STANDARD OPERATING PROCEDURE

SOCIAL MEDIA

SOP-HREC-014 (VERSION 1) REVISED AND UPDATED: JANUARY 2025

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.
PREVIOUS VERSIONS / (REASON FOR REVISION)	Revised
CONTENT:	 INDEX POLICY STATEMENT Social Media for Participant Communication Social Media to Recruit Participants Social Media to Contact Participants who no longer want to be in a study Guidelines for the use of WhatsApp groups in clinical settings in South Africa DEFINITIONS AND ABBREVIATION REFERENCES
APPROVALS:	Signature of Chair / Co-Chair: Paul Ruff Date: 2025/01/13

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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, recruitment of participants, contacting participants who no longer want to be part of a study, and guidelines for the use of WhatsApp groups in clinical settings in South Africa.

1.1 Social Media for Participant Communication:

The use of social media for participant communication in research studies is becoming more prevalent and there is a requirement to maintain confidentiality and protect personal information of participants. Therefore, research participants need to be aware of the potential lack of confidentiality on these platforms.

Sensitive/Personal Health Information:

Sensitive/personal health information should be communicated **directly to participants** and not via social media.

Groups:

The committee considers that there are confidentiality implications to adding people to **Groups** on software platforms such as WhatsApp and/or Telegram, and if these are going to be used for discussion regarding the study, the following should be considered:

- Participants should first consent to being added to discussion Groups on software platforms such as WhatsApp and/or Telegram. Consent is voluntary and if participants do not provide consent, they should not be added to the Group.
- Participants must be informed that by consenting to be part of a WhatsApp and/or Telegram Group, they understand that their name and cell phone number will be visible to all participants of the Group
- Explain to the Group that personal health information should not be shared.
- 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 on the Group).
- 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.

Link to the Whatsapp Privacy Policy: https://www.whatsapp.com/legal/privacy-policy

1.2 Social Media to recruit participants (advertisements):

The use of social media to recruit participants was discussed and approved by the University of the Witwatersrand, Human Research Ethics Committee: (Medical) at the meeting held on 26 January 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, such as Facebook, Twitter, Telegram, Instagram, TikTok etc. to broaden their outreach, recruitment, and retention strategies. In terms of abiding by all GCP Regulations and ethical considerations regarding the use of social media, sites must be committed to:

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- Ensuring social media strategy complies with the Law and SA GCP regulations.
 Ensure to only post HREC approved recruitment materials online.
- Include the use of social media in all future WHREC applications as part of a study's recruitment strategy.
- Ensure WhatsApp and related 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).
- Updating all relevant Site SOPs to incorporate procedures and rules around social media interaction; and train all study personnel on these SOPs.
- State clearly the limits of confidentiality e.g., participants sharing a social media platform may not respect confidentiality of information shared on the platform.
- Check the readability (reading level and reading difficulty, for example) and literacy considerations of the social media campaign.

1.3 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 their details accessed by any means, including their or their families/friends social media accounts.

1.4 Guidelines for the use of WhatsApp Groups in Clinical Settings in South Africa http://www.samj.org.za/index.php/samj/article/view/12929

Guidelines for healthcare practitioners and group administrators using WhatsApp groups

2. Definitions and Abbreviations

GCPGood Clinical PracticeHRECHuman Research Ethics Committee

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POPIA WITS	Protection of Personal Information Act University of the Witwatersrand

3. References

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- http://www.samj.org.za/index.php/samj/article/view/12929 Protection of Personal Information (POPI) Act (Act 4 of 2013) ٠
- Department of Health, 2020. South African Good Clinical Practice: Clinical Trial Guidelines. Third Edition (SA GCP 2020) ٠