POPIA AND RESEARCH DATA MANAGEMENT

This infographic was created by the Undergraduate Research Ethics Committee (UREC) for **undergraduate and honours student researchers** conducting **minimal risk research**. It aims to provide a bird's-eye-view summary of the application of the Protection of Personal Information Act (POPIA) to the processing of personal information for research purposes.

Student researchers should complete the Division for Information Governance's **privacy impact self-assessment** to determine the risk level of the data they will be collecting. Some conditions that apply to more than minimal risk-level data are not addressed in this infographic; in such cases, researchers should consult the ASSAf POPIA Code of Conduct for Research for information pertinent to their research.

Student researchers are advised to read this document in conjunction with the ASSAf POPIA Code of Conduct for Research and guidance from SU's Division for Information Governance.

Note: POPIA guidance is still evolving so check our website regularly for infographic updates

Definitions

- **Personal information:** includes information about a person's demographics, background, biometrics, contact details, identifiers (e.g., ID number, photos), opinions and preferences, financial information, correspondence, and criminal record.
- **Special personal information:** includes information about children, and information about a person's race or ethnic origin, health, DNA, religious or philosophical beliefs, political opinions, sex life, and criminal behaviour.
- **Data subject:** the research participant whose information is being processed during the research project.
- **Principal Investigator:** the leading researcher on a project who takes responsibility for the research.
- **Responsible party:** Practically, the responsibilities of the responsible party outlined in POPIA will fall on the researchers designing and leading the research study. Legally, ultimate responsibility lies with the research institution with which the Principal Investigator is employed or affiliated.
- **Information Officer:** The designated individual assigned by the university to ensure compliance with POPIA.

POPIA's 8 conditions for lawful processing

1. **Accountability** (POPIA Chapter 3, Part A, section 8)
2. **Limit processing** (POPIA Chapter 3, Part A, sections 9-12)
3. **Specify the purpose** (POPIA Chapter 3, Part A, sections 13-14)
4. **Limit further processing** (POPIA Chapter 3, Part A, section 15)
5. **Ensure quality of information** (POPIA Chapter 3, Part A, section 16)
6. **Openness** (POPIA Chapter 3, Part A, sections 17-18)
7. **Safeguard confidentiality** (POPIA Chapter 3, Part A, sections 19-22)
8. **Allow data subject participation** (POPIA Chapter 3, Part A, sections 23-25)

1 Research planning and design

Accountability

- The responsible party must ensure that all the **conditions for lawful processing** are complied with through all phases of the research project.
- The responsible party who will ensure compliance with POPIA must be identified in the research protocol.

Specify the purpose

- Personal information must be collected for a **specific** and **lawful** purpose which must be outlined in the research protocol.
- The **data subject must be made aware**, in the consent form, of the explicit research-related purpose for which their information is being collected.

Openness

- The responsible party must maintain the **documentation** of all processing operations under its responsibility. This record should include: i) the lawful basis for processing, ii) documentation of the consent process, iii) measures for ensuring the quality and security of information, and iv) any further processing or sharing activities.
- The **data subject** must be informed: i) why their information is being collected, ii) who is collecting the information and where it will be held, iii) what rights the data subject has to access/delete/correct their information, and iv) whether the information will be transferred.

2 Information and data collection

Limit processing

- **Lawfulness of processing:** personal information processed for research purposes must be processed in compliance with the lawful conditions set out under POPIA; the processing must be reasonable and must not infringe on the privacy of the data subject.
- **Minimality:** researchers should collect and process only the minimal amount of personal information required. Only personal information needed to address the research objectives should be collected.
- **Justification and consent**: personal information may only be processed if there is a lawful basis for doing so, as set out in POPIA. The most applicable lawful bases for research-related processing are: i) consent is provided by the data subject to do so or ii) processing is necessary for pursuing the legitimate interests of the responsible party - where 'legitimate interests' are research activities.
- **Objection:** a data subject may withdraw consent or object to the processing of their information at any time.
- **Collection directly from the data subject:** personal information must be collected directly from the data subject. POPIA makes provision in Section 12 for instances where direct collection is not possible.

Special personal information

- POPIA places a **general ban** on the processing of special personal information.
- Researchers processing special personal information must ensure that their processing falls under the "**General authorisation concerning processing special personal information**" provided under Section 27 of POPIA, and that appropriate safeguards are in place for securing personal information and protecting the rights of the data subject.
- Generally speaking, under Section 27, POPIA permits the use of such information in research provided that there is **lawful basis** for such processing and/or that the **data subject consents** to the processing of their special personal information. See below for additional conditions for processing **health-related information**.

Information about children

- POPIA places a **general ban** on the processing of the personal information of children.
- Generally speaking, under Section 32, POPIA permits the use of such information in research provided that there is **lawful basis** for such processing and/or a **competent adult consents** to the processing of the child's personal information.
- Researchers processing the personal information of children must ensure that their processing falls under the "**General authorisation concerning personal information of children**" provided under Section 32 of POPIA.
- The **best interests of the child** must be considered and upheld at all times.

POPIA Ch 6

Special personal information, information about children, and highly identifying information is considered by POPIA to be higher risk.	Responsible parties should ensure that there is a clear and enforced policy that stipulates the access controls for keeping such information secure.	In addition, certain processing activities are higher risk and require responsible parties to obtain prior authorisation from the Information Regulator. See Ch 6.

3 Data management, storage & sharing/re-use

Ensure quality

- The responsible party must ensure that all personal information collected and stored is **accurate, up-to-date, complete,** and **not misleading**.
- A record keeping system must be in place which details how the responsible party will **ensure and check the quality** of personal information collected, stored, and processed.

Security and safeguards

- The **data management plan** should outline how personal information will be kept secure to maintain confidentiality and integrity and prevent data breaches.
- Both **technical** (ICT software and hardware) and **physical** measures (locked doors, access control systems) should be in place to prevent data breaches and staff must be **trained on data security**.
- Should there be a **data breach**, the Information Regulator and data subject must be notified immediately.

Allow data subject participation

- Data subjects have the right to **access** and request **correction or destruction** of any records containing their personal information.
- All research institutions must have a **privacy statement** and **PAIA manual** publicly available which informs data subjects how they can request access to, correct, and/or delete personal information held by the responsible party.

Limit further processing

- Further processing of personal information must be in alignment or **compatible with the initial purpose of collection**; if so, it does not require re-consent from the data subject.
- The further processing of personal information is not incompatible with the purpose of collection if, i) the data subject has **consented** to the further processing, ii) the information is available in or derived from a **public record** or has deliberately been made public by the data subject, iii) further processing is necessary to prevent or mitigate a **serious threat** to public health or an individual's health or life, or iv) the information is used for **research purposes** and the responsible party ensures that the further processing is carried out solely for such purposes and **will not be published in an identifiable form**.
- Responsible parties undertaking further processing of personal information for research purposes must ensure that there are **safeguards** in place to prevent the personal information being processed for any other purpose besides research.
- **Trans-border flow of information**: Personal information cannot be transferred to a third party in a foreign country unless the responsible party complies with the provisions of section 72 of POPIA. NB: Cloud storage services (e.g., Dropbox) are 'foreign' (i.e., in foreign countries).

4 Preservation and disposal

Specify the purpose

- The retention of records containing personal information is allowed for research purposes where there is a **specifically defined need** to retain such information for research and where **relevant safeguards** are in place, both of which must be outlined in the research protocol.
- Records containing personal information must not be retained longer than is necessary and must be deleted or destroyed after the purpose for collection and processing has been fulfilled.
- The responsible party must outline in the research protocol what processes will be used to destroy or de-identify personal information, and when this will occur, in a manner that prevents its reconstruction through a reasonably foreseeable method.

Special authorisation for processing health information

The prohibition on processing health information does not apply if the processing is for research purposes and either the data subject gives consent or:

The purpose serves a public interest and the processing is necessary for the purpose concerned or **It appears to be impossible or would involve a disproportionate effort to ask for consent** and **Sufficient guarantees are provided to ensure that the processing does not adversely affect the privacy of the data subject**

POPIA allows for the processing of information concerning or containing **inherited characteristics** (e.g., genetics) for research purposes, provided that researchers ensure that relevant safeguards are in place given the inherent identifiability of such information.

Policy and guidance documents

- Protection of Personal Information Act (POPIA)
- ASSAf POPIA Code of Conduct for Research
- SU Division for Information Governance POPIA-related guidance
- SU data privacy regulations
- SU data management policy
- SU Library & Information Service's research data management guide

Researchers should consult the DoH (2015) ethics guidelines regarding ethical considerations in research

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