POPIA = children).



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Special personal information does not mean you cannot process that information:

- It can be processed for research purposes given certain conditions (i.e. for research purposes)
- CIOMS: highlights the **danger of excluding vulnerable populations** from research, as their specific interests and needs would not be addressed
- Take into consideration that some data is more sensitive than others (as per list, but also other data such as banking details), thus requiring **justification** for processing, **rather than** special procedures



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What conceptual safeguards are necessary (or sufficient) to protect research participants?



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Safeguards

- This presentation will not address **technical and organisational safeguards** (e.g. access, acceptable software, storage security, back-up, secure transfer, etc.)
- Instead, we focus on principles that impact **reidentification of individual participants**



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Examples of sufficient guarantees include:

- Deidentifying, anonymising or pseudonymising the personal information;
- Adhering to a POPIA code of conduct or other industry standard (best practice);
- Appropriate participant consent;
- Successfully obtaining ethical approval from a Research Ethics Committee;
- Encryption or providing a restricted environment for high-risk research.



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Deidentification, Anonymisation and Pseudonymisation

Deidentification	Anonymisation	Pseudonymisation
Destroys all identifying information	Destroys all identifying information	Masks any identifying information
The process cannot be reversed	The process cannot be reversed	The process is reversible
POPIA does not apply	GDPR does not apply	GDPR/POPIA still applies

Modified From: De Stadler et al. 2021. Over-Thinking the Protection of Personal Information Act. Cape Town: Juta p 92

Note:

Anonymisation is used by the General Data Protection Regulations of the EU and UK, and POPIA refers to deidentification.

Do we need POPIA consent when the research data is collected for the first time?

You do not need POPIA consent to collect special personal information for research purposes if:

- it will only be used for research purposes; AND it will not be published in an identifiable form;

AND

- the research is in the public interest OR it appears impossible or would involve a disproportionate effort to ask for consent;

AND

- there are sufficient guarantees (safeguards) in place to ensure that the research does not adversely affect the research participant's privacy to a disproportionate extent.

Can special personal information be placed in open access databases?

Open vs Managed



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Open Access

- Berlin Declaration: Open access (OA) means free access to information and unrestricted use of electronic resources for everyone. (e.g. Any kind of digital content can be OA, from texts and data to software, audio, video, and multi-media.) (<https://openaccess.mpg.de/Berlin-Declaration>)
- Managed access: Access would be granted by a Data Access Committee and parties will enter into a legally binding Data Access Agreement. (Participants agree to good governance of their data by a trusted third party who makes decisions on their behalf)



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If research data is being contributed to a research data repository, POPIA consent will usually not be required if:

- there is a Data Access Committee who controls who the research data is released to;
- recipients of research data are asked to conduct a legitimate interest assessment which also involves balancing individual privacy against the interests of the public and the researcher (this is often already part of ethics approval);
- agreements are in place to ensure that the use and sharing is restricted;
- recipients must ensure that they comply with POPIA equivalent rules or standards (industry best practice).

Take-home messages

1. An **industry standard** (best practice) is helpful in showing **sufficient guarantees** (safeguards) are in place to ensure that the research does not adversely affect the research participant's privacy to a disproportionate extent.
2. POPIA is not a barrier to research but **encourages** good practice, i.e., adequate safeguards.



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Thank you



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