

---

12-4-2020

## Power-Laden (Mis)Understandings Surrounding Written Voluntary Informed Consent Procedures in Postcolonial Southern Africa

Michelle R. Brear

Monash University, [michelle.brear@monash.edu](mailto:michelle.brear@monash.edu)

Follow this and additional works at: <https://nsuworks.nova.edu/tqr>

 Part of the [Quantitative, Qualitative, Comparative, and Historical Methodologies Commons](#), and the [Social Statistics Commons](#)

---

### Recommended APA Citation

Brear, M. R. (2020). Power-Laden (Mis)Understandings Surrounding Written Voluntary Informed Consent Procedures in Postcolonial Southern Africa. *The Qualitative Report*, 25(13), 71-89. Retrieved from <https://nsuworks.nova.edu/tqr/vol25/iss13/6>

This Article is brought to you for free and open access by the The Qualitative Report at NSUWorks. It has been accepted for inclusion in The Qualitative Report by an authorized administrator of NSUWorks. For more information, please contact [nsuworks@nova.edu](mailto:nsuworks@nova.edu).

**Qualitative Research Graduate Certificate**  
*Indulge in Culture*  
Exclusively Online • 18 Credits  
**LEARN MORE**

NSU  
NOVA SOUTHEASTERN  
UNIVERSITY

NOVA SOUTHEASTERN

## Power-Laden (Mis)Understandings Surrounding Written Voluntary Informed Consent Procedures in Postcolonial Southern Africa

### Abstract

Written voluntary informed consent (VIC) procedures are the standard approach for operationalising the ethical principle of respect for persons' autonomy in qualitative research. However, achieving fully informed and truly voluntary consent is challenging, particularly in qualitative research and/or postcolonial contexts. Evidence about (mis)understandings (i.e., unintended meanings) surrounding VIC comes primarily from participants in quantitative, biomedical research. I aim to advance knowledge about qualitative research participants' (mis)understandings of VIC. I used ethnographic methods to document the evolving (mis)understandings participants attached to written VIC procedures in two postcolonial settings, Eswatini and South Africa. All participants provided me consent to document their interactions as co-researchers in participatory research, in which they learned about, designed and implemented VIC procedures. I analysed the data interpretively and abductively, informed by Bourdieu's theory of practice. Participants valued the opportunity to decide and sign consent to participate but held (mis)understandings of study information and signing, which evolved as they participated. Many (mis)understandings were shaped by what the unfamiliar act of signing symbolised to them (i.e., binding, contractual agreements that protected the researcher/university and through which they relinquished their rights), from their positions of marginalisation amidst economic/material, cultural and social power inequalities. In postcolonial settings, requiring qualitative research participants to sign consent forms likely undermines the ethical principle of respect that VIC is intended to operationalise. Based on these findings I recommend alternative non-written procedures are used to operationalise the principle of respect in postcolonial qualitative research settings.

### Keywords

Power, Post-Coloniality, Voluntary Informed Consent, Research Ethics

### Creative Commons License



This work is licensed under a [Creative Commons Attribution-NonCommercial-Share Alike 4.0 License](https://creativecommons.org/licenses/by-nc-sa/4.0/).

### Acknowledgements

I greatly appreciate the time, knowledge, and energy the participants contributed to this research. During the fieldwork and preparation of this article I was supported by an Australian Postgraduate Award (Monash University) and a Postdoctoral Research Fellowship (University of the Free State). An earlier version of this paper was presented at the 4th World Conference on Qualitative Research (WCQR2019) in Oporto, Portugal, October 16th to 18th 2019. <https://2019.wcqr.info/world-conference-on-qualitative->

---

research/

## **Power-Laden (Mis)Understandings Surrounding Written Voluntary Informed Consent Procedures in Postcolonial Southern Africa**

Michelle R. Brear

School of Education Studies, Faculty of Education and Afrimontane Research Unit,  
University of the Free State, Qwaqwa Campus, South Africa  
Global and Women's Health, Monash University, School of Public Health and Preventive  
Medicine, Australia

### **Abstract**

Written voluntary informed consent (VIC) procedures are the standard approach for operationalising the ethical principle of respect for persons' autonomy in qualitative research. However, achieving fully informed and truly voluntary consent is challenging, particularly in qualitative research and/or postcolonial contexts. Evidence about (mis)understandings (i.e., unintended meanings) surrounding VIC comes primarily from participants in quantitative, biomedical research. I aim to advance knowledge about qualitative research participants' (mis)understandings of VIC. I used ethnographic methods to document the evolving (mis)understandings participants attached to written VIC procedures in two postcolonial settings, Eswatini and South Africa. All participants provided me consent to document their interactions as co-researchers in participatory research, in which they learned about, designed and implemented VIC procedures. I analysed the data interpretively and abductively, informed by Bourdieu's theory of practice. Participants valued the opportunity to decide and sign consent to participate but held (mis)understandings of study information and signing, which evolved as they participated. Many (mis)understandings were shaped by what the unfamiliar act of signing symbolised to them (i.e., binding, contractual agreements that protected the researcher/university and through which they relinquished their rights), from their positions of marginalisation amidst economic/material, cultural and social power inequalities. In postcolonial settings, requiring qualitative research participants to sign consent forms likely undermines the ethical principle of respect that VIC is intended to operationalise. Based on these findings I recommend alternative non-written procedures are used to operationalise the principle of respect in postcolonial qualitative research settings.

*Keywords:* Power, Post-Coloniality, Voluntary Informed Consent, Research Ethics

Voluntary informed consent (VIC) procedures are intended to translate the principle of respect for persons into ethical research practice, that is, to ensure prospective participants make autonomous (fully informed and uncoerced) decisions about whether or not to participate in research (Hoeyer & Hogle, 2014). However, written VIC procedures often fail to achieve their intent (Hoeyer & Hogle, 2014) especially in qualitative (Pollock, 2012) and/or postcolonial research settings (Sabati, 2019). In this article I present findings about

participants' power-laden (mis)understandings of written VIC procedures in qualitative studies in the Kingdom of Eswatini and the Republic of South Africa (RSA).

### **Origins of written voluntary informed consent (VIC) procedures**

Voluntary informed consent was first formalised in biomedical research ethics guidelines, designed to regulate positivist, experimental research (Hoeyer & Hogle, 2014). It typically involves providing prospective participants with written study information and asking them to sign a consent form if they agree to participate. These written VIC procedures are intended to fulfil the ethical principle of respect for persons, which captures a researcher's commitment to regard participants' autonomy in deciding about research participation (Hoeyer & Hogle, 2014). The institutionalisation of written VIC procedures was a response to, and an attempt to prevent future instances of, forced and/or deceptive medical experimentation in the Global North (e.g., Nazi doctors' experiments on prisoners of war, deceptive experiments on Black men with syphilis in the United States; Sabati, 2019). These extreme instances of unethical medical experimentation, although often presented as anomalies within an otherwise principled history of research (Sabati, 2019), occurred amidst ubiquitous, albeit more subtle, forms of research participant coercion and/or deception in the colonies of the Global South (e.g., collaborating with authoritarian traditional chiefs who enforced participation; Graboyes, 2010).

It is perhaps unsurprising, given this history, that once-off, written VIC procedures, quickly became a cornerstone of biomedical research ethics. They have since been adopted, essentially unchanged and with limited debate, in qualitative research (Bell, 2014; Emmerich, 2017; Hébert et al., 2015). Ethical review boards now typically expect qualitative researchers to operationalise the principle of respect by incorporating written VIC procedures into their study designs (Bell, 2014; Emmerich, 2017; Librett & Perrone, 2010). The potential for written VIC procedures to operationalise the principle of respect rests on numerous assumptions about individual understanding, autonomy and agency (Corrigan, 2003). Available evidence suggests these assumptions, which are underpinned by positivist, Western/modernist worldviews, are unfounded (Bell, 2014; Corrigan, 2003; Geissler, 2013; Sabati, 2019).

### **Assumptions underpinning and limitations of written VIC procedures**

From the Western/modernist perspective, prospective participants are rational, autonomous individuals who decide freely about research participation based solely on study information presented to them (Miller & Boulton, 2007). Participants cannot, from this perspective, make legitimate decisions without "fully" understanding the nature of study participation (Dixon-Woods et al., 2007). "Fully informed" (in writing, about study risks and benefits and their right to decline or withdraw) is presumed the ideal basis for making a consent decision (Miller & Boulton, 2007). Prospective participants are assumed to understand information exactly as researchers' intended them to (i.e., "fully") and have the capability to enact their right to decline or withdraw, so long as they have read study information (Afolabi et al., 2014; Miller & Boulton, 2007). Research shows that these assumptions are unfounded and limit the extent to which written VIC procedures fulfil their ethical intent in diverse research contexts. The limitations are amplified in qualitative (Bhattacharya, 2007; Emmerich, 2017) and/or postcolonial (Sabati, 2019) research settings.

Assuming that all participants will not only derive the same specific meaning from, but achieve "full" understanding of a study based on written information, is incongruent with empirical evidence. For example, participants understand the same information differently because they interpret it with reference to their familiar social norms, circumstances and

expectations (Dixon-Woods et al., 2007; Molyneux, Mulupi, Mbaabu, & Marsh, 2012). When information and expectations diverge, prospective participants may “resist the explanation offered in the text” (Dixon-Woods et al., 2007, p. 2218), resulting in them deriving meanings that researchers did not intend them to [herein termed (mis)understandings]. For example, some participants sign consent (mis)understanding that they will benefit from participation, after reading study information stating they will not benefit (Dixon-Woods et al., 2007; Molyneux et al., 2012).

Presenting prospective research participants with written study information also assumes that the primary reason, and only legitimate motivation for participation in research, is “full” understanding of and support for the research agenda (Miller & Boulton, 2007). Empirical evidence suggests to the contrary, that participants’ motivations are diverse. For example, many participate hoping for personal (e.g., free medical treatment) and/or societal benefits (e.g., availability of better treatments for others like them; Miller & Boulton, 2007; Molyneux et al., 2012).

### **Concerning effects of written VIC procedures**

Asking participants to sign a form stating they have fully understood and agree to accept the risks and benefits of participating, places the onus for understanding, and importantly the responsibility for risk, on readers (i.e., participants; Bell, 2014). It effectively makes ethical, experiments that would otherwise be considered inappropriate (Hoeyer & Hogle, 2014). The quasi-legal written consent form, presented in study information as a type of participant protection, equally protects (powerful) research institutions from compensation claims, should participants experience harms (Dixon-Woods et al., 2007; Hoeyer & Hogle, 2014; O’Connell Davidson, 2008; Sabati, 2019).

The ways in which signed consent forms shift responsibility to participants is a significant concern, given that participants’ often (mis)understand what participation entails and/or their right to decline or withdraw. The increasing willingness to decline research participation in Western settings, appears to result from rights-affirming social processes and lifestyle changes (e.g., women’s increasing workforce participation). Substantive changes to VIC procedures that might plausibly explain this increased willingness to decline have not occurred (Miller & Boulton, 2007). Despite the changes, participants in Western settings continue to provide consent without voicing concerns or questions (Wade, Donovan, Lane, Neal, & Hamdy, 2009; Woolfall et al., 2013).

### **Limitations of written VIC procedures in qualitative research**

The limitations of written VIC procedures are amplified in qualitative research. The contractual, quasi-legal procedures required by ethical review boards are, according to some scholars, entirely “incommensurable with the relational, emergent” (Sabati, 2019, p. 1056) nature of qualitative research, in which it is impossible to fully inform prospective participants about the nature of participation. The mismatch occurs because studies are intended to be open-ended, exploratory and iterative (Bell, 2014; Bhattacharya, 2007; Josselson, 2007). Written VIC procedures epitomise a contractual approach to ethics that is incongruent with the relational ethics of care that qualitative researchers consciously attempt to develop with participants (O’Connell Davidson, 2008).

The [typically “unknown” because it is unarticulated (Geissler, 2013)] second purpose of the consent contract, [i.e., protecting researchers and their institutions (Dixon-Woods et al., 2007; O’Connell Davidson, 2008; Sabati, 2019)], is inconsistent with this relational ethics. It requires the researcher “do no harm,” regardless of the participant’s consent (Bhattacharya,

2007; Hoeyer & Hogle, 2014; O'Connell Davidson, 2008). Further, the consent “contract” is limited to the data collection aspects of research, whereas in qualitative studies harm is more likely to occur from data interpretation and negative/deficit representation/objectification of research participants (Chilisa, 2017; Librett & Perrone, 2010; O'Connell Davidson, 2008; Sabati, 2019; Smith, 2013; Yanar, Fazli, Rahman, & Farthing, 2016). It is meaningless to ask qualitative research participants for consent until they know how they will be represented in research reports (Brear, 2019; O'Connell Davidson, 2008). However, ethical review boards do not require researchers to inform participants about their (somewhat mystical) interpretive analytical and narrative creation processes; they only need permission to collect data (Miller & Boulton, 2007).

Written VIC procedures that are intended to respect and protect participants, paradoxically, increase potential for harm in qualitative research (Librett & Perrone, 2010; O'Connell Davidson, 2008). The process of signing one's name on a written form, which the researcher keeps as part of their record, makes participant anonymity impossible (Librett & Perrone, 2010). It potentially undermines confidentiality, which is especially salient in qualitative research because being identified in deficit representations is often the biggest risk (Librett & Perrone, 2010; Sabati, 2019).

These limitations of written VIC have been highlighted primarily by qualitative, especially ethnographic, researchers reflecting on their own practice. Empirical studies of qualitative research processes and/or participant perspectives are limited. However, an emerging body of empirical (primarily quantitative, biomedical) research documenting the limitations of written VIC in postcolonial contexts, broadly concurs with the insights developed by reflexive, qualitative researchers.

### **Limitations of written VIC procedures in postcolonial contexts**

The empirical, biomedical research literature from postcolonial contexts demonstrates that participants often (mis)understand the plausible risks and benefits of (Tam et al., 2015), and/or their right to decline (Brear, 2018; Molyneux, Wassenaar, Peshu, & Marsh, 2005), participation. Study participation is often motivated by reasons other than support for the study aims. Most prominently, participants are motivated to participate by the hope of accessing essential goods and services (Molyneux et al., 2012), amidst economic/material inequalities that are typically unacknowledged (Geissler, 2013).

Evidence from postcolonial contexts indicates that many participants in medical experiments (mis)understand that drugs are being tested (i.e., are unproven), a phenomenon referred to as “therapeutic misunderstanding” (Tam et al., 2015). For example, 29% of participants in a trial of vaginal microbicides designed to prevent HIV in the Democratic Republic of Congo, did not understand the experimental nature of the drugs, at one or more of four “continuous” consent sessions (Vallely et al., 2010). A systematic review of 21 studies measuring consent comprehension of trial participants in African countries showed that only half of consenting participants in 10 trials understood the risks of study participation (Tam et al., 2015).

The right to decline or withdraw from participation is also poorly understood in postcolonial settings. In the above-mentioned review of research conducted in African countries, one in five participants in eight studies did not comprehend the concept of voluntary participation and less than a third understood the right to withdraw. Prospective participants' willingness to decline or withdraw was limited by perceptions that doing so would be disrespectful and/or result in restricted access to health services (Tam et al., 2015). The extent to which participation is voluntary in postcolonial settings is also limited by economic/material deprivations, that are actively “unknown” (i.e., obscured because they go unstated and

unacknowledged, although everybody knows about them; Geissler, 2013). Although academics maintain a façade of participant autonomy, many biomedical research participants report that accessing otherwise inaccessible forms of health care for themselves or their children, is the key motivation for study participation (Geissler, 2013; Molyneux et al., 2012; Tam et al., 2015). The Western research ethics expectation that participants engage in research autonomously, on terms set by academics (i.e., not for benefits) is especially problematic in postcolonial contexts. It “actively unknow[s]” (Geissler, 2013, p. 13) research participant’s lived experiences of economic deprivation and delegitimises their embodied knowledge in ways incongruent with the decolonial ethics of respect for indigenous belief systems (Chilisa, 2017; Dixon-Woods et al., 2007).

There are other limitations of written VIC procedures related to philosophical differences, in postcolonial contexts (Sabati, 2019). The notion of individual autonomy is not given the same primacy in many Indigenous/colonised belief systems, as it is in Western/colonial belief systems, for example because relational conceptualisations of decision-making and social life are embraced (Chilisa, 2017; Smith, 2013) and/or due to historic denial of individual rights and autonomy (Brear, 2018; Graboyes, 2010). Written VIC procedures may be foreign and even culturally insensitive or intimidating, in societies which follow oral traditions (Baydala et al., 2013; Chilisa, 2017) and/or in which people have historically been deceived into signing away their rights (Ferreira & Serpa, 2018; Smith, 2013). The limitations of maintaining impersonal relations between researchers and research participants, from positivist research philosophies, are also amplified in postcolonial contexts, where purposefully developing equitable relations of respect and understanding is fundamental to a “decolonising” research ethics (Chilisa, 2017; Smith, 2013). The neglected ethics of representation requires more attention and has potentially greater adverse consequences in postcolonial contexts given the history of deficit-focused representations of colonised people in the “scientific” literature (Smith, 2013). These deficit narratives result from Western researchers analysing data and writing research reports from a philosophical perspective that assumes the superiority of Western/modern norms and views all divergence from these as deficits of other (colonised) groups, often to justify colonial domination (Chilisa, 2017; Sabati, 2019; Smith, 2013).

## **Aims**

Given this historical context, specific guidance regarding the design and implementation of VIC procedures in qualitative, postcolonial research settings, has great potential to optimise ethical practice. However, empirical evidence documenting (mis)understandings about VIC among qualitative research participants in postcolonial settings is lacking. My aim therefore is to improve understanding of the nature and process of (mis)understandings in qualitative, postcolonial research settings. The research questions are:

1. What (mis)understandings occur in relation to written VIC procedures in qualitative, postcolonial research settings?
2. How do these (mis)understandings occur?
3. How could VIC procedures be transformed to minimise these (mis)understandings?

## **Study design**

I abductively (Timmermans & Tavory, 2012) analysed ethnographic data documenting the VIC-related experiences of 21 community co-researcher participants. They were involved in participatory research (PR) projects, in two postcolonial, southern African nations, the

Kingdom of Eswatini (formerly Swaziland; duration 15 months, 2013-2014) and the Republic of South Africa (RSA; duration 9 months, 2018-2019). Both studies utilised multiple methods approaches (i.e., involved two inter-related component studies) that incorporated an ethnography of the process and outcomes of PR and a PR project implemented in partnership with community co-researchers. In Eswatini the PR research topic was health capability in a rural community caring for children affected by AIDS. In RSA, the topic was migration and sustainable development. In each PR, the co-researchers (as participants) provided me written VIC to collect ethnographic data about them. They also (as co-researchers) developed and implemented procedures to obtain written VIC from participants in the qualitatively-driven PR projects.

### Setting and participants

Both the Swazi and South African study communities were characterised by considerable structural marginalisation and economic/material deprivation. The Swazi study occurred in a rural, subsistence farming community where all of the approximately 1,000 community members were *Emaswati* (of the *Swati* linguistic group) and Black people (a term the participants used to identify themselves and other community members, and opposed to White, a term they used to describe me and others with skin tones similar to mine). I use the terms Black and White, cognisant that the use of race categories in social research has potential to perpetuate a racialized view of the world. I feel such a racialized view is necessary in this study because, (a) the legacy of racism and self-identification with a race category was salient for the participants and my analysis and (b) alternative categories that adequately capture historic experiences of racism on the African continent have not yet been developed (Erasmus, 2012; Erwin, 2012)]. Food insecurity, poverty and unemployment were widespread and basic services (e.g., health, education, water and electricity) were difficult to access due to geographic isolation and limited infrastructure. The community was governed according to a quasi-feudal system, in which a chief administered unwritten laws, on behalf of the Swazi King, Africa's last absolute monarch. In RSA, the study community had developed little since the Apartheid-era when it was created as a Black "homeland" (i.e., racially-segregated area). The population of some 330,000 remained almost exclusively Black [as opposed to White or Coloured, the other "race" categories constructed in the Apartheid era and widely used in social research, including the national census and demographic and health survey (Erwin, 2012)] and predominately Basotho (of the *Sotho* linguistic group) people. Poverty and unemployment were widespread and basic services (waste management, water and electricity) functioned sporadically (Stats SA, 2018). These deprivations occurred despite decades-old democratic governance structures and constitutional guarantees of agency and opportunity (Nishimwe, 2018).

The partner communities and organisations were selected because I had historically participated in their development activities. Individual participants were selected purposively because they were co-researchers in PR projects I was facilitating. In Eswatini, the co-researchers were selected for age and sex diversity, and with input from community development activists, from a group who expressed interest in being co-researchers in response to local advertisements. Written VIC procedures were conducted in individual sessions in the two-weeks prior to the study. Prospective participants were given time to share information with, and consult others (e.g., their families), before deciding. In RSA, the co-researchers were selected via the leaders of two community-based youth-focused organisations that I partnered with to conduct the PR. I conducted written VIC procedures with the prospective participants as a group, at the commencement of a series of workshops I conducted to generate data for the ethnographic component of the study. This was my first opportunity to meet with the

prospective participants independently of their organisation's leaders, who I was concerned might coerce them to accept my invitation. As such, prospective participants in the South African study were asked to make an immediate decision, amidst other prospective participants. All invited individuals in both countries decided to participate and provided consent by signing a form. The participants were 10 women and 11 men aged 18-45 years at the time the studies commenced.

### **Methodology and research procedure**

Data were primarily generated during workshops, in which the co-researchers undertook a range of participatory activities (e.g., debates, small group discussions and role plays). I adapted the activities from participatory methods tool kits (Chambers, 2002; IAA, 2009) to facilitate the co-researchers' participation in (a) study design and (b) reflecting on their experiences being co-researchers. Each project included several activities dedicated to thinking critically about and developing locally specific protocols for operationalising, the Western ethical principles and procedures (including respect and VIC) that I was required to adhere to as a university-affiliated PhD student (Eswatini) and postdoctoral fellow (RSA). In addition to teaching the participants about the academic intentions and philosophy of VIC and respect for persons, the activities encouraged them to consider local norms and reflect on their own experiences and understandings of providing me consent, to inform the design of VIC procedures for their PRs, that would be academically-compliant and culturally-appropriate. Data were also generated through informal discussions before, during and after these workshops.

### **Data collection and preparation**

In both studies the core method of data collection was participant observation. I collected data openly (i.e., took notes in view and with knowledge of the participants) as I facilitated the participatory activities and workshops and during related informal discussions. Supplementary data were collected through audio-recorded individual interviews (RSA, N=4) and focus group discussions (Eswatini, N=22, of which 3 enquired explicitly about VIC) during which I enquired directly about the co-researchers' experiences providing and/or obtaining written VIC. All data were collected in English, the participants' second language. Handwritten participant observation notes were expanded during transcription within 24 hours of the events they documented. I transcribed interviews and focus groups verbatim.

### **Data analysis**

In the initial stage of data analysis, which occurred iteratively throughout the projects, I used directed content analysis (Hsieh & Shannon, 2005) to categorise each ethnographic data corpus into meaningful categories. This qualitative content analysis approach enables systematic but subjective categorisation, in relation to existing theory (deductive) and insights generated through examining the data (inductive; Hsieh & Shannon, 2005). For each study I deductively developed an initial coding frame, which I expanded inductively, as I read, re-read and coded the entire data corpus. My deductive coding frame for the first (Eswatini) study broadly categorised data excerpts as related to "PR process and outcomes" and "health capability," each with several sub-codes. For example, based on existing theory indicating that PR should be empowering, and improve the research design and efficiency, I included sub-codes for empowerment, research changes and efficiency). I inductively added "ethics" as a sub-code of both empowerment and research changes in my early analysis. As the ethnographic

data corpus expanded and I undertook further reading and coding, I split the “ethics” codes into more specific topics (VIC, beneficence, confidentiality, research integrity). In the ensuing South African study, I included the ethics codes in the initial (deductive) coding frame.

In both studies, my directed content analysis indicated that VIC was an important aspect of the process and outcomes of PR, that required further consideration, from a different perspective. I therefore conducted sequential analysis, that is, analysis of a focused data set utilising a different analytical technique (Simons, Lathlean, & Squire, 2008), in this case interpretive (Denzin, 2001), abductive (Timmermans & Tavory, 2012) analysis of the data tagged to the VIC code. Interpretive analysis focuses on critically inferring meaning from people’s narratives of their experiences, and connecting personal dilemmas to broader social issues (Denzin, 2001). Abductive analysis refers to a “recursive process of double-fitting data and theories... through a dialectic of cultivated theoretical sensitivity and methodological heuristics” (Timmermans & Tavory, 2012, pp. 179-180). While it incorporates grounded theory’s systematic methodological techniques (iterative readings, systematic coding, attention to surprising data and constant comparison) it rejects the notion that researchers should (or even could) approach data analysis from a theoretically naïve standpoint. Rather, abductive analysis requires a researcher to have read and be able to consider a range of literature and theories and their degree of fit with the data at hand (Timmermans & Tavory, 2012). I considered my data in relation to existing research ethics literature (see introduction) and Bourdieu’s (1990) theory of the “logic of practice”. I had come (through related analyses of my PhD data) to consider Bourdieu’s theory well suited to the data, after also considering theories that under-emphasised the influence of social structure or individual agency [e.g., Habermas’ (1984) “deliberative democracy” and participatory development and research theories (Chambers, 1997, 2015)].

### **Theoretical framing**

Bourdieu’s (1990) logic of practice posits that all actions are structured by *habitus*, which theoretically represents embodied historic experiences, and constantly structures, and is structured by, new experiences (Bourdieu, 1990). A purely theoretical construct, *habitus* conceptualises the “active [but hidden] presence of past experiences” (Bourdieu, 1990, p. 54), in tacitly motivating future practices. *Habitus* shapes an individual’s unique knowledge of what is “possible... and likely to be positively sanctioned” (Bourdieu, 1990, pp. 55-56), for people like them (i.e., with a similar place in the social power hierarchy in which they operate). *Habitus* motivates people to choose practices that best match their position of social power, within a specific social *field* (a defined set of social relations), more reliably than “all formal rules and explicit norms” (Bourdieu, 1990, p. 54). All individuals participate in multiple, overlapping social fields in which they occupied a different position in the power hierarchy. Their position is determined by the field-specific value of the power/capital (Bourdieu used these terms interchangeably) they possess (Bourdieu & Wacquant, 1992).

Bourdieu conceptualised multiple forms of (economic, social and cultural) power/capital, as each occurring in actual (explicit) and symbolic (hidden) forms (Bourdieu, 1986). He proposed that social relations were inherently characterised by power inequalities and that the rules that governed social interactions were always written by and in favour of those atop the power hierarchy of a particular field (Bourdieu & Wacquant, 1992). Cognisant of the power relations inherent to research, and the ways these predisposed academics to uncritically accept the value of their practices (e.g., ethical procedures), Bourdieu advocated reflexive sociology. He advised researchers to turn their ethnographic gaze inward in order to systematically and critically examine their own research processes (Bourdieu & Wacquant, 1992).

Bourdieu's logic of practice and reflexive sociology provide a comprehensive framework for understanding how prospective research participants "know" what they are expected to do without (or despite) explicit instructions. It conceptualises practices, not as technical behaviours but as logical responses to power inequalities, which are a defining feature of post-colonial societies and research interactions (Bell, 2014; Sabati, 2019). It is thus well-suited as a framework for interrogating my data documenting participant (mis)understandings of written VIC procedures in qualitative, post-colonial research processes.

## Findings

### Evolving (mis)understandings

Both male and female participants of various ages had (mis)understandings (i.e., unintended but not necessarily incorrect understandings) when they signed their consent forms. (Mis)understandings differed among participants who had read the same information. They evolved during the studies and occurred, to greater or lesser degrees, for all participants. They were related to: (1) the value of written VIC procedures; (2) researchers' and participants' rights and responsibilities; (3) the nature of participation; and/or (4) risks and benefits.

### Value of VIC

Participants valued having been provided with study information and having an opportunity to decide for themselves. For example, they valued the study information because it helped them "know before I came here what we will be doing" (Eswatini-18-01-2013) and "what to expect" (RSA-07/11/2019). The participants also reported, "It was good because before I signed the consent form, I was given the explanatory statement ... also the opportunity that if I don't feel like, I don't have to participate" (Eswatini-13/12/2012) and "it was a very important thing for me taking a decision for myself... signing" (RSA-09/01/2019). Participants described deciding as a relational rather than an individual process. For example, in Eswatini some participants talked to their families before signing their consent form (13/12/2012). They perceived that in their PR, older community members would take guidance from the *umphakatsi* (chiefly local government authority), and children from their parents (18/01/2013). In RSA, where the participants (as co-researchers) obtained written VIC from parents of youth participants (who provided written assent), they perceived both youth and parents should and would consider advice from family members and/or friends in addition to the study information, before deciding about participation (11/10/2018).

However, the value of signing was also (mis)understood. Signing was valued, in both settings, as an opportunity and symbol of social status. For example, participants reported that, "signing the form made me happy because it was my first time signing" (Eswatini-13/12/2012) and "it is special for a Black person [to sign a form], you tell yourself 'yeah' [*nodding his head and sticking his chest out*]" . When I asked if it is only Black people that take pride in signing, other participants said, "mostly Blacks" and "White people are mostly the ones making [Black people] sign [for example to] grab opportunities for volunteering [doing unpaid work for experience]" (RSA-11/07/2019). The "formal and professional" (Eswatini-13/12/2012) appearance of written VIC procedures and documents was partly what symbolised their importance. However, the participants had no inherent attachment to written VIC procedures. They suggested that both information and consent could alternatively be provided verbally, for example "us[ing] a tape recorder... we ask to record their names if they agree to participate and read the explanatory statement for them" (Eswatini-18/01/2013).

Participants also valued signing consent because of its (mis)understood association with being a co-researcher. It meant “going to varsity” (RSA-16/11/2018) and/or getting a “job” (Eswatini-18/01/2013; RSA-08/12/2018) or “salary” (Eswatini-13/12/2012). In Eswatini, where the study was community-based and the participants did not visit the university campus, all received a stipend as co-researchers. Many reported (mis)understandings like, “in my mind... it’s not like I agreed to participate [in the ethnography]... it was my first document to sign, like I was getting a job” (Eswatini-18/01/2013). In both settings, participants placed great value on their university association and symbols of it. These included certificates of participation (both countries), the university-branded vehicle that transported them from community to university (RSA-11/07/2019), and stationary, including university-branded folders containing reading materials (Eswatini-19/12/2012). The participants valued these symbols of university association because they made them feel important.

From their perspective as co-researchers, written VIC procedures also had utilitarian value, in terms of recruiting participants to, and developing robust results from, their PRs. In Eswatini, participants perceived that inviting rather than forcing participation would improve their study, because “they can give me the information [if they want to]... not to force them” (14/01/2013). As co-researchers, the participants also valued written VIC as a form of proof that could be produced, if needed, to demonstrate their adherence to academic ethics procedures. For example, they described the consent form as “a witness that the participant... will follow everything that is involved in the research” (Eswatini-13/12/2012) and “proof” that participants agreed (Eswatini, 13/12/2012).

### **Nature of participation**

Participants’ (mis)understandings regarding the nature of participation also evolved throughout the study. When they signed their consent forms, most participants (mis)understood the participatory workshop approach. For example, many commented to the effect that they were “expecting another style of teaching” (RSA- 08/11/2018), in which there is, “a teacher who comes and tells you everything” (Eswatini-22/01/2013) and that I “was going to judge” (RSA-08/11/2018), “preach” (RSA-11/07/2019) and/or “forc[e] [them] to speak English” (Eswatini-22/01/2013). Some even (mis)understood that “the purpose of [me] writing the things down [as participant observation data] was so that they [participants] could be tested” (RSA-16/11/2018). Expecting they would “have to do tests about the [English-language] readings” (RSA-08/11/2018) and “not [be] given the opportunity to say that [they] do not believe [what is written in the books]” (Eswatini-22/01/2013), the participants were surprised that I expected them to learn, “in groups sharing and doing exciting activities... [feeling] free to speak in [our mother tongue] Sesotho... [while] making new friends” (RSA-08/11/2018). What they learnt was also surprising. Rather than taking away facts about research, health or sustainable development that could help them pass the tests they expected, the participants emphasised actually having learnt to think for, and have confidence in, themselves (both settings). Several explicitly recognised, in hindsight, that they were not entirely clear about what participation involved, when they signed their consent forms. For example, one reported that he, “needed to see [the workshop activities] practically to fully understand” (RSA-07/11/2018). Others reported that they had understood what I was asking them to do when they signed their consent form but also that they were surprised about or not expecting one or more aspect/s of their participation (e.g., being able to speak their mother tongue).

### **Risks and benefits**

Participants also (mis)understood risks and benefits. Two participants narrated (mis)understanding the plausible risks of study participation. In Eswatini, one reported signing despite wondering, “am I not handing you, the facilitator, great power to illtreat me” (Eswatini-13/12/2012). Although he reported later perceiving that my intention was not to illtreat him, he came to (mis)understand a risk he had not foreseen, that negative representations might, “inconvenience the people... [when] it appears in your thesis that the people in [our community] are doing this [illegal] thing ...it can be sort of dangerous” (Eswatini-10/04/2013). One RSA participant reported that some parents he obtained consent from were concerned that “there is something that you are up to... they thought maybe there is something that you are going to take and... then the university will get maybe a big huge amount [a] lumpsum [from the] government and they don’t get to benefit” (RSA-08/01/2019). Most participants initially reported not imagining any risks associated with participation. However, many showed through their behaviours (e.g., by not sharing their opinions in group discussions), that they were afraid of getting wrong answers and/or other participants laughing at them. For example, one reported, “even though I knew that you were not going to beat me [like the teachers did at school]... I thought the others will laugh at me if I give the wrong answer” (Eswatini-18/02/2013).

The participants assumed benefits would arise from participating in a (untested and imagined-to-be-didactic) learning intervention associated with a university. The symbols of their university association and related feelings of importance the participants valued (see above), were construed as benefits. Even those who had initially (mis)understood that they would “get a paying job from it” (RSA-08/11/2019) reported “not feeling bad [but] happy with the knowledge that they had gained” (RSA-08/12/2019). They referred to participating in the workshops as an “opportunity” (RSA-11/07/2019), and “[a] taste of being at the university, being taught by... Dr [NAME]” (RSA-08/01/2019).

### **Rights and responsibilities**

The participants held further (mis)understandings about their own and my researcher rights and responsibilities, when they signed forms documenting their consent to participate. Notably most, at least initially and often persistently, (mis)understood that the consent form was an agreement that bound participants to do certain things and protected the researcher. For example, one reported, “by signing on this form I was meaning that I agreed to cooperate and do whatever you as my facilitator will ask me to do... willingly or with my full interest” (Eswatini-18/01/2013). Others reported thinking they had bound themselves “to participate in every session” (RSA-18/11/2018) and “be on time” (RSA-10/01/2019) for all workshops. In Eswatini participants’ (mis)understandings about rights and responsibilities were also apparent in what they assumed they would need to do as co-researchers. For example, one reported, “At first I was thinking that [as a community researcher] I will... force them [prospective participants]... later I realised that you have to ask... are [they] willing to participate” (Eswatini-14/01/2013).

### **Logic of (mis)understandings**

Paradoxically, the evolving (mis)understandings detailed above, occurred amongst participants who could remember and repeat, and often perceived they understood, written study information. Their historic experiences made deriving the meanings I intended them to, from the abstract principles of voluntary and informed, was illogical unlikely. In Eswatini,

participants reported that “voluntary” locally meant not getting paid rather than deciding for oneself (03/01/2013). They conceptualised VIC as, “very interesting... if I don’t feel like I want to participate, it’s like I have to not sign” (13/12/2013). South African participants also found it difficult to comprehend the notion of choosing freely or accept written information as truth, because of their historic experiences. For example, many participants commented to the effect that they thought “of that [information about the right to withdraw] as something written on the form [not]... the reality of what would actually happen” (RSA-16/11/2018). One explained that he showed his certificate of participation to parents he conducted consent procedures with, “just to show them. Like we are not just talking and giving them all this good information [about their children getting certificates of participation], but yes, this will be done” (RSA-08/01/2019).

The participants’ historic experiences of limited educational and/or employment opportunities, which if available typically came with more responsibility than rights, also shaped their (mis)understandings. For example, participants reported because, “you are in varsity and you know that others in varsity have a [government] bursary and that comes with a condition [of...] minimum requirement in your course marks” (RSA- 16/11/2013) and because it was “so strange [that] a person... applying for a job [gets] a voluntary opportunity [to decide what] to do... so it was like maybe I’m handing... you some authority” (Eswatini-18/01/2013). One participant, who was surprised that he received a stipend for participating in the co-learning and co-designing workshops, explained his (mis)understanding arose because when he previously trained (to work in a retail store), “We weren’t paid anything... [training] for five hours [per day]... for the whole month” (Eswatini-18/01/2013).

Historic experiences of signing, or knowing others who signed, also structured participants’ (mis)understandings. The participants (mis)understood “signing as something that binds you to do something, often there are conditions, so despite what the form says [about being able to withdraw] it just seems like something extra that is outside the scope of what you are actually signing for” (RSA-14/11/2018). Historic experiences of being exploited by signing, also shaped some participants’ (mis)understandings. For example, one participant spoke of how the Basotho people were historically tricked into signing over their land in the colonial era and how he thought this influenced the meanings attached to signing forms (RSA-08/01/2019). Others associated signing with positive opportunities, including having a bank account and being “admitted in some colleges” (Eswatini-18/01/2013).

(Mis)understandings evolved (as described above) primarily because of knowledge the participants derived from their lived experiences of being co-researcher participants. Although I constantly encouraged them to voice their opinions and try new behaviours (e.g., presenting in front of the group), and some reported sometimes feeling guilty when they didn’t, most participants explicitly reported that they experienced not feeling forced. They also reported that they came to understand VIC differently, through hearing me, “explain more about the consent and the study during the workshops” (RSA-16/11/2019). The participatory nature of the workshops in which we co-designed VIC procedures involved participants making decisions (i.e., experiencing “deciding for themselves”). These lived experiences of (albeit limited) autonomy produced historic knowledge (embodied as *habitus*) through which they came to understand informed consent differently.

## Discussion

The findings must be interpreted with cognisance of the strengths and limitations of the study. The data were generated through ethnographies about the process and outcomes of PR. Participants’ reflected on and narrated their experiences and perspectives of VIC, primarily for the purpose of designing culturally appropriate ethical procedures for their PRs. Their

responses would likely have been different, and produced different narratives of their (mis)understandings, had I conducted an abstract study in which they discussed VIC separately from their co-researcher-participant roles. As such, the results are presented as one possible version of the “truth” about VIC-related (mis)understandings. Given the current limited knowledge about participants’ (mis)understandings of VIC in qualitative and/or post-colonial research settings, the findings extend what is already known (i.e., that (mis)understandings of VIC are relatively common in biomedical research). Although the findings are derived from two specific contexts, they provide novel insights and have implications for other theoretically similar research settings (i.e., postcolonial contexts characterised by historic and ongoing structural marginalisation and limited autonomy).

### **Nature of (mis)understandings**

Participants in this qualitative study held many (mis)understandings that have already been noted in other research settings. For example, they did not fully understand what participation entailed, nor their right to withdraw or decline, in accordance with the ethical intent (Molyneux et al., 2005; Tam et al., 2015; Vallely et al., 2010). They inferred risks and benefits that I did not intend them to, a phenomena already noted in experimental, biomedical research in African post-colonies (Afolabi et al., 2014; Molyneux et al., 2012; Tam et al., 2015) and qualitative studies in Western countries (Bhattacharya, 2007; Dixon-Woods et al., 2007; Wade et al., 2009). The participants understood VIC procedures as binding them, relinquishing their rights and handing authority to me as a researcher (Molyneux et al., 2005). They “resist[ed] the explanation[s]” (Dixon-Woods et al., 2007, p. 2218) I provided in the study information.

More novel are the findings showing how participants disregarded as untrue, and/or discerned information actively unknown in, the study information. Some participants did not believe they actually had a right to withdraw from the study, although they comprehended the text that told them this. Not knowing that universities actually derive considerable economic and cultural power/capital from doing research (i.e., through funding and ranking models that privilege the quality and quantity of publications, information I elided from the benefits section of the study information), some nonetheless suspected that the university would benefit economically. The findings further show that (mis)understandings about (assumed) economic/material benefits and unintended motivations to participate noted in biomedical research, extend to qualitative research settings, which offer access to non-economic/material power/capital.

### **Influence of economic cultural and social inequalities**

In addition to accessing economic power/capital (e.g., stipends and going to university for free), participants also perceived as beneficial, and were also motivated to participate by, opportunities to access (actual or symbolic) social and cultural power/capital (e.g., networking with university educated people, learning and signing forms). Like biomedical treatments, these opportunities were restricted during the colonial era. In the postcolonial context, opportunities continued to be dominated by people unlike the marginalised Black research participants (i.e., White and more powerful Black people).

The need to acknowledge economic/material power/capital inequalities in the design and implementation of biomedical research is already recognised (Geissler, 2013). Informed by Bourdieu’s (1986) conceptualisation of power/capital as having multiple (economic, social and cultural) types, these findings suggest the need to go beyond acknowledging economic/material inequalities. Inequalities in, and perceived opportunities to gain, social and

cultural power/capital structured decisions about research participation in these studies. Although many participants perceived they were making their own decisions about participation, the findings show how their choices were structured by their historic experiences [i.e., their *habitus* (Bourdieu, 1990)] of being denied opportunities. Deciding to participate was profoundly related to hoping to acquire the power/capital to access opportunities historically denied, including the “opportunity” to sign a consent form, which symbolised power/capital for the participants.

### **The symbolic power of signing**

Similar to the ways in which previous studies have shown that prospective participants interpret study information with reference to social norms (Dixon-Woods et al., 2007; Molyneux et al., 2012), these findings demonstrate that they also infer meanings on signing consent forms, in relation to what it usually means for them and other people in similar positions of power [i.e., based on their *habitus* (Bourdieu, 1990)]. In these two postcolonial contexts, meanings inferred on signing ranged from accessing a rare opportunity, to taking on (what could be construed as) reasonable responsibilities (e.g., being on time), to signing away fundamental rights (e.g., to fair treatment). These (mis)understandings occurred because signing a form was something marginalised people like the (Black) participants rarely (if ever) had the chance to enact from their positions of limited social power. Signing was something that symbolised (economic, social and cultural) power/capital, because the participants perceived, that except in exploitative conditions, it was only done by more powerful others, including those with money, jobs, connections to White people and/or education. They assumed, as Bourdieu’s (1990) theory posits, that the unwritten rules of VIC procedures were designed in favour of those (myself and the academic institutions to which I was affiliated) already in power. They could not imagine signing to protect their own rights, nor understand why, if the agreement was not intended to bind them, they should need to formalise it in writing.

Despite (mis)understandings associated with the unfamiliar written VIC procedures, the respectful intent of VIC (i.e., being informed and deciding for oneself), was valued. Notably, the principle of respect and the procedures of signing were constructed as unrelated and valued, from the same position of marginalisation, for different reasons. The participants valued respect at least partly because their autonomy was often denied. They did not construct it as mutually exclusive to the traditional relational decision-making norms of some postcolonial African societies (Chilisa, 2017).

### **Transforming VIC procedures for more ethical qualitative research**

The findings demonstrate the importance of qualitative researchers in postcolonial settings implementing formal VIC procedures. However, they indicate that written procedures should be assumed inappropriate in contexts where prospective participants have little experience signing documents and embodied experiences that influence them to (mis)understand signing, for example as a way to gain opportunity (e.g., a job), accept responsibility (e.g., to participate in certain ways) and/or renounce their rights (e.g., to property). Researchers maintain the responsibility to do no harm regardless of a participants’ signature on a form (Hoeyer & Hogle, 2014). If research is to meet minimum ethical standards, it is imperative to ensure participants in postcolonial settings, who have embodied direct and indirect experiences of exploitation, understand this. Based on these findings I recommend that ethical guidelines for qualitative research be revised to advise against asking participants in postcolonial settings to sign consent forms. Alternative procedures, for example audio recording a consent conversation or documenting such a conversation in a research diary,

should be recommended to guide researchers and ensure that VIC procedures remain formal and structured.

The findings further demonstrate that although providing more or better study information cannot alone overcome (mis)understandings, avoiding actively unknowing is essential. Truths that participants easily (albeit sometimes unconsciously) discern, should be stated explicitly in study information. These findings indicate that participants will be better able to understand the academic reasons for doing research if they are informed about how individual researchers and their institutions benefit. Whatever social good (i.e., better knowledge) is intended to come of academic research, publishing results is always also intended to advance careers, salaries, research funding and reputations (i.e., the social, cultural and economic power/capital of researchers and universities). Unknowing these benefits by eliding them from study information contributes to (mis)understandings, because participants assume (from a position of limited power in which the odds are typically stacked against them) that the more powerful players in research interactions must benefit. I therefore further recommend that these individual and institutional gains in economic, social and cultural power/capital be made explicit in the study information provided to prospective participants. For example, information about how many research articles are expected to be published and how much the university or researcher would benefit (in terms of economic, cultural and social capital) should be included.

Conducted in the Bourdieusian tradition of reflexive sociology (i.e., turning the ethnographic lens on the research process; Bourdieu & Wacquant, 1992), this study has demonstrated the value of systematic, theoretically-informed and critically reflexive enquiries focused on ethical procedures in qualitative research. Imported largely unchanged from biomedical traditions, qualitative ethical procedures have been adopted with little critical scrutiny (Bell, 2014; Emmerich, 2017; Hébert et al., 2015). Previous critically reflective analysis has documented the concerns of qualitative researchers, but largely elided the perspectives of participants. This study demonstrates the importance of systematically documenting participant perspectives regarding what (mis)understandings occur and how. This study has contributed to filling this gap in knowledge only minimally. It demonstrates the need for further reflexive sociological studies to elucidate how taken-for-granted approaches to operationalising ethical principles (and other procedures), translate into practice and meanings in qualitative research.

## Conclusion

Participants draw on their embodied historic knowledge to interpret the meanings of study information and the act of signing. In postcolonial societies this knowledge is predominantly developed from experiences of marginalisation, including lack of information, opportunity, autonomy and respect. Because they have been taught by past experience not to believe everything they read (or are told) and/or not to expect their rights to be respected, participants in postcolonial research settings do not uncritically accept study information as the truth nor develop the researcher's intended understandings. They inevitably and logically imbue written study information and the act of signing with meanings derived from their own experiences. The ethics of VIC procedures can be enhanced by providing better study information, in particular avoiding actively unknowing in favour of explicitly acknowledging, the ways in which researchers and universities benefit economically, socially and culturally from the knowledge participants contribute to qualitative research. However, providing more or better written study information alone cannot ensure participants' consent is either adequately informed or entirely voluntary. Replacing written VIC procedures, with alternatives, that are more culturally familiar and do not imply associations with exploitation

and/or benefits, also has great potential to enhance the ethics of qualitative research in postcolonial contexts.

### References

- Afolabi, M. O., Okebe, J. U., Mcgrath, N., Larson, H. J., Bojang, K., & Chandramohan, D. (2014). Informed consent comprehension in African research settings. *Tropical Medicine & International Health*, 19(6), 625-642.
- Baydala, L. T., Worrell, S., Fletcher, F., Letendre, S., Letendre, L., & Ruttan, L. (2013). "Making a place of respect": Lessons learned in carrying out consent protocol with First Nations Elders. *Progress in Community Health Partnerships: Research, Education, and Action*, 7(2), 135-143.
- Bell, K. (2014). Resisting commensurability: Against informed consent as an anthropological virtue. *American Anthropologist*, 116(3), 511-522.
- Bhattacharya, K. (2007). Consenting to the consent form: What are the fixed and fluid understandings between the researcher and the researched? *Qualitative Inquiry*, 13(8), 1095-1115.
- Bourdieu, P. (1986). The forms of capital. In R. Richardson (Ed.), *Handbook of theory of research for sociology of education* (pp. 241-258). Westport, CT: Greenwood Press.
- Bourdieu, P. (1990). *The logic of practice*. Cambridge, UK: Polity Press.
- Bourdieu, P., & Wacquant, L. (1992). *An invitation to reflexive sociology*. Cambridge, UK: Polity Press.
- Brear, M. R. (2018). Ethical research practice or undue influence? Symbolic power in community- and individual-level informed consent processes in community-based participatory research in Swaziland. *Journal of Empirical Research on Human Research Ethics*, 13(4), 311-322. doi:10.1177/1556264618761268
- Brear, M. R. (2019). Process and outcomes of a recursive, dialogic member checking approach: A project ethnography. *Qualitative Health Research*, 29(7), 944-957. doi:10.1177/1049732318812448
- Chambers, R. (1997). What works and why? In *Whose reality counts? Putting the first last* (pp. 130-161): Intermediate Technology Publications Ltd (ITP).
- Chambers, R. (2002). *Participatory workshops: a sourcebook of 21 sets of ideas and activities*. New York: Earthscan (Taylor and Francis).
- Chambers, R. (2015). PRA, PLA and pluralism: Practice and theory. In H. Bradbury (Ed.), *The SAGE handbook of action research* (3rd ed., pp. 31-46). London: SAGE.
- Chilisa, B. (2017). Decolonising transdisciplinary research approaches: An African perspective for enhancing knowledge integration in sustainability science. *Sustainability Science*, 12, 813-827.
- Corrigan, O. (2003). Empty ethics: The problem with informed consent. *Sociology of Health & Illness*, 25(7), 768-792.
- Denzin, N. K. (2001). Doing interpretation. In *Interpretive interactionism* (2nd ed., pp. 119-142). Sage.
- Dixon-Woods, M., Ashcroft, R. E., Jackson, C. J., Tobin, M. D., Kivits, J., Burton, P. R., & Samani, N. J. (2007). Beyond "misunderstanding": Written information and decisions about taking part in a genetic epidemiology study. *Social Science & Medicine*, 65(11), 2212-2222.
- Emmerich, N. (2017). Remaking research ethics in the social sciences: Anthropological reflections on a collaborative process. In *Finding common ground: Consensus in research ethics across the social sciences* (pp. 125-148). Emerald Publishing Limited.
- Erasmus, Z. (2012). Apartheid race categories: Daring to question their continued use.

- Transformation: Critical Perspectives on Southern Africa*, 79(1), 1-11.
- Erwin, K. (2012). Race and race thinking: reflections in theory and practice for researchers in South Africa and beyond. *Transformation: Critical Perspectives on Southern Africa*, 79(1), 93-113.
- Ferreira, C. M., & Serpa, S. (2018). Informed consent in social sciences research: Ethical challenges. *International Journal of Social Science Studies*, 6(5), 13. <https://doi.org/10.11114/ijsss.v6i5.3106>
- Geissler, P. W. (2013). Public secrets in public health: Knowing not to know while making scientific knowledge. *American Ethnologist*, 40(1), 13-34.
- Graboyes, M. (2010). Fines, orders, fear... and consent? Medical research in East Africa, C. 1950s. *Developing World Bioethics*, 10(1), 34-41.
- Habermas, J. (1984). *The theory of communicative action, Vol. 1, Reason and the rationalization of society*. Boston: Beacon Press.
- Hébert, J. R., Satariano, W. A., Friedman, D. B., Armstead, C. A., Greiner, A., Felder, T. M., . . . Braun, K. L. (2015). Fulfilling ethical responsibility: Moving beyond the minimal standards of protecting human subjects from research harm. *Progress in Community Health Partnerships: Research, Education, and Action*, 9, 41-50.
- Hoeyer, K., & Hogle, L. F. (2014). Informed consent: The politics of intent and practice in medical research ethics. *Annual Review of Anthropology*, 43, 347-362.
- Hsieh, H.-F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277-1288. doi: 10.1177/1049732305276687
- IAA, International HIV/AIDS Alliance. (2009). *Tools together now! 100 participatory tools to mobilise communities for HIV/AIDS*. doi:<https://www.aidsalliance.org/resources/275-tools-together-now>
- Josselson, R. (2007). The ethical attitude in narrative research: Principles and practicalities. In D. J. Clandinin (Ed.), *Handbook of narrative inquiry: Mapping a methodology* (pp. 537-566). Sage.
- Librett, M., & Perrone, D. (2010). Apples and oranges: Ethnography and the IRB. *Qualitative Research*, 10(6), 729-747.
- Miller, T., & Boulton, M. (2007). Changing constructions of informed consent: Qualitative research and complex social worlds. *Social Science & Medicine*, 65(11), 2199-2211.
- Molyneux, S., Mulupi, S., Mbaabu, L., & Marsh, V. (2012). Benefits and payments for research participants: Experiences and views from a research centre on the Kenyan coast. *BMC Medical Ethics*, 13(1), 13.
- Molyneux, S., Wassenaar, D., Peshu, N., & Marsh, K. (2005). "Even if they ask you to stand by a tree all day, you will have to do it (laughter)...!": Community voices on the notion and practice of informed consent for biomedical research in developing countries. *Social Science & Medicine*, 61(2), 443-454.
- Nishimwe, R. (2018). Multidimensional poverty among the villages of the South African former homeland of Qwaqwa. *International Journal of Economics and Financial Issues*, 8(3), 241-249.
- O'Connell Davidson, J. (2008). If no means no, does yes mean yes? Consenting to research intimacies. *History of the Human Sciences*, 21(4), 49-67.
- Pollock, K. (2012). Procedure versus process: Ethical paradigms and the conduct of qualitative research. *BMC Medical Ethics*, 13(1), 25.
- Sabati, S. (2019). Upholding "colonial unknowing" through the IRB: Reframing institutional research ethics. *Qualitative Inquiry*, 25(9-10), 1056-1064.
- Simons, L., Lathlean, J., & Squire, C. (2008). Shifting the focus: Sequential methods of analysis with qualitative data. *Qualitative Health Research*, 18(1), 120-132. doi:10.1177/1049732307310264

- Smith, L. T. (2013). *Decolonizing methodologies: Research and indigenous peoples* (2nd ed.). London, United Kingdom: Zed Books Ltd.
- Tam, N. T., Huy, N. T., Thoa, L. T. B., Long, N. P., Trang, N. T. H., Hirayama, K., & Karbwang, J. (2015). Participants' understanding of informed consent in clinical trials over three decades: Systematic review and meta-analysis. *Bulletin of the World Health Organization*, 93(3), 186-198H. doi:10.2471/BLT.14.141390
- Timmermans, S., & Tavory, I. (2012). Theory construction in qualitative research: From grounded theory to abductive analysis. *Sociological Theory*, 30(3), 167-186.
- Vallely, A., Lees, S., Shagi, C., Kasindi, S., Soteli, S., Kavit, N., . . . Hayes, R. J. (2010). How informed is consent in vulnerable populations? Experience using a continuous consent process during the MDP301 vaginal microbicide trial in Mwanza, Tanzania. *BMC Medical Ethics*, 11(1), 10.
- Wade, J., Donovan, J. L., Lane, J. A., Neal, D. E., & Hamdy, F. C. (2009). It's not just what you say, it's also how you say it: Opening the "black box" of informed consent appointments in randomised controlled trials. *Social Science & Medicine*, 68(11), 2018-2028.
- Woolfall, K., Shilling, V., Hickey, H., Smyth, R. L., Sowden, E., Williamson, P. R., & Young, B. (2013). Parents' agendas in paediatric clinical trial recruitment are different from researchers' and often remain unvoiced: A qualitative study. *PLoS One*, 8(7), e67352.
- Yanar, Z. M., Fazli, M., Rahman, J., & Farthing, R. (2016). Research ethics committees and participatory action research with young people the politics of voice. *Journal of Empirical Research on Human Research Ethics*, 11(2), 122-128. <https://doi.org/10.1177/1556264616650114>

### Author Note

Michelle is social scientist whose research spans basic and applied approaches and incorporates methods and tools from multiple disciplines, including health, development, anthropology and education. Her research is broadly focused on developing research approaches and empirical data that improve understanding of power and how these influence participatory processes. She has specific interests in epistemic, gendered and racial power inequalities and how they play out in participatory research in postcolonial southern African settings. She is affiliated with the School of Education Studies, Faculty of Education and Afrontane Research Unit, University of the Free State (South Africa), Qwaqwa campus; and Global and Women's Health, Monash University (Australia), School of Public Health and Preventive Medicine.

Corresponding author: Michelle Brear; Monash University (Australia), Level 4, 553 St Kilda Rd, Prahran. [michelle.brear@monash.edu](mailto:michelle.brear@monash.edu)

**Acknowledgements:** I greatly appreciate the time, knowledge, and energy the participants contributed to this research. During the fieldwork and preparation of this article I was supported by an Australian Postgraduate Award (Monash University) and a Postdoctoral Research Fellowship (University of the Free State).

An earlier version of this paper was presented at the 4th World Conference on Qualitative Research (WCQR2019) in Oporto, Portugal, October 16th to 18th 2019. <https://2019.wcqr.info/world-conference-on-qualitative-research/>

Copyright 2020: Michelle R. Brear and Nova Southeastern University.

### Article Citation

Brear, M. R. (2020). Power-laden (mis)understandings surrounding written voluntary informed consent procedures in postcolonial southern Africa. *The Qualitative Report*, 25(13), 71-89. <https://nsuworks.nova.edu/tqr/vol25/iss13/6>

---