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Navigating Ethical Standards in International Health Research: Insights Drawn from Qualitative Engagements with Persons with Disabilities in Uganda

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Abstract

As Canadian investigators engaged in a qualitative project involving adults with and without disabilities in Uganda, we secured approval from four research ethics boards—two based in Canada and two located in Uganda. Ethical oversight in Canada is guided by the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2), while Ugandan researchers adhere to the National Guidelines for Research Involving Humans as Research Participants (NGRU). Despite obtaining authorization from all committees, the planning and execution of this study surfaced distinct ethical challenges, particularly around safeguarding participant privacy and ensuring adequate financial resources to support ethical practice. Our experience in the field brought forward three core areas that merit attention. First, we show that global health research often demands ongoing methodological and logistical recalibration to protect the confidentiality of participants—especially individuals with disabilities—even when researchers comply with both Canadian and Ugandan ethical standards. Strategies for gathering and storing data had to be continually reshaped in response to the practical context on the ground. Second, we found that stable and sufficient funding played a decisive role in enabling privacy-protective, disability-responsive research procedures. Without proper financial backing, it would have been impossible to recruit participants by disability category, region, or sex, or to employ local sign language interpreters. Third, although both the TCPS2 and NGRU highlight the centrality of privacy, they provide little explicit guidance on how these concerns manifest in global health and disability-focused research, nor do they adequately address ethical questions linked to financial constraints and resource allocation.

Research conducted in settings with limited resources and among participants with diverse access needs requires a thoughtful, context-aware application of ethical frameworks. We propose that both the TCPS2 and NGRU incorporate more explicit attention to global health research, disability inclusion, and responsible research practices. Strengthening these guidelines should be accompanied by comprehensive training opportunities for researchers at all levels, as well as for funding bodies, to better support ethical global health scholarship.

Keywords: Ethical standards, Disability, TCPS2, NGRU

Introduction

Within Canada, all researchers—regardless of seniority or training level—and the research ethics boards (REBs) overseeing their work must abide by the ethical framework laid out in the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2) [1, 2]. Adherence to this framework is not optional; it is a condition set by the federal granting agencies—the Canadian Institutes of Health Research, the Natural Sciences and Engineering Research Council of Canada, and the Social Sciences and Humanities Research Council—for obtaining and administering research funds. When studies extend beyond the Canadian context, as is often the case in global health research, investigators must also seek approval from the appropriate in-country REBs, whether at national or regional levels [3]. Conducting research in global health settings introduces a distinct constellation of ethical

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concerns, including limited local resources, heightened vulnerability among study populations, variations in human rights protections, and the unique position of doctoral and postdoctoral researchers working abroad [4]. Previous scholarship has underscored the value of engaging with how ethical guidelines operate in practice, especially in African contexts, in order to strengthen collaborative health research [5].

Our team, based in Québec, Canada, carried out the qualitative portion of a larger mixed-methods study in Uganda between November 2017 and April 2018. This broader project explored how laws and health policies shape access to sexual and reproductive health (SRH) services for persons with disabilities in Uganda. The qualitative component—described in detail elsewhere [6, 7]—included in-depth semi-structured interviews (n = 45) with individuals with varied disability types (physical, visual, hearing, mental, and intellectual), representatives of national organisations, and policy actors; focus group discussions (n = 9) involving healthcare professionals, disabled people's organisations, and people with disabilities; and non-participant observations of seven healthcare facilities located in three northern districts (Gulu, Amuru, and Omoro) and in the capital city, Kampala.

Ethics approval in Canada was sought from our institutional REB, which evaluates studies according to the TCPS2 principles of respect for persons, concern for welfare, and justice (TCPS2, article 1.1) [1]. The TCPS2 promotes a proportional review process, encouraging REBs to assess the specific vulnerabilities of populations such as minors, pregnant women, and people with disabilities, as well as the potential risks inherent in a given research design [1]. Additional ethical approval was obtained in Uganda at both national and regional levels, where the National Guidelines for Research Involving Humans as Research Participants (NGRU) [8] govern ethical review. The NGRU outline procedures intended to safeguard participant rights and welfare, uphold ethical standards, and ensure that research respects the sociocultural contexts of participating communities [8].

During the preparatory phase in Canada—and throughout the entire study period in Uganda—we completed all required review processes, receiving approval from the Centre de recherche du Centre hospitalier de l'Université de Montréal (CR-CHUM) (17.127-CÉR, 1 August 2017); later, following a change in Canadian affiliation, from the Research Ethics Committee in Sciences and Health of the Université de Montréal (CERSES-20-074-D, 13 May 2020); and from the Lacor Hospital Institutional and Research Ethics Committee (LHIREC-019/07/2017) and the Uganda National Council for Science and Technology (SS-4451, 14 November 2017). Despite this extensive formal review, the realities of working within Uganda's field environment compelled us to repeatedly reassess how the prescribed ethical norms translated into daily practice. Two central ethical challenges emerged—both connected to privacy—and an additional challenge related to the availability and stewardship of financial resources. These issues were especially critical because: (1) privacy is a core ethical requirement in both the TCPS2 and NGRU and is recognized as a fundamental right in Québec [9], Canada [10], Uganda [11], and internationally [12]; and (2) adequate and responsible financial support was indispensable for implementing procedures that respected participant privacy—particularly for persons with disabilities—and for upholding the principle of justice as articulated in the TCPS2 [2] and international documents such as the International Ethical Guidelines for Health-related Research Involving Humans [13].

Privacy in this context comprises three interconnected elements: privacy, confidentiality, and personal data protection. Privacy is generally understood as an individual's "right to be left alone" [14] and to remain free from unsolicited intrusion [1]. Within the TCPS2, confidentiality refers to the ethical and legal obligation of individuals or institutions to prevent unauthorized access, use, disclosure, modification, or loss of information entrusted to them [1]. Québec's legal framework on personal information protection [15] further emphasizes safeguarding data collected during and after research activities. Although the NGRU references privacy and confidentiality, it does not define them explicitly [8]. Uganda's 2019 Data Protection and Privacy Act expands on these concepts, stipulating that those who handle personal data must remain accountable to the data subjects and maintain robust security measures to protect the information they collect, process, or store [11].

Because neither the TCPS2 nor the NGRU provide explicit guidance on how financial considerations should be treated as ethical issues, we relied on the principles articulated in Canadian and Québec frameworks on responsible conduct of research to understand financial management obligations. According to the Canadian policy, researchers must ensure that all grant and award funds are used in strict accordance with agency

regulations and must submit documentation that is "true, complete and accurate" for any expenditures charged to those accounts [16]. Similarly, the Québec policy states that both individuals and institutions bear responsibility for the appropriate stewardship and distribution of research funds, emphasizing adherence to sound academic and financial practices and the efficient use of available resources [17].

Guillemin and Gillam highlight how qualitative research often exposes a gap between "procedural ethics"—the formal rules and review processes—and "ethics in practice," meaning the ethical decisions made in everyday fieldwork realities, a distinction made clearer through reflexive engagement by researchers [18]. In this paper, we offer our own considerations about applying ethics norms within global health qualitative research involving people with disabilities in Uganda, focusing particularly on issues of participant privacy and the ethical dimensions of securing and managing financial resources.

Main text

Management of participant privacy

Before departing for Uganda, we obtained approval from all required REBs. The submitted protocol described our planned procedures for data collection and analysis, the use of audio recordings, the transcription process, and the intended period of data and document retention. The consent material emphasized confidentiality and privacy, particularly for participants with disabilities. To facilitate comprehension among individuals with diverse disabilities, the forms were rewritten in simplified language, supplemented with pictograms, and translated into Luo/Acholi. Participants were told that their information would be kept secure and shielded from unauthorized access or misuse. The notion of "anonymity" was further employed to communicate that recordings and de-identified transcripts would be safeguarded in a secure space for ten years, in accordance with the requirements of the first Canadian REB (CR-CHUM).

During fieldwork in Uganda, and consistent with ethical commitments to autonomy, dignity, and respect for persons, each participant provided informed consent in the preferred language—Luo/Acholi, sign language, or English—[1, 8]. Individuals were reminded that participation was voluntary, withdrawal was possible at any time, and all personal information would remain confidential. When interviews were held with people with disabilities at their home or within local health facilities, efforts were made to ensure privacy. However, limited infrastructure meant that fully enclosed spaces were not always available. At times, interviews occurred outdoors—under a mango tree or behind a facility compound—where confidentiality could be compromised despite efforts to minimize visibility and noise.

Interactions with individuals with hearing impairments required additional logistical adjustments. Local sign language interpreters were engaged to ensure accurate communication. Because sign language is visible from a distance and private indoor spaces were often unavailable in rural villages, the research team carefully arranged seating and interpreter positioning to reduce the likelihood of being seen. These improvisations reflected an effort to work sensitively within local constraints. Some participants with disabilities even expressed a preference for outdoor interviews, considering them more comfortable and accessible. Interviews with national-level stakeholders, such as policy-makers, occurred privately within office settings. Focus groups were also held in discrete rooms—either within health facilities or in the offices of disabled people's organizations. For individuals who were deaf (7 of the 32 participants interviewed alone and 6 members of two focus groups), the use of sign language interpreters was indispensable, particularly because the researcher (MMS) did not speak Ugandan Sign Language or Luo/Acholi. To strengthen confidentiality protections, research assistants employed for the five-month field period signed a confidentiality agreement. Interpreters hired on an occasional basis provided verbal commitments to uphold confidentiality.

Data storage raised additional concerns. Although consent forms stated that transcripts would be preserved for ten years, how this long-term storage would be managed remained uncertain. Once data collection ended, the regional Ugandan REB asked that all original consent forms be stored in secured boxes in the administrative department of the collaborating hospital. The Canadian REB made a similar request. Unlike what the Canadian REB expected, these documents were not placed in locked offices in Canada but in a protected section of the Ugandan hospital, accessible only to authorized personnel. To meet Canadian requirements partially, MMS photocopied the forms and transported these copies to Canada, where they are now kept at MMS's home due to the absence of institution-provided

secure storage. Because the originals remain in Uganda, monitoring their long-term security—as mandated for the ten-year retention period—remains challenging.

Ambiguities also emerged regarding the secure storage of interview and focus-group recordings and transcripts. All files were password-protected, access was limited, and storage was handled through the Université de Montréal's cloud platform, which uses two-factor authentication. In 2018, Canada's three federal research funding agencies launched an online consultation on research data management [19]. The consultation revealed that many researchers perceived a lack of clear guidance within the TCPS2 and expressed uncertainty about whether responsibility for safeguarding personal data should lie primarily with individual researchers or with their institutions [20].

Research financing and its management

Ensuring adequate funding for the fieldwork in Uganda was central to upholding key ethics norms, particularly those concerning the equitable participation of women and men with a wide range of disabilities. Securing the financial resources allowed us to hire sign language interpreters and two research assistants who also provided translation support. These funds also enabled travel by boda-boda (motorcycle taxis) into rural villages—locations that cannot be reached by larger vehicles—to meet participants and engage with local stakeholders. These choices were not simply logistical decisions; they carried clear ethical implications. First, individuals—both with and without disabilities—who did not speak English or who relied on Ugandan Sign Language could be fully included in the research. Second, the study was not limited to the district urban centers or the capital but extended into more remote communities over several weeks, thereby broadening representation. Without these financial accommodations, respecting the TCPS2 principle of justice [1], related international guidelines [13], and ethical discussions in the literature [21] would have been impossible. Justice, as defined in the TCPS2, requires fair and equitable treatment of individuals and emphasises that recruitment itself is fundamental to this obligation [2]. In practice, this required us to recruit people across different impairment categories and not exclude anyone on the presumption that their disability rendered them unable to respond independently [22]. Achieving this goal, however, depended on having the means to reach participants with physical, sensory, or cognitive impairments in their homes or, alternatively, arrange transportation for them to interview sites. This included compensating boda-boda drivers and covering fuel costs, employing sign language interpreters, and paying for the travel expenses of guides assisting participants with visual impairments. Such decisions regarding the use of research funds directly influence whether people with disabilities are meaningfully included or inadvertently excluded.

Despite the ethical significance of these funding-related decisions, neither the TCPS2 nor the NGRU provide explicit guidance on research financing or the responsible allocation of funds. Although both documents discuss conflicts of interest, neither addresses how financial management should support ethical commitments such as inclusion. Instead, this topic is elaborated in other documents, namely the Canadian Tri-Agency Framework on Responsible Conduct of Research [16] and the Fonds de recherche du Québec's policy on responsible research conduct. Improving coherence and alignment across these various normative frameworks would offer clearer direction for researchers navigating such issues.

How can ethics norms be better addressed when conducting global health research with people with disabilities?

Many of the methodological and logistical adjustments carried out during the qualitative study were possible because MMS had previously worked for years alongside people with disabilities in sub-Saharan Africa. This experience informed decisions such as simplifying consent form language, incorporating pictogrammes, hiring sign language interpreters, and allocating funds specifically for these adaptations to ensure data collection was sensitive to disability-related needs. Such practical knowledge about communication and accessibility was essential for responding to on-the-ground ethical challenges—issues that could not have been fully anticipated or managed by relying solely on the general privacy principles outlined in normative ethics documents or REB requirements. Historically, people with disabilities—especially those with intellectual impairments—have either been exploited in research as "experimental subjects" or excluded entirely due to discriminatory attitudes and excessive paternalism [23]. To uphold the TCPS2 principles of fairness and equity in participation [1], earlier professional experience had shown us that careful financial planning was

indispensable. Funding made it possible to involve participants with different impairments, provide them a platform to articulate their perspectives, and ensure their voices were recognised [24]. The Canadian Coalition for Global Health Research similarly identifies the inclusion of historically marginalised groups as a foundational element of ethical global health research [25]. Exclusion is reinforced by entrenched power asymmetries, which can be countered not only by acknowledging marginalised communities but by deliberately amplifying their perspectives and contributions [26]. Scholars in global health increasingly argue that a more equitable research environment requires embracing epistemic positionality and committing to research practices geared toward social justice [27].

Drawing from these experiences of "ethics in practice," we offer three recommendations. First, the updated 2018 TCPS2 [2] would benefit from more explicit integration of ethics guidance related to global health research and disability, similar to the dedicated considerations already provided for qualitative methods and research involving Indigenous communities. Although there is extensive scholarship on global health research ethics [28–30], and more modest discussion on disability within global health due to persistent under-prioritisation [31], these areas remain insufficiently addressed in both the TCPS2 and the NGRU. Strengthening these sections would support researchers, funders, and REBs in addressing privacy-related concerns in a more robust and context-responsive manner. Previous studies have shown that some REBs lack comprehensive training on the full meaning and scope of privacy [32], highlighting the need for further national and provincial dialogue in both Canada and Uganda.

Second, because adequate funding and the ethical use of financial resources are deeply intertwined with the ability to achieve research objectives and uphold ethics norms, the TCPS2 and NGRU should more explicitly articulate guidance on financial availability and management. Neither document contains a dedicated section outlining how funding mobilisation relates to ethical principles such as justice. Providing practical examples of how financial decisions influence ethical conduct—especially in field contexts—would help researchers move beyond theoretical guidance and better anticipate the financial implications of meeting ethical commitments [18]. It would also draw attention to the ethical consequences of insufficient funding.

Finally, any enhanced attention to global health, disability, and responsible research conduct within these normative frameworks should be accompanied by expanded ethics training for global health researchers and trainees. Literature on qualitative research similarly stresses the need for improved training on privacy and related ethical considerations [33]. Such training could occur before or during protocol development and emphasise legal and ethical responsibilities associated with each stage of the privacy lifecycle, including data collection, use, storage, and destruction [34]. Ultimately, applying ethics norms related to privacy and financial management requires grounding theoretical principles in lived practice, particularly in the complex realities where global health research unfolds.

Conclusion

Carrying out studies in environments with limited resources and involving participants who have diverse needs necessitates a careful, context-aware application of research ethics within global health. This demands continuous reflexive engagement and a deliberate effort to anticipate and navigate the tension that often arises between formal, procedural ethics guidelines and the lived realities of qualitative global health research involving people with disabilities [4, 6, 18]. Upholding ethics principles and ensuring genuine participation of groups that have historically been marginalised, including people with disabilities, depends on forming a research team that recognises and respects disability rights [6]. Yet, ethical participation requires more than sensitivity alone—it calls for integrating disability-responsive methods into every stage of research, such as designing accessible materials (for example, consent documents enhanced with pictogrammes [6] or incorporating tools like photovoice [35]) and selecting team members with the necessary competencies.

Guided by on-the-ground experience in Uganda, our team had to repeatedly modify procedures to ensure the protection of participant privacy while maintaining fidelity to research goals. Critically, many essential accommodations would not have been achievable without sufficient financial support. To advance a fuller and more practical understanding of ethics norms, we propose strengthening the attention to global health research, disability, and responsible conduct of research in frameworks such as the TCPS2 and NGRU. This enhanced integration should be reinforced by dedicated

training—such as structured online courses—to help researchers develop rigorous data management plans and better grasp how to carry out responsible financial stewardship throughout the research process.

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