

HUMAN RESEARCH ETHICS COMMITTEE: (MEDICAL)

STANDARD OPERATING PROCEDURE

SOCIAL MEDIA

SOP-HREC-014 (VERSION 2) REVISED AND UPDATED: SEPTEMBER 2026

SUBJECT	Social Media
DIVISION / SCOPE:	University of the Witwatersrand, Human Research Ethics Committee: (Medical)
REVISION:	Ethics Secretariat
PURPOSE:	This statement aims to provide policy regarding Wits HREC (Medical) requirements for the use of social media digital platforms and technologies
PREVIOUS VERSIONS / (REASON FOR REVISION)	SOP-HREC-014 Version 1 - Revised
CONTENT:	INDEX 1. POLICY STATEMENT 2. Social Media for Participant Communication 3. Social Media to Recruit Participants 4. Social Media to Contact Participants who no longer want to be in a study 5. Guidelines for the use of Social Medical Platforms in clinical settings in South Africa 6. DEFINITIONS AND ABBREVIATION 7. REFERENCES
APPROVALS:	Signature of Chair / Co-Chair: <i>Paul Ruff</i> Date: 2026/09/18

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1. Policy statement

This policy provides the views of the University of the Witwatersrand, Human Research Ethics Committee: (Medical) regarding the use of social media in relation to participant communication in health research. This includes recruitment of participants, contacting participants and other guidelines for the use of social media platforms in health care research settings in South Africa.

2. Social Media for Participant Communication:

The use of social media for participant communication in health research studies is becoming more prevalent and there is a requirement to maintain confidentiality and protect personal information of participants. Therefore, researchers and research participants need to be aware of the potential lack of confidentiality of these platforms. The consent trail needs to be explicit, as if the original informed consent form did not specifically mention social media as a contact method, participants may not have anticipated this.

Sensitive/Personal Health Information:

Sensitive/personal health information should be communicated **directly to participants** (preferably face-to-face) and not via social media platforms such as WhatsApp or Facebook.

Social Media Groups

The committee considers that there are confidentiality implications to adding people to **Groups** on software platforms. If these platforms are going to be used for discussion regarding the study, the following should be considered:

- a) Participants should first **consent** to being added to discussion groups on social media platforms. Consent is voluntary and if participants do not provide consent, they should not be added to the group(s).
- b) Participants must be informed that by consenting to be part of a social media group, they understand that their name and cell phone number will be visible to all participants of the group and that the app developers store personal information, including messaging content, on servers that are outside of South Africa.
- c) Explain to the group that confidential personal health information should not be shared on such platforms.
- d) Personal and health information (hospital numbers; IDs; diagnosis etc) should only be discussed and shared with individual study participants during the normal course of the study (not via social media).
- e) The participant should be made aware that once they download a software platform to their mobile device, they agree to the terms and conditions of the software platform.
- f) Researchers should make it clear that they have no data transfer agreements with the app developers and thus from a confidentiality perspective they have no control of how the app developers use personal information. Participants must be aware of this and consent accordingly.

3. Social Media to Recruit Participants (advertisements):

The use of social media to recruit participants was approved by the University of the Witwatersrand, Human Research Ethics Committee: (Medical) in 2018, on condition that all recruitment material is first reviewed and approved by the ethics committee:

As part of the growing global and local increase in social media use, research sites are requesting to utilize social media platforms to broaden their outreach, recruitment, and

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retention strategies. In terms of abiding by all GCP Regulations and ethical considerations regarding the use of social media, sites must be committed to:

- a) Ensuring social media strategy complies with the South African Law, South African Ethics in Health Research Guidelines (2024) and SA GCP (2020) regulations.
- b) Ensure that only HREC approved recruitment materials are posted online.
- c) Include details of the use of social media in all future HREC applications as part of a study's recruitment strategy.
- d) Ensure social media platforms respects all relevant ethical norms, confidentiality and privacy of participants (e.g., use of "broadcast lists" as opposed to groups to protect people's identities).
- e) Updating all relevant Site SOPs to incorporate procedures and rules around social media interaction; and train all study personnel on these SOPs.
- f) State clearly the limits of confidentiality e.g., participants sharing a social media platform may not respect confidentiality of information shared on the platform.
- g) Check the readability (reading level and reading difficulty, for example) and literacy considerations of the social media campaign.

4. Social media to contact participants who no longer want to participate in a study

Once a participant has withdrawn consent from a study, they should not be contacted or have their details accessed by any means, including their or their families/friends social media platforms.

5. Guidelines for the use of Social Medical Platforms in research settings in South Africa

- a) Social media platforms are not POPIA-compliant as healthcare data platforms.
- b) These servers frequently sit outside South African jurisdiction.
- c) Patient-linked data transiting servers often lack the protections required by legislation in South Africa.
- d) Even a broadcast message with no patient identifiers in the body creates a link between a phone number (personal information under POPIA) and study participation - which in itself is sensitive health information.
- e) Some social media platforms automatically save received messages to certain communication devices. If a participant's phone is accessed by a friend or household member, their study enrolment could become visible.
- f) Any staff member replying to participant messages via a personal social media account takes on personal legal exposure. The site should use a dedicated institutional or study account, not a personal cell phone.
- g) Participants must be informed that they can opt out of using social media contacts and be reached by phone instead.
- h) The research site must have a documented procedure for secure handling of any participant social media replies.

6. Definitions and Abbreviations

SA GCP	South African Good Clinical Practice Guidelines (2020)
HREC	Human Research Ethics Committee

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POPIA

Protection of Personal Information Act 4 of 2013

WITS

University of the Witwatersrand

7. References

- WhatsApp Privacy Policy: <https://www.whatsapp.com/legal/privacy-policy>
- Bouter, C., Venter, B., & Etheredge, H. Guidelines for the use of WhatsApp groups in clinical settings in South Africa. *S Afr Med J* 2020; 110(5): 364-368.
<https://doi.org/10.7196/SAMJ.2020.v110i5.14558>
- Protection of Personal Information (POPI) Act (Act 4 of 2013)
- Department of Health, 2020. South African Good Clinical Practice: Clinical Trial Guidelines. Third Edition (SA GCP 2020)
- South African Ethics in Health Research Guidelines: Principles, Processes and Structures, 2024, Third Edition, Version 3.2 (NDoH 2024, 3rd ed. (v3.2))