



# The need for improved ethics guidelines in a changing research landscape

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Globally, ethics guidelines for conducting research involving human subjects have been informed by practices and procedures developed for, and with reference to, medical research.<sup>1,2</sup> This indication is clear from international guidelines on research ethics practices, including the Belmont Report<sup>3</sup> and the Declaration of Helsinki<sup>4</sup>. Historically, developments of guidelines in research ethics, and procedures for ethics review, have often been reactive responses to critical events (i.e. ethics breaches) in medical research practice. The context for research ethics and clinical practice changes continually owing to developments in technology and medical procedures including genetics and robotics. Thus, ethics guidelines for research involving human subjects often lag behind developments in technology and medical science. Despite such guidelines, there are limitations as to the extent to which they can be applied to research that involves human subjects but in non-medical and non-therapeutic settings (here termed human participants). In this context, the term non-medical refers to the application of social science and humanities methodologies and instruments relating to human participants outside of medical, clinical or therapeutic settings. This type of research includes data collection using qualitative and interactive methods, such as interviews, questionnaires, workshops, focus groups and ethnographic observations.

Based on the foregoing, it is appropriate to ask whether national and global guidelines on research ethics involving human participants are fit for purpose, because (1) these guidelines have been developed mainly for medical rather than non-medical research and (2) they do not speak to the specific methods of data collection and analysis, and the nature of risk and vulnerability, used in many areas of the social sciences and humanities. The important point is that new research instruments and participant groups now available to social science researchers may give rise to new types of ethical issues related to confidentiality, anonymity, privacy and consent that are not covered by existing guidelines.

I contextualise these issues here using the example of human research ethics practices in South Africa, by first discussing the regulatory framework for research ethics, and then highlighting three key characteristics of non-medical human research in the 21st century that have implications for the applicability of national and international research ethics regulations and guidelines. Finally, I explore how research ethics guidelines might be changed, at both a national and international level, to address these issues. A key argument is that, at present, national and international research ethics guidelines are not fit for purpose because they do not consider the unique challenges of non-medical research in the 21st century. Thus, alternative guidelines are needed.

## Research ethics context in South Africa

The ethics of research practices involving human participants are regulated in South Africa according to the *National Health Act (Act 61 of 2003)*. The National Health Research Ethics Council (NHREC) was established under Section 72 in 2006 as the regulatory body to: provide oversight of the conduct and practices of human research ethics committees in South Africa; set and provide guidelines on the norms and standards for research involving human subjects/participants (and animals); and act as an adjudicating and disciplinary body to handle complaints and research ethics violations. The remit and scope of the NHREC accord with Section 12(2) in the Bill of Rights in the South African Constitution. In its 2015 guidelines<sup>5</sup>, the NHREC notes that non-medical research involving human participants should not follow the recommended ethics procedures for medical research, but there are no clear guidelines on what these procedures should be. Because there are no clear guidelines, different research institutions in South Africa have developed their own guidelines, which thus may give rise to uneven practices and procedures. Several international studies have discussed how such institutional review boards should operate, with a focus on their composition, guidelines and review workflow.<sup>6,7</sup> Specific issues related to the operation of institutional review boards in Africa are discussed by Kruger et al.<sup>8</sup> but these are framed almost entirely in a medical context.

## The changing context of non-medical human research in the 21st century

The context for non-medical research has changed in recent decades in response to technological change and new political and sociocultural contexts. Previous studies reflecting on some of these changes have been viewed through narrow disciplinary lenses.<sup>9-11</sup> Three key overarching issues affecting all disciplines and types of data are discussed here. It is notable that none of the existing national and international ethics guidelines explicitly consider all the factors discussed here.

### 1. Data types and methods of data collection

Recently, more complex ideas on the definition of research 'data' in the social sciences and humanities have arisen together with the data collection methods to be used.<sup>9</sup> The term 'data' currently encompasses a range of evidence, or information, from primary and secondary sources, and in a range of formats, many of which are informal and transient. Previously, the main data types were written (textual) and verbal information obtained directly from individual research participants. However, multimedia and digital data types are also now used, and may be based on indirect (rather than face-to-face) interactions with individuals or larger groups, such as in online communities.<sup>12</sup> In addition, data may be derived from secondary sources, such as online discussion forums, vlogs or communication modes such as Twitter, where individuals respond to or report other people's thoughts or ideas either in the public domain or in semi-closed (members') forums. In addition, the instruments used to collect data of these types have also changed, to include smart phones and Internet technologies, 'big data' of different sorts (including data on individuals), telemetric systems, the Internet of Things, datafied spaces, smart cities, and streamed data and audiovisual services.<sup>13</sup> These data types can be considered to be transient;

they change in meaning, context and availability, often with uncertain and unclear demarcations of public and private spaces, together with varying degrees of confidentiality and anonymity of individuals.<sup>14,15</sup> In addition, data archiving and the ability of other researchers to validate data sources is problematic if these data are no longer available, as is often the case with digital data.

These data types and different data collection methods pose problems for the traditional model of a research project where the project is initiated, data collection takes place, and the project terminates. In the digital world, start and end points are more difficult to identify and to circumscribe within the confines of a research project. This also means that traditional concepts such as researcher–participant relationships are more complex.

## 2. Relationships between researcher and participant

There are few guidelines as to how researchers should engage with participants in different types of studies. This dearth may reflect a traditional viewpoint that participant groups are uniform, amorphous and characterless, and that researchers may treat individuals as powerless objects to be exploited. However, researchers no longer exist in ivory towers distant from participants. Researchers and participants now enjoy more informal, direct, lively and interactive exchanges, often in the form of interactive data collection methods including ethnographic observations and participatory methods including workshops, art activities, participatory mapping and autoethnography. Within these different research methods, participants may be active agents of data creation and collection. This approach is often collaborative, and participants are not mere passive vessels from which the researcher extracts pre-formed data. Also, participants now often have greater engagement with the researcher throughout the research process, not just in its data collection phases, and they may show greater interest in the nature, purpose and outcomes of the research. A current emphasis in social science research attempts to ensure the authentic voice of the participant. This idea is set within wider issues in social science research, and in global society more generally, of awareness of patriarchy, power relations/privilege, gender, sexuality and race, which may impact on researcher–participant relations, data quality and data interpretation.<sup>16</sup> In a South African context, these issues fall within the broader concept of ‘transformation’.

These changed contexts of researcher–participant relationships and their changed nature of interactions require more careful consideration of consent, anonymity and confidentiality, which may be more difficult to obtain if researcher–participant interactions are informal, of short duration, or not face-to-face.

## 3. Managing participant confidentiality, anonymity and data protection

Issues of confidentiality and anonymity are more difficult to handle in cases in which research involves the use of digital or open-source data including social media, or in which human-subject issues are in the public domain. It may also be more difficult to guarantee confidentiality and anonymity for both data collection and results reporting. Several recent studies have concerned issues regarding social media privacy settings<sup>17</sup>, highlighting the fact that users are commonly unaware that their personal data may be potentially shared with other commercial entities or analysed for research purposes. Issues of confidentiality and anonymity are also important where potentially sensitive data may be disclosed. The Department of Health ethics guidelines<sup>5</sup> list race, political opinion, religion, trade union membership, physical or mental health, sex life and criminal convictions in this category of ‘sensitive data’.

Another key issue is the potential ephemeral nature of digital data (if a webpage has since been removed, does it remain a valid source of data?), the validity of data of different types, especially in an online community space (‘fake news’), and the viewpoint that not all different data types are of equal value. With such data, there may be tensions with data protection rules, where restricted data access may limit the capacity of future workers to get access to, to verify or validate previous data interpretations, or to identify any incorrect, falsified or suppressed data.

In South Africa, the *Protection of Personal Information Act (POPI) (Act 4 of 2013)* clarifies the individual’s right to privacy, with implications for how researchers manage the collection, storage and management of or access to data, and takes into account both anonymity and confidentiality issues. ‘Privacy’ is easier to assure with data such as old-style individual interviews, questionnaires and focus groups, and for which present guidelines can be applied. However, the use of digital and online materials as source data is potentially problematic for privacy, and with respect to the interpretation of the POPI Act when secondary data, such as those from the public domain, are reused. There may also be potential contradictions between fulfilling the requirements of data privacy under the POPI Act and fulfilling the requirements of some public funding bodies (such as South Africa’s National Research Foundation) to ensure data availability/access. The ethical implications of these different data access strategies have not yet been fully explored.

## Future directions in human research ethics

The nature of human research in the social sciences and humanities has changed significantly in the last decades, mainly as a consequence of changing technology which has enabled new types of interactions between researchers and participants.<sup>18</sup> This change has in turn led to challenges in the ways in which research may be conducted ethically, particularly with respect to participant anonymity and confidentiality. Existing national regulations and international guidelines on research ethics lag behind changing technologies and the needs of both researchers and participants, who thus may not be adequately protected under these regulations and guidelines. Moreover, these guidelines do not help researchers or institutional review boards to manage sufficiently the ethical issues related to these new modes of data collection. Action is needed at national and international levels to address this gap.

New technologies have made longitudinal and more interactive studies easier and richer, given the more complex data types, sources, data volumes and individual voices involved. However, a downside is that issues of anonymity, confidentiality and informed consent are more complex, as the research process becomes more multifaceted. These issues are particularly relevant to the developing world where consideration of risk, vulnerability and coercion are important historically<sup>19</sup>, and where wider issues of power, privilege, gender, race and corruption also influence researcher–participant relationships. In South Africa, continued socio-economic, political and cultural change provides a dynamic landscape in which to undertake social and humanities research.<sup>20</sup> However, this requires research ethics practices that are responsive to the changing needs of both society (including government) and researchers, and balancing the generation of appropriate data in order to find developmental solutions for communities that are often vulnerable or marginalised, while retaining and listening to their authentic voices.

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