RHODES UNIVERSITY

Where leaders learn

RHODES UNIVERSITY HUMAN RESEARCH ETHICS COMMITTEE

SOP 4.2 ANONYMITY AND CONFIDENTIALITY REGARDING PARTICIPANTS

Approved by:	Name	Signature	Date
Human Research Ethics Committee	Dr Janet Hayward (Chair)		2/4/2024
Endorsed by:			
VC Legal Unit	Mr Ismail Amojee		22/4/2024
DVC: RISP	Dr Kwezi Mzilikazi		25/05/2024

COMPILED BY Dr Janet Hayward, Chair, Rhodes University Human Research Ethics Committee

DOCUMENT HISTORY

Version 1.01 (November 2014): Rhodes University Ethical Standards Handbook (comprising Institutional Policy, Terms of Reference and Standard Operation Procedures).

Version 2.0 (April 2024): Derived from division of previous version into separate documents and revised to align with RU Research Policy (2021) and DoH Guidelines (2015; 2024).

ANONYMITY AND CONFIDENTIALITY REGARDING PARTICIPANTS

1. Purpose

The purpose of these guidelines is to define the ethical principles of anonymity and confidentiality and how researchers are to ensure this where possible or provide adequate reasons where it is not possible during the course of conducting research with human participants.

2. Definitions[1]

2.1. **Privacy:** a person's interest in controlling access to their personal information.

2.2. **Confidentiality:** whether and how research data might be disclosed carelessly or inadvertently, thus revealing the participant's identity or category, making them vulnerable to harm.

2.3. **Individual data**: datasets that contain records with information about individual study participants.

2.4. **Aggregated data:** data combined from several sets of individual data that are averaged by geographic area, year, or other means.

2.5. **Identifier:** information such as a name, initials, address, folder number, or biometric identifier (e.g. fingerprint) that can identify a particular participant.

2.6. Individual consent of participants is required in the use of identifiable data including:

1) Directly identifying individual data which contains direct identifiers e.g. name, identity number.
2) Identifiable information which can reasonably be expected to identify an individual alone or in combination with other information.
3) Indirectly identifying information: where various indirect identifiers (e.g. date of birth, address, unique personal characteristics) allow for the identification of an individual when combined with one another.

2.7. Consent is not required from participants when anonymous or anonymised data is used, including:

1) Coded information: direct identifiers have been removed and replaced by code.
2) Anonymised information: information has been irrevocably stripped of direct identifiers (no code).
3) Anonymous information: never had identifiers.
4) Aggregated data that is sufficiently aggregated to disable backtracking to individual information.

3. Privacy of participants

3.1. The University recognizes and supports the freedom of persons and communities to reveal or withhold all information about themselves not already in the public domain, by deliberate, fully informed decision, and with the assurance that the participant's anonymity will be protected, and all records of participation will be kept confidential.

3.2. The Principal Investigator must account for differing sensibilities among participant groups in the matter of invasion of privacy especially if the participant group is vulnerable,[2] or of a background different from that of the researcher.

[1] DOH Ethics in Health Research Ethics 2015 p 20 & 54

[2] UNAIDS defines 'vulnerable community' as having some or all of the following characteristics: limited economic development; inadequate protection of human rights and discrimination on the basis of the health status; inadequate community/cultural experience and understanding of scientific research; limited access to health care and treatment options; limited ability of individuals in the community to provide informed consent (Department of Health Guidelines, 2015:22).

3.3. The use of institutional records in a project requires obtaining consent from the individuals involved as well as from the institutional authorities.

3.4. POPIA requirements must be considered concerning the privacy of third parties where the participant is asked to disclose information or opinions about such third parties.

3.5. Mechanical methods of observation, such as TV cameras, microphones, tape recorders, and one-way mirrors, may be used only with the consent of participants and/or their legal guardians. Where the participant has been recorded, the participant must be given the opportunity to call for erasure of the recording when such participation is complete.

3.6. Any disclosure of a mechanical recording to persons who are not involved in carrying out the project (for instance, as an audio-visual demonstration) must be expressly consented to by the participant.

3.7. Location of research on private property must be disclosed in the application and approved in advance by the property owner. Shopping centres and commercial businesses are private property.

3.8. A researcher who is given access to a government or community institution or agency has a responsibility not to make public exposure of conditions or practices with which the researcher disagrees without first reporting them to the responsible authority and giving reasonable time for an investigation to be made and a decision reached.

4. Anonymity of participants and confidentiality of data

4.1. The participant's anonymity must be strictly protected, and all data collected must remain confidential.

4.2. All persons having access to confidential data must be briefed by the Principal Investigator on the duty to observe the rules of anonymity and confidentiality.

4.3. Where individual (identifiable) data is collected, the participant must give written consent (or verbal if this is sufficiently justified in the ethics application), the participant must be explicitly informed about risks associated with disclosing personal information, and such information may be disclosed only within the strict limits of the terms of the consent.

4.4. The responsibility is on the Principal Investigator to describe positive measures to be taken to preserve the anonymity of the research participant, in the informed consent document, published results of the project, and records retained by the project supervisor.

4.5. Where confidential data will be stored for possible re-use, the method of recording and storing the data must be strictly designed to confer anonymity on the participant, the participant must be informed of this and sign their consent in the informed consent document.

4.6. Upon provision of a satisfactory motivation, data may be reused without consent from participants only upon approval from Rhodes University Human Research Ethics Committee (RU-HREC) and if:

1) this may cause unnecessary anxiety to the participant,
2) the validity of the study is prejudiced,
3) there is no disadvantage to participant's rights (e.g., anonymity) and dignity, and
4) it is practically impossible to obtain such permission.

4.7. In certain circumstances a researcher may acquire information on illegal activities or information relevant to a criminal investigation. A researcher who acquires information about illegal activities may be called as a witness in court proceedings and can be compelled to make full disclosure of such information received. It is recommended that the Principal Investigator appraises all co-researchers associated with the project of the legal implications in this connection, where possible.

4.8. Computer files (including back-up copies) should be stored in secure password-protected online locations. People with access rights should sign a non-disclosure agreement and should only access data for legitimate purposes.

4.9. Electronic communication of confidential information should be carried out in encrypted form.

5. Internet surveys

5.1. Strictly speaking any internet user can be tracked back to individual logins, as this is prescribed by South African law for crime prevention. However, the identity information is normally not available to the survey provider.

5.2. The risk that internet surveys that do not ask for identifiable information may be tracked back to the individual user filling out a survey is more likely when the service provider is linked to the institution that the participant is logged into (e.g. RUConnected) and therefore preferable to use unrelated/independent service providers (e.g. Google forms) when collecting data from human participants online.

5.3. The research must clearly explain to participants (and RU-HREC) how personal information will be stored and which identifiable information will be stored with the survey data stored, if applicable.

5.4. If no personal data is stored, the informed consent may be given anonymously, to avoid a participant identifying herself/himself.

5.5. If the survey includes a lucky draw incentive, in which case, contact information needs to be entered and stored to facilitate access to the winner, personal information must not be linked with survey data. Two separate databases should be used, one for submission of survey data, followed by an optional link to the lucky draw part where participants can enter contact information on a voluntary basis (or withdraw from the lucky draw by not using the link or not entering contact data). The contact information should be the minimal information required to contact a winner, e.g. an email address.

6. Using information from student or staff records

6.1. Student and staff statistics in aggregated form (from which it is impossible to identify individuals) can be used without ethical approval, provided permission of the relevant department or division has been obtained.

6.2. Individual student and staff data can only be made available to researchers if individual permission of each student or staff member was obtained.

6.3. Individual student and staff data can be used without individual permission if the research falls under the mandate of Rhodes University (e.g. for surveys studying teaching quality). However, personal data cannot be made available to researchers directly. For such research, the Information and Technology Service Division may process the data in the role of a trustee and hand over only anonymised data to the researcher.

6.4. It is strongly suggested that researchers consult RU-HREC or one of its subcommittees during the conceptual phase of research using data from students or staff.

7. Effective date of this SOP

2 April 2024 with the next revision date being 2 April 2027, or as deemed necessary by a quorate meeting of RUHREC.