

## **Ethnography, ethics and ownership of data**

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# Ethnography, Ethics and Ownership of Data

## Abstract

Establishing trust and obtaining informed consent with participants is reliant upon on a process whereby unequally positioned agents constantly re-negotiate (mis)trust and consent during ethnographic encounters. All research has been increasingly subject to an intensification in ethical regulation, within a context whereby Eurocentric norms and ethical guidelines arguably diminish individual accountability under the guise of quasi-contractual relationships. This phenomenon has particular implications for ethnography and its management of ethics given its intimate, longitudinal and receptive nature. Two expert ethnographers working with children and young people draw upon their work to reveal how issues of informed consent and data ownership can shift and be a source of tension and unequal power dynamics. The ethnographer requires autonomy while managing ethics soundly in situ to work within the messiness and unpredictability of participants' everyday lives.

## Key words

Ethnography, Ethics, power, **Informed Consent** and Data Ownership.

## Introduction

*'If qualitative research endeavours to create a truly egalitarian framework for researchers and participants, power relations must be confronted with "real" research practices' (Karnieli-Miller, Strier and Pessach, 2009, pg282).*

Much of the literature regarding ethics deals with the management of ethical review boards (Dennis, 2009). This paper takes a reflective view on how ethics works in terms of **informed consent and** data ownership in practice for the ethnographer working with children and young people. Ethics and its need to be managed in situ, while simultaneously recognizing the participant's voice is acknowledged. The need to **challenge conventional forms of informed consent and** look at how data ownership works in practice for ethnographers is contextualised within the backlash against the increasing global shift regarding the dominance of the hegemonic approach to research, that has a tendency to objectify its participants as passive subjects, rather than as active agents with inherent power, rights and needs (Moodie, 2010, **Wilson and Hodgson, 2012**). **As Hoeyer and Hogle (2014) argue:**

*'Policies enforcing the consent requirement assume that there is a universal subject, that all subjects weigh information and make "informed" choices similarly, and that they "voluntarily" participate with similar expectations' (Hoeyer and Hogle 2014, pg352).*

**Consequently,** participants' needs and rights may contradict professional, institutional and regulatory body guidelines and preferences that make managing ethics in the field potentially problematic. This tension is of particular significance when conducting research that deals with issues of social justice. In this instance the ethnographer is more likely to face competing power relations between participants, their own personal, moral, political and professional viewpoint and their related university and funding body preferences. All of these aspects have direct implications

for how **ethnographers gain informed consent as well as, how** data is used, owned and thus how 'knowledge' is (co)constructed and presented. When working with children and young people the power balance is often uneven and while much has been written regarding how to mediate these power relations to gain valid data that may not be otherwise accessed, there is a dearth of knowledge regarding the specificities of 'data ownership' and how this works when managing ethics in practice within ethnography. **Intersubjectivity is posed as an alternate framework to the often unchallenged Cartesian model used and reproduced in many ethical review discourses, processes and constructions of 'knowledge' – whereby a shared understanding of what is deemed 'knowledge', rather than an individualistic notion adhered to by the Cartesian model is an epistemological frame that is separate to, but has consequences for understandings regarding methodology, ethics and data ownership. Since if knowledge is co-constructed and dependent upon social interaction, it is shared and context specific and so cannot also be so readily framed as a modified outcome or commodity that can be predetermined.**

The significance of research that deals with issues of social justice and the implications this has for ethics is outlined. **Ethnographers need to regain some professional autonomy and be astutely aware that any ethical framework may be 'tainted' by the different stages of the research process, their differing audiences and sometimes competing needs,** but also malleable enough to **consider** the unpredictable nature of ethnography. Power relations and its relation to data ownership and knowledge (co)construction is then problematized before outlining two ethnographies' and their illustrations regarding the need to reflect and acknowledge the ethical complexities that may occur within and beyond the field. We do this by asking how *informed* consent can be operationalised in the field and how the ethnographer manages the tension when outside organisations' authority and demands contradict that of the participants (and in some instances the ethnographer's).

## **Social Justice Research and Ethics**

Ethnographers delve into the everyday experiences of their participants and as such are more likely to become involved with their participants and occurrences in the field. Ethnographers don't just conduct an interview and then walk away, but build relationships with people to understand the field, **and consequently** experience a level of intimacy and unpredictability that is unique to ethnography as a methodological process and product. **This has direct consequences for ethnography's epistemological stance on what knowledge is and how it comes into being. Hegemonic ethical review boards often assume the Cartesian model for understanding selfhood and human relations (Metro, 2014), thus epistemologically knowledge is regarded as something that is certain and has a complete absence of doubt. Within this frame knowledge is a commodity, something that can be owned and even predetermined. Ethnographers, however, often understand knowledge as something that is co-created between the researcher and the researched in specific social situations within particular moments in time, it does not reside in the sole word of the ethnographer or the affiliated institution (Voloshinov, 1986). Metro (2014) offers an alternate theoretical concept – intersubjectivity – emerging from semiotics, consequently the self cannot be seen as pre-existing bounded consciousness, but rather is viewed as emerging through discursive engagements with others – knowledge is thus understood as something that develops in reaction and relation to other people, it isn't bounded and pre-determined and therefore by implication cannot be exclusively owned. If intersubjectivity is given dominance over the**

**Cartesian model for understanding the self, mind and body, methodologically how one gains and (co)creates knowledge (such as in participatory ways) has implications for the management of ethics. If it is context specific and reliant upon day-to-day interactions, it cannot be predetermined as posited by many ethical review boards as knowledge, since meaning and understandings cannot be decided in advance, rather ethics need to bend to manage who ethnographers are researching with, where, when and why. There is thus an increasing call for a need to critically analyse and challenge traditional concepts about what counts as research, data and legitimate inquiry in this current era of audit culture of global neoliberalism (Denzin, 2017; Pels et al, 2018).**

**Denzin (2017)** states that qualitative researchers need to think carefully about who speaks for who and how participant and researcher voices are represented and used. He asserts that research should matter for the lives of those who experience social injustices on a daily basis, thus bringing into question a new way to think about ethical procedures. Indeed, others too such as, **Shannon (2007); Lederman (2007); Bosk (2009);** Hammersley (2009) and Dennis (2010) have questioned the recent increase in ethical regulation and its relevance to ethnography, after all, ethnography is unpredictable and ethical issues cannot always be foreseen in advance of fieldwork. **So how the ethnographer conceptually frames knowledge i.e. via an understanding of intersubjectivity is separate to, yet related with how the ethnographer then goes on to manage questions of informed consent and data ownership – since they are not viewed as context bound. By implication the ethnographer must manage ethics in situ (Author, 2016). Ethics must be viewed as a process rather than a tick box exercise that morphs with the research process, from the writing of bids and gathering of research funds to the conducting of fieldwork (often using multiple and unanticipated research methods) and ultimate analysis, presentation, dissemination and use of data. Ethnographers that deal with issues of social justice think very carefully about these issues and are sometimes stuck managing tension between what is deemed ethically sound research practice and what is the morally right thing to do (Dennis, 2010; Wilson and Hodgson 2012).**

Those ethnographers that are interested in issues of social justice are often united in their commitment to expose and critique forms of inequality and discrimination (Dennis, 2010). Denzin (2017) claims that critical qualitative inquirers are ethically responsible to conduct 'responsible activist research' (pg9) that makes a difference to the oppressed. **However, there is also evidence of ethnographic work that takes a top-down approach, whereby the ethnographer works with participants of a powerful nature, such as Nader's (1972) work researching practices of insurances companies in America. Nader (1972:288) argues that 'studying up as well as down would lead us to ask many common sense questions in reverse.' She contends that if anthropology was to be reinvented to study the powerful then our understanding of the powerless would be transformed as social structures of inequality are uncovered in previously hidden ways.**

**Examples in the current paper though refer to a bottom-up, from the oppressed to the more powerful, process. Denzin (2017) proposes that we as scholars should have our own voice in setting ethical guidance in this quantitative dominated era and suggests the following goals that should form part of our ethically responsible agenda:**

- 1) Places the voices of the oppressed at the center of inquiry;
- 2) Uses inquiry to reveal sites for change and activism;
- 3) Uses inquiry and activism to help people;
- 4) Affects social policy by getting critiques heard and acted on by policy makers;
- 5) Affects changes in the inquirer's life, thereby serving as a model of change for others.

(Bloom and Sawin, 2009, pp 338, 340-342, 344 cited in Denzin 2017, pg8).

**Ethical decisions need to thus be made** in response to the research process itself rather than as a set of principles externally established in advance. The ethnographer's own moral, political, methodological and theoretical views matter and shape ethics just as they shape the research process (Author 2005). As ethnographers we should be more forthcoming in setting our own ethical agenda that suit our needs, but we must also have some understanding about what these 'goals' mean in practice. If we really are to place the voice of the oppressed in the centre of research and activate real change that alters the lives of participants, we must be aware that doing ethnography may put researchers into contact with unethical behaviour that is part of the everyday lives of participants. Further we must recognise that doing this may lead the ethnographer to engage in behaviour that is in conflict with ethical regulations as well as funding and university body guidelines (Wilson and Hodgson, 2012). There are key differences that must be acknowledged between ethics as a regulatory concept and ethics in practice.

### **A History of Methodological and Ethical Inequality**

Ethnographers and anthropologists alike have long concerned themselves about ethics and the increased pressure academics feel with regards to accountability and managing data in accordance with university employers and funding agencies prerequisites, (Pels, Boog, Florusbosh, Kripe, Minter, Postma, Sleeboom-Faulkner, Simpson, Dilger, Schonhuth, Poser, Castillo, Lederman and Richards-Rissetto, 2018). Such forms of governance habitually define 'data' as a commodified product that can be bought, sold and re-used under a Cartesian way of framing knowledge and meaning. This is problematic for ethnographers, since it artificially alienates data from the inextricable link that ethnographic data has with social relations made within the field, whereby knowledge and indeed research methods and designs are often co-produced between the ethnographer and the participants. Fears that these global neoliberal forms of governance serve to monitor, control and audit data are increasingly evident and continue to fuel ethical debates in the field (Pels et al, 2018). There is a concern that ethical review boards worry more about the reputation of universities than actual ethical conduct towards research participants (Wilson and Hodgson, 2012).

*"In its worst guises, neoliberal ethics served merely as a badge of good conduct, with sovereignty about ethical judgement monopolised by top-down standards set in review procedures that both determined access to and modified research" (Pels et al, 2018, p392).*

Ethnographers manage issues of trust with participants to access meaningful data, they sometimes 'bend the rules' of ethical review board stipulations, but almost always prefer to operate within a system of care that prioritises the participants voice and experiences. Tensions arise when the ethnographer prioritises a trustful relationship with the participants by sometimes taking actions that serve their best interests, while also trying to abide by ethical guidelines (Wilson and Hodgson, 2012).

Ethical regulation of social research has increased significantly in the UK (Hammersley, 2009). Bodies such as the Economic and Social Research Council (ESRC), **the European Union General Data Protection Regulation (GDPR) implemented in 2018**, university ethical review committees, the British Educational Research Association (BERA) are key in terms of setting this

agenda and imposing a 'one size fits all' ethical approach – something which can clearly be at odds when considering the unpredictable and intimate nature of ethnography (Dingwall, 2012) and when epistemologically the ethnographer accepts that there are a variety of different forms of data that cannot be simply 'owned' nor equally accessed, since they were co-produced within everyday life social relations. Notably, ethical guidelines published by the Association of Social Anthropologists of the UK and the Commonwealth (ASA) do not promote this 'one size fits all' approach.

### **The Epistemology of Ethnographic 'Data'**

The ethnographer accepts that 'data' are variable and dependent upon how and why it was collected. Moreover, the ethnographer often relies upon multiple modes of data that may be text-based, audio-visual, artefacts, digital or participatory in forms that act to co-produce knowledge via different means and different people during the research process. A process of 'mutual learning' occurs (Pels et al, 2018), thus the methods and ethics the ethnographer must adopt are often mutually supportive that rest on the same epistemological foundation of reciprocated social relations built on trust. Ethnographers should make an epistemological distinction between 'raw' and 'processed' data. The ethnographers' 'raw' data is saturated with personal aspects with regards to specific social relations built in situ. Consequently, such 'raw' data is not so easily transferable, since if it is edited too far arguably the 'data' itself is rendered useless. It is the context in which it was derived that makes it meaningful. As a consequence, many ethnographers and anthropologists alike have resisted the sharing of data, since the ethnographer is usually acutely aware of the tensions around processed data and how it is made public - namely that if it is torn apart from the social relations in which it was developed, it's very meaning may become void.

This epistemological understanding of 'data' has consequences for questions of ownership of data, since it was mutually gained, perhaps it should be mutually owned? Unfortunately, the formal written consent process often forced upon the ethnographer by their affiliated institutions and funding bodies do not so readily recognise this, resulting in a tension between how the ethnographer and participants define and recognise the appropriate ownership and management of data and how the individual ethical review boards and related institutions do (Metro, 2014).

### **Power Relations and Data Ownership**

Ethnographers have long discussed the need to diminish power relations between the researcher and researched to gain valid data that empowers rather than diminish participants' viewpoints, experiences and needs (Author 2007; Author 2014; Author 2016). Ethnography alongside other traditions of qualitative inquiry view research as a researcher-participant co-production of knowledge, whereby control over representation is increasingly shared (Karnieli-Miller et al, 2009). Indeed, the very notion of ownership of the research is purported to be redistributed with participants (Wolf, 1996). Those paradigms and traditions that sit in the nonpositivist camp (such as postpositivism, constructivism, critical theory and post modernism) celebrate the co-construction of knowledge between the participant and the researcher. The extent of this co-construction **matters as it shapes** the level of ownership that one party holds over the other. Moreover, this feeling of ownership may alter alongside the different stages of the research process. This power

relationship is even more nuanced when the relationship between the researcher and participants **is scrutinised**, as in ethnography participants are usually the main source of data and the ethnographer is deemed a tool. Democratising these power relations sounds positive, but again in the messiness and unpredictability of the field these power relations shift and are subject to other domineering forces such as ethical procedure committees, funding body and university research guidelines and legal requirements.

Power relations change according to the ethnographer's personality, moral stance, political motivation, personal background and institutional responsibility. As researchers and disseminators we facilitate the knowledge that we (and our participants) deem as 'truth'. Sometimes the researcher and participants may be in conflict with the question of who actually owns the data and what purpose the data holds.

### **Managing Competing Versions of 'Knowledge'**

Ethnographers and academic researchers and their related university and funding body institutions generate knowledge *about and with* people that is structured to depict participants day-to-day living. This knowledge is sometimes institutionally actionable in ways that people's knowledge of their own lives is not (Nichols, Griffith and McLarnon, 2017). Nichols et al (2017), in their research about young people's experiences of housing insecurity in Ontario, discuss how public sector documents are often prioritised as fact over and above the young people's own life circumstances and accounts. Set institutional texts framed how professionals working with these young people managed and supported them. Consequently, Nichols designed professional development initiatives to address the concerns identified in her research to create programs of intervention and inform policy change. This is an example of how an ethnography cannot always foresee how data will be used in the future and by whom. While pointing to the dominance of the written word over young people's actual verbal accounts and every-day practices, this work highlights issues of power relations in research, data ownership and how ethnographers, participants and other institutions (in this case the public sector) co-create knowledge that is documented as 'reality'.

There is an increasing recognition that there has been a disconnect between the actions of researchers and the expectations and rights of certain participants (Moodie, 2010). Research stands the risk of objectifying participants as passive subjects, rather than people with inherent power and collective rights in deciding how research should be developed, conducted, analysed and published. Moodie in her work with indigenous peoples, believes that 'researchers have been conditioned to believe that they own the data they collect' (Moodie, 2010; p819), and that many balk at the idea that they as researchers do not own and control access to the research data.

The paper now turns to outlining the two ethnographies on which the 'real life' ethical issues are explored to uncover how 'data ownership' shifts and manifests within and beyond the field which develops the nuanced understanding we have regarding knowledge co-production and the ethical management of it in situ. The first ethnography regards author's research with NEET young people, here the issue of data ownership and the consequences this has for the construction of 'knowledge' is problematized by analysing who and what constitutes data. The **second ethnography** draws upon data exploring children's discourses of identity and friendships in a multi-ethnic primary school. **Data gathered** relating to children's discourses around armed militias in North and Sub-Saharan Africa that played out in their games and conversations are considered within the context of the UK's controversial 'Prevent Strategy'.

## **Young People Not in Employment, Education or Training (NEET)**

The first ethnography is a Leverhulme Funded project that explored the lives of 24 NEET (Not in Employment, Education or Training) people as they 'churned' through employment and education across two English northern local authorities. The main corpus of data includes over 280 hours of observation data and 78 interviews (with young people, professionals, parents and employers) collated between 2010 and 2013. The fieldwork was participant-led, the young people dictated when and where fieldwork took place. Each participant completed a life history map during the initial meetings to reduce power relations and ease the participant into the fieldwork, here the purpose of the research was outlined, the funding body, related university institution and informed consent **via verbal face-to-face means (Metro, 2014) and by means of the more formally accepted written consent form format** was initiated. The participant had a blank sheet of paper and recorded significant life moments in a manner pertinent to them; some drew images (of things like houses and hearts), others used arrows to indicate strength of relationships between transitions and life critical moments. This was then used for interview elicitation purposes in future interviews and the young people often changed or added to the life history maps as fieldwork progressed and different 'moments' or significant 'people' came to mind or transpired. Many of the young people were interviewed more than once, which enabled a checking, editing and development of data that was previously collected. Fieldwork was conducted in various places including in young people's homes, during car journeys, restaurants, employment and training provisions and social gatherings. This paper reflects on how the ethnographer gained informed consent during fieldwork and the implications this had for data ownership. Author also questioned her own moral and professional stance in light of fieldwork notes that could have been potentially used in a child custody case.

## **Identity and Peer Friendships**

The second study draws on a longitudinal ethnography with a multi-ethnic primary school in Northern England. Data collected during the first stage of fieldwork is discussed. Participant observations formed the key method of data collection. During the first phase of fieldwork weekly full-day observations were undertaken for a 10-month period (October 2010 to July 2011). Children collaboratively designed research activities which were used to initiate research conversations based on the pedagogical principles of 'sustained shared thinking' (Siraj-Blatchford & Sylva 2004:6). Adopting a participatory approach helped reduce some power differentials between the adult researcher and child participants (Cheney 2011) and thus created an opportunity to problematise data ownership in relation to the collection of sensitive data. While formal ethical approval was gained before all stages of the fieldwork from Author's university ethics committee, reflection on this issue was ongoing. Within the context of the UK's controversial 'Prevent Strategy' Author reflects on observational data that was collected relating to children's discourses around armed militias in North and Sub-Saharan Africa.

## **Gaining Informed Consent In Situ**

**Ethnographer and anthropologists alike have outlined the drawbacks of using written consent forms in situ with people who may feel intimidated or uncomfortable with such**



means of communication, due to language barriers that may ensue when working with different cultural groups or with individuals who manifest an anti-establishment culture or an anti-colonial stand (Annas, 2006; Katz, 2006; Hoeyer and Hogle 2014). Metro (2014) describes feeling 'embarrassed' at the idea of imposing written consent forms approved by ethical review boards since it created unnecessary anxiety and feelings of mistrust between her the researcher and the Burmese refugee and migrant teacher participants in Thailand who she was working with. Consent forms are usually designed for formal activities that are separate from everyday life and are not contingent on the intimacy ethnography often endures (Lederman, 2006). Author in one of her first fieldwork encounters with Isla a NEET young person, like Metro (2014) struggled to clearly separate between the people who were participating in the research and those who were not.

Isla and author first met during an employability course where author was trying to gain access to NEET young people via a professional who worked with young people who had been in care. During this initial encounter author was trying to gain rapport **and trust** with several young people. Informed consent was gained during this initial encounter with all young people **via a face-to-face agreement, whereby the author introduced herself as a researcher interested in the young people's experiences of being out of work and in training and asked people as she went along if they felt comfortable participating, making note and adhering to anyone who seemed as though they did not want to participate.** During these encounters author was acutely aware of how she had been introduced by the professional in a position of power and consequently actively ensured all participants did actually want to take part with the study, developing links and arrangements to meet up again, only if the participant wanted to, and at a time and place convenient to them. This face-to-face in situ informed consent was done alongside written consent forms only after the author was happy with her professional judgement that this person did actually want to participate. In these instances, like Metro (2014) author felt a sense of unease around asking young people to sign forms for fear that it would actually endanger relations in the field and act as a barrier to gaining rapport with NEET young people (Shannon, 2007). Rather an embedded shifting ethics of care, that acknowledged the complications of the entangled day-to-day activities and relations ensued. Some drifted away for various reasons and decided not to further participate over a longitudinal basis. Others discussed other NEET young people author had met – this was partially due to the snowballing sampling technique used to try and gain access to these NEET young people. Thus, from the very start, data was entwined with various people **who could not always be easily separated out and disentangled from one another.** The vignette below reveals how some young people continued with the research directly, alongside others who became part of fieldnote data indirectly, **thus complicating the notion of informed consent and an ability to separate out what data can and cannot be used for analytical and dissemination purposes.**

### **Initial encounters**

**9.15am – 12.00** – Employability course ran by Holly (as Jon is off on sick leave).

As I enter the café area I see Holly sat with two young people enjoying a coffee/tea, Holly asks if I'd like one and adds it to her bill. Holly introduces me and I say what I'm doing, at that moment Carl arrives with Michael, Carl says

I'm a nice lady and that 'I don't bite' (we have met before), I thank him for this and ask how he is. He is excited to tell me that he is away on holiday in March with his brother.

Others start to arrive and we get the lift down to our workshop area near the hall space. Franky is charged with carrying the box of drinks and biscuits. Holly provides water, cola, cloudy lemonade and biscuits readily made available on a table for the young people to help themselves. Holly organises sandwiches – Katie refuses to eat, (Observers Comments [OC] she appears thin and doesn't look too well), she is complaining of feeling ill, she has a lump on her jaw line, is feeling dizzy and tired and can't eat, she says she spent most of last night throwing up. Holly advises her to get to the chemist to get some vitamins and iron tablets – she has a history of being anaemic. Holly offers her some toast but she refuses, she says she had some toast this morning.

While the group make their own ground rules for the day, Holly receives a text from Charlotte saying her and Connie are on their way, they'll be late, they are on the bus.

Holly is also informed that one girl Sarah was arrested last night, she was thrown off the course, the group seem pleased about this and the two girls Shelby and Carrie laugh about this saying 'good'.

When Charlotte and Connie arrive later, Holly does not say a word about their lateness. Charlotte says that she needs a bath and says she wasn't home all night; I get the impression she was with Sarah. She says Connie is not allowed back to her flat now, Connie asks why and Charlotte shrugs her shoulders and laughs. (OC Later I see Jane, Jane thinks Charlotte was responsible for throwing food at her window, she reported this to the police, the 'open futures' project – the people who supervise her flat informed Jane that Connie was in all night – I know that this isn't right as it contradicts Jane's fieldnote data collected earlier in the week).

There is a slow start to the morning, the young people are just chatting and eating.

Franky eats his sandwich, screws his paper up and asks, 'do you reckon I can get it in from here?' – he tries and just misses, he then gets up to put it in the bin placed near the door.

One of the girls Isla is 8 weeks pregnant – she asks if it is safe to eat tuna on her sandwich – I tell her it is as long as she doesn't eat too much of it. Holly suggests she join a teenage mum group session after the employability course finishes as this should fit in nicely with baby's arrival. Isla talks about having had a miscarriage earlier. The girls ask why people have miscarriages; Isla explains that they can happen for any reason, it's just like a bleed. Shelby says her sister had one but needed an 'operation to get it out'.

(author's fieldnotes 03/02/2011).

Thirteen people are directly and indirectly referred to in this fieldnote extract alone, including nine potential long-term participants, some of which author had met previously (such as Carl and Michael) plus others author mentions in her observer's comments (OC) as she is aware of the encounter being discussed via another participant's fieldnote data collected elsewhere. Some move in and out of the space during the employability course (Michael who leaves to sort out Carl's CRB ready for his placement), and so consequently author had no firm idea about who would transpire to be a participant. Gaining access **and informed consent** was a challenge as the field itself was very unpredictable **and social relations entwined within and outside of the employability programme**. Isla for example attended this course once, subsequent meetings were held in her home. This fieldnote data illustrates the complexities of the field when looking at the everyday practices of people. At this stage strong confirmations about who was and who wasn't part of the research on a longitudinal basis were not clear. It is only upon the young people's willingness to participate (or not) in future encounters that this **transpired**. As such the research team and participants are co-creating knowledge regarding the number of participants – but even this 'simple' task is nuanced, it shifted with the longitudinal nature of ethnography as some moved in and others left.

Carl and author had already met, as had Jane and author, but Jane was not directly involved here, others were introduced by Holly – which puts into question the power of professionals against these young people's willingness to participate. Consent processes have long attracted significant attention (**Shannon, 2007; Bell 2014; Kamuya et al, 2015**), and although consent remains a core theme in research ethics, the extent to which entirely autonomous individual informed consent is even possible, or even desirable remains **relatively unchallenged in ethical review board, university and many funding body institutions**. Numerous guidelines and documents describe the need for **written** informed consent, but very little discussion **regarding how verbal face-to-face consent is managed with potential participants as they emerge and disappear from the field**. These are important aspects of consent and the consequent presentation of data must be carefully explored taking into consideration the nature of negotiations between research staff, potential participants and indeed their significant others, who often become indirectly part of ethnographic data. Others may opt for a 'silent refusal' (Kamuya et al, 2015) and may not explicitly state that they do not want to take part, but may drift away or appear unwilling to respond. **Others too may indeed want to participate, but feel unable at a specific moment in time to do so. Like Wilson and Hodgson (2012), author experienced times where participants did not open their door, declined to answer their phone or did not meet in the prior arranged place at the prior arranged time, yet they did continue with the NEET research at other times and places. Thus a reflexive approach to the management of ethics and informed consent was needed throughout the fieldwork process that relied on the ethnographer's professional judgement with regards to whether a participant couldn't participate at that particular moment in time or didn't want to participate full stop. It wasn't uncommon, for example, for some NEET young people to have other important engagements to attend (such as a doctor's appointment or a friend/family get together) that on some occasions trumped their desire to participate with the ethnography at a certain point in time.**

Power relations are constantly at play in the field and beyond it, the participants themselves can exude power by refusing to participate. Significant others enter fieldnotes, Lucas for example is Isla's boyfriend, he figures quite heavily in the fieldnote data regarding Isla, but author never met him. This has consequences for the construction of knowledge, but also has implications for the ownership of data, what happens for example if the participant wants to not only view the data, or even omit and edit it, but also asks for it as evidence to support her child custody case?

## Whose truth?

**12.00-1.00pm** As soon as I enter Isla informs me that she and Lucas split up. She has taken an injunction out against Lucas. She describes going out to her cousin's 21<sup>st</sup> birthday party, a male friend came by and slept on the sofa in the living room with his baby. Oscar was at the parent-in-laws overnight. Lucas suddenly got mad, broke a bowl and threw it off the table in a random rage, he went up to bed and she didn't go with him as she didn't want to go to bed with someone who was 'like that' – he later came down the stairs shouting saying she needed to leave the house, she refused and he started a chainsaw threatening to saw her legs off if she didn't get out. She ran out of the house to her neighbours with no shoes and phoned the police.

(author's fieldnotes 09/02/12).

Issues of trust, privacy and legitimacy of fieldnote data have long been problematized along with the blurred boundaries of what the role of the ethnographer actually is (Ruth, 2015). So too has the issue of what is seen and what is not, or what is recorded as data and what is not, as well as nuanced concerns about how that data is interpreted, presented and understood by others (Ruth, 2015). Consent requires continual negotiation especially when the researcher spends long periods of time in the field. Lucas (father) and indeed Oscar who was too young to talk did not give their consent to participate, yet parts of their (intimate) lives were made available for author to observe, document and analyse through the eyes of Isla. Furthermore, Isla's family members and friends and professionals who worked with her made an appearance in authors written fieldnotes, in interview data and photographs taken by Isla.

In their raw form fieldnotes have sometimes been seen as a personal record kept only for the eyes of the researcher. Questions of data authenticity arise if ethnographers allow their participants to view fieldnotes, edit interview transcripts, select photographs or indeed any other data source, as they may edit data according to their own agendas. However, it is not uncommon for the ethnographer to allow participants to see all data as it is being recorded (**Author, 2018**) and after it has been documented, indeed many view this as being ethically sound practice that allows the ethnographer to gain trust (Author 2005). The ethnographer has to be highly reflexive and keep reflective accounts to uphold the validity of findings, but also has to be aware of how to manage sensitive data that involves other people who are not directly part of the research. Isla later asked author to provide a statement for her child custody case. Author felt a moral obligation to use herself and potentially her fieldwork notes in this way, as others had abandoned Isla for fear of her boyfriend Lucas and his violent nature. Author appeared in county family court with another member of the research team, but was never actually called. Author could only really comment upon what she had witnessed and could not offer data on Isla's opinions. Concerns about who might ask for the fieldnotes and other data consequently arose. The fieldnotes depicted Isla's day-to-day activities and at the time of writing them author had no idea who might want to see the raw material. This was an unforeseen ethical dilemma that opened up questions regarding who owned the data and what constituted its purpose? This episode confirms that the question of data ownership is important. The ethnographer needs to be aware of power dynamics evident in the field and beyond and think about how these might affect their position and rationale to use fieldnote data (Author 2018).

## Sensitive Data in a Surveillance Society

The research landscape is further complicated via the predominance of unchallenged discourses of fundamentalism, extremism and radicalism which in turn label non-conformists as the dangerous 'other'. These Western representations of the 'other' are rooted in colonial discourses of superiority and inferiority (Marranci 2008). The patriotic discourses around nationhood that are thrown up by these representations are by their very nature exclusionary (Raghavan 2017). Public policy can, and increasingly is, being built on these 'othering' discourses, that are rooted in post-colonial thinking. One such example of this in the UK is the UK Government's controversial Prevent Strategy.

The Prevent Strategy, **which** was first published in 2008, places a number of statutory duties on schools and other organisations in relation to the following areas:

*'The statutory guidance makes clear that schools and childcare providers are expected to assess the risk of children being drawn into terrorism, including support for extremist ideas that are part of terrorist ideology... Schools and childcare providers should have clear procedures in place for protecting children at risk of radicalisation. ...*

*... Schools can build pupils' resilience to radicalisation by providing a safe environment for debating controversial issues and helping them to understand how they can influence and participate in decision-making. Schools are already expected to promote the spiritual, moral, social and cultural development of pupils and, within this, fundamental British values.'* (DfE 2015:5&8).

**Murtuja and Tufail (2017) contend that the Prevent Strategy has been built on exclusionary discourses that rely on stereotypes of Muslim communities as suspect and 'othered.'** These Islamophobic and racist foundations of the policy promote rather than challenge hegemonic discourses resulting in a climate of fear and self-censorship. Consequently, Prevent has been widely criticised as stigmatising cultural minority communities, promoting division and facilitating discriminatory practices which have been epitomised in a number of high-profile cases involving children as young as four (Stanford and Ahmed 2016; O'Donnell 2016; Murtuja and Tufail 2017).

Within the context of education Prevent is scrutinised for its inability to engage with the contested nature of the concepts of 'radicalisation' and 'extremism **and is** critiqued for the way in which it defines 'vulnerability' as being 'resonant with colonial discourses of contagion and immunity' (O'Donnell 2016:53). This all contributes to an environment where dissent is silenced and a sanitised view of 'British values' are promoted, ignoring (but paradoxically drawing upon discourses relating to) the UK's colonial history and current foreign policy actions. Consequently, Prevent has been critiqued by community groups (GRC 2013) and teachers (Teaching Times 2016) as unfairly targeting and stigmatising marginalised sections of UK based Muslim communities. A number of trade unions (including the National Union of Teachers [NUT] and the Union and Colleges Union [UCU]) have called for Prevent to be scrapped or boycotted. The UCU have also expressed concerns about how the Prevent Duty may become a barrier for social research that seeks to explore and understand why individuals are driven towards violent forms of religious extremism (UCU 2015).

The universities who should be challenging these hegemonic discourses are themselves facing increased surveillance by these policies. Consequently, the political biases within these discourses are feeding into university structures and sources of control, such as curriculum reviews and ethical review boards, as universities develop forms of self-censorship to ensure they do not fall foul of the policy (Murtuja and Tufail 2017). Questions of data ownership are raised as university policies relating to Prevent come into conflict with long held research practices and values that challenge the commodification of data as something that can be owned and passed on. These issues were raised in Author's research fostering concerns over who may ask for her fieldnotes and what protections she had to resist such requests within the increasing surveillance environment of Prevent.

The first iterations of the Prevent Strategy were published in 2008, two years before the fieldwork commenced. During author's first stage of fieldwork in 2010-2011 the strategy was reviewed resulting in the statutory Prevent Duty being introduced during the second phase of her fieldwork in 2015. The example below illustrates the wider impact the Prevent Duty has on ethnography. While Author's research was exploring notions of identity and peer friendships within a multi-ethnic classroom all stages of Author's fieldwork produced instances of sensitive data relating to children's discourses around armed militias in North and Sub-Saharan Africa. Ethnography's emergent nature regularly produces data that is unforeseen requiring the ethnographer to be continually reflexive.

Fieldnotes from the first phase of data highlight one example which raised ethical issues relating to publishing sensitive data. The child in this study was four years old at the time of the observation which is the same age as some of the youngest children who have been reported to the Prevent Duty and been interrogated under this legislation.

### **A data bomb**

**14.00 – 14.40** - I am sitting in the outdoor play area just under the cover watching Kareem and Lina play in the home corner. Abdul<sup>1</sup> comes over and sits at the Lego tray and starts to build a model car. I watch as he pushes it around making 'brum' noises. He lies on his tummy and pushes it under the bench. When he reaches where I am sitting he asks me to move my legs to that he can continue to push the car past me. When he gets to the end of the bench he turns the car around and comes back with it.

Abdul adds some Lego bricks to the car before taking it to the top of the ramp. He pushes the car off and shouts 'bang, bang' as the car hits the floor and smashes into pieces.

He picks up the pieces and puts the car back together quietly saying to me 'It's a bomb.' 'A bomb?' I ask. 'Yes', he replies, 'a car bomb'. He pushes the car off the ramp again and shouts 'bang' as it smashes.

(Authors fieldnotes 03/02/2011).

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<sup>1</sup> When editing the fieldnote above author gave Abdul a second pseudonym so that this data cannot be connected to a wider narrative in previous publications.

Author's reflective notes taken on the same day highlight her initial thoughts on dealing with this data:

### **Reflective notes**

As I think back to watching Abdul play in the outdoor area this afternoon I have lots of questions. Where did Abdul get this idea of a game from? Is his game part of a wider fascination with guns and fighting that lots of young boys seem to have or is it something else?

What should I do next? I want to explore this further but is this too sensitive an issue? What happens if I write about this and someone interprets it wrongly? How do I make sure that Abdul is protected and that this observation isn't taken out of context and twisted in line with a right wing political agenda?

Author continued to reflect on this after writing these notes and decided to continue recording similar observations and decide at a later date whether or not to include them in her PhD thesis. Author's reflective notes all show that she had no concerns about any of the games she saw or conversations that she overheard in relation to discourses of armed militias. In the same phase of fieldwork Author did have a safeguarding concern about a child's relationship with his mother's boyfriend. Author supported the child to talk to school staff about his experiences at home in line with the school's safeguarding policy.

When analysing data about armed militias Author had no concerns for the children's safety. Her interpretation of this data corresponds with Holland's (2003) and Paley's (2014) findings that uncover the gendered meanings that young boys often ascribe to fighting implements such as sticks and guns. Despite this, Author felt that the children in her study could be stigmatised and potentially put under investigation due to their ethnic and religious identities within the context of Prevent. If Author had observed a white non-Muslim child playing with the Lego as Abdul did these concerns may not have come to the fore. The racially stigmatising and discriminatory undertones of Prevent that target specific communities caused Author to approach this data in a different way.

Consequently, Author did not discuss this data in her final written work. Author was (and is still) not clear what powers Prevent has over research data and if for example research data can be subpoenaed by this Statutory Duty. Within this surveillance environment what protection of anonymity and confidentiality can the researcher give their participants? As Abdul is no longer in the country Author feels that it is now possible to share this data, albeit with a second pseudonym, to ensure that Abdul's identity is further protected. This context raises further ethical issues of informed consent and data ownership. This is particularly relevant in the context of an exploratory and responsive methodology, such as ethnography, when unexpected data may be shared.

Author's reflections above show how her awareness of the wider political context impacted on her decision to not publish these findings as she was unsure if she could protect Abdul from harm in a way that she felt ethically bound to do. Given the wider political context Author was concerned that

publishing this and other similar narratives may cause children and/or their families to be targeted under what she sees as a morally dubious Prevent Duty.

Additionally, she was concerned that if written as part of an identity narrative and subsequently taken out of context this data may give fuel to right wing groups who want to further stigmatise **and ‘other’** Muslims living in the UK. Within the stigmatising and divisive context of Prevent she felt that her ethical responsibility to protect her participants from potential harm by not including this data in the wider identity narrative as advocated by Salway et al. (2012) outweighed the benefit of sharing this part of Abdul’s story.

## Conclusions

This paper offers a reflective account of how ethnographers manage ethics in situ, paying particular attention to the issue of data ownership and (co)construction and the relation that has with informed consent and confidentiality. We argue that at times self-censorship of data is needed to protect participants when published data could be taken out of context and mistakenly used to reproduce a dominant discriminatory discourse, such as a negative view of single mothers or **cultural** minority groups. These aspects need to be carefully scrutinised when undertaking an exploratory and responsive methodology such as ethnography **particularly when political biases that ‘other’ the powerless permeate public opinion and social policy. Ethnographers who engage people on the margins of society often question top-down, sometimes discriminatory and post-colonial views about participants being construed as vulnerable and in need of protection through vigilant application of ethical guidelines founded on biomedical models of research that are more concerned with institutional risk and reputation management than the support of social scientific research and indeed the participants’ wants, desires and needs (Dingwall, 2012). Rather participants are viewed as active, capable and knowledgeable instruments of data (co)production and (co)ownership. Thus, a theory of intersubjectivity is postulated as an alternative viewpoint that has implications for how ethnography understands and manifests itself methodologically as a process and how data is viewed as co-produced and thus arguably co-owned.**

Ethnographers need to **reclaim their professional autonomy** and work actively to surmise some ethical guideline goals that may be more applicable to ethnography and work against the traditional problematic ethical guidelines and increased ethical regulation era that fails to acknowledge and therefore properly manage research ethics when working in education contexts with young people whilst doing an ethnography. Ethics must be malleable, **based on an ethics of care** and acknowledge the difference in power relations and the effect this has on data ownership and knowledge construction – especially when researching issues related to social justice.

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