

Confidentiality and Consent in Health Research With Youth Living in Zimbabwe: Ethical Challenges for the Responsible Conduct of Health Research Using Social Media in Africa

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E D C T P

BACKGROUND

- Background:** Explosive growth of mobile telephone ownership and social media use in Africa creates new modes of communication, education, information sharing, and opportunities for research and data generation. Social media is prevalent in Zimbabwe, including 1 million Facebook users, 40% of which are under 25 years old. COVID-19 physical distancing, quarantine and lockdowns have impacted the way that people socialize and has led to many using social media platforms to stay connected.
- What we know:** There are beneficial impacts of social media services on access to health information and improving health behaviors and outcomes.
- What we don't know:** How social media is used in global health research, specifically the characteristics of social media research and if ethical guidelines are being used to conduct social media health research with youth in Africa.
- Why needed:** Visuality of social media challenges the central principles of traditional research ethics. The networked nature of social media calls for an investigation of the ethical practices being employed.
- Goal:** To identify the types of social media-based health interventions, the study design of social media research, and the use of ethical frameworks among social media research with youth in Africa.
- Approach:** Systematically identify social media research studies in low middle-income countries. Assess robustness of current ethics guidelines for health-related social media research. Describe perceptions of risk and expectations of privacy when sharing personal health data on social media and during research. Interviews with youth and key informants in Harare, Zimbabwe explored the guidelines and perceptions of social media use in research, and those findings are presented here.



QUALITATIVE STUDY METHODS

- Study Populations:** Group 1: Under 25 years, who attended a one-week training workshop in research methodologies and research ethics (N=16) in Harare Zimbabwe.
Group 2: Zimbabwean research ethics and media professionals (n=2).
- Data Collection:** Group 1: participated in pre and post one-week workshop questionnaires that were conducted to explore internet privacy and risk perceptions. Additionally, two focus group discussions were conducted.
Group 2: participated in key informant interviews.



QUALITATIVE STUDY RESULTS

- Findings:**
- Social media technology rapidly evolves
 - Social media requires flexible ethical guidelines
 - In-country ethical review boards vary greatly
 - Inaccurate application of existing guidelines on social media research projects
 - Generational use of social media creates gaps in knowledge among ethical reviewer boards
 - Nearly impossible to define "social media expert" due to the vast landscape of social media applications
 - Unclear potential for social media in health research
 - Ethical use of social media in research is self-regulated by researchers, institutions and external funders, not accounting for local review boards.
 - Currently social media serves a variety of roles in research



SOCIAL MEDIA PERSPECTIVES

- Ethics of internet-based health research in Zimbabwe driven by external standards:**
-"MRCZ has not yet developed its own guidelines so it requires externally-funded studies to be compliant with EU General Data Protection Regulations (GDPR)." Zimbabwe health research professional
- Internet service providers determine guidelines about digital health research ethics:**
-"Most proposals are starting to use mobile platforms which are supposed to be CDPR compliant...but we find here people flout those rules." Zimbabwe health research professional
- Lack of staff leads to reliance on standardized review process:**
-"Considering if someone wants to do an internet-based study or via WhatsApp, you are [required] to format according to the standard template...do these generalities apply to the specifics of internet-based health research?" Zimbabwe health research professional
- Staffing and Infrastructure Issues:**
-"Capacity to do these reviews is low...people don't have time to actually review studies in an ethical manner...people on the boards are working people, so they can only manage to sit once a month." Zimbabwe health research professional
- On internet privacy and health information:**
-"It's not necessary to wear your private life on your sleeve. You can enjoy internet life without posting your private data. Posting private data is one of the key drivers of victimization and cyber bullying." Female, 23 years, 14 hours per week
-"It is two-sided. Sometimes sharing health information helps and encourages others who view the health information, the other bad side is you might be posting information that will not help or worsen other people's life." Female, 22 years

NEXT STEPS FOR SCOPING REVIEW

- Implications:**
- Identify the ways that social media is being used as a research tool
 - Create categories of social media research
 - Determine the frequency of ethical guidelines being used in social media research
- Impacts:**
- Categorizing social media research to facilitate the amendment of ethical guidelines
 - Will serve as evidence for social media ethical guideline recommendations



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