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*Ethics Review Governance in the UK and the
Implementation of the GDPR (General Data Protection
Regulation) in the Social Sciences and Humanities*

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Ethics Review Governance in the UK and the Implementation of the GDPR (General Data Protection Regulation) in the Social Sciences and Humanities

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This short paper² aims to highlight some issues that we have experienced with research ethics review and research ethics committees (RECs) in the UK and relate this to recent developments in ethics review. In this context, we discuss how the introduction of the EU General Data Protection Regulation (GDPR) may exacerbate difficulties experienced in the process of ethics review, or, alternatively, form an opportunity for anthropologists and others engaging with ethnographic research methods to negotiate guidelines that are more suitable for ethnographic fieldwork. The report provides a brief overview of the institutionalisation of UK research ethics and the issues faced by researchers in the social sciences and humanities, in addition to the challenges we might face when negotiating ethics review and data protection procedures introduced by our universities following the introduction of the GDPR.

The standard research model for ethics review in anthropology, inherited from the biomedical sciences, is associated with procedural research, formalised ethics review, informed consent and institutional permissions, and it has radically altered the expectations of ethnographic research through formalised guidelines. It has regulated the various stages of research planning, fieldwork and writing up; it has affected the way moral issues are reflected upon by highlighting and formalising particular ethical issues rather than others (see EthNav 2019; Verhallen 2016; Van den Hoonaard & Hamilton 2016); and it has created an institutional industry around ethics review, which has generated a high workload for research ethics committees. Formalised ethics review has also impacted the ethical conduct of researchers. The questions asked on ethics review forms force researchers to translate their methodological values, research rationale and research epistemology into the ethical principles of standard research models (cf Caplan 2003; Simpson 2011; Simpson 2016). In other cases, researchers find themselves stretching the meaning of their planned activities in order to tick the right boxes (Lederman 2016; Rowley 2014). Thus, the planned visits to hospitals becomes 'interviewing managers'; conversations with patients and children become 'interviewing people community members and their families', exploring a particular institutional network becomes 'snowball sampling'; and, making friends and building rapport becomes 'acquiring access permission based on informed consent' (see also Hodge 2013). The use of ethics review forms in those cases seem to encourage evasive behaviour, thereby not addressing issues that may be in need of further ethical reflection or theoretical scrutiny.

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The challenges faced by anthropologists were expected to increase because of the introduction of the GDPR on May 25 2018. The GDPR regulates the legal protection of data and the privacy of individuals in the EU. Universities had one year to make the collection and storage of personal data GDPR-compliant. These alterations are expected to affect the ways in which universities conduct research, store data and treat ethics review. In light of a long history of data breaches of sensitive data of many users, a recent example of which was the data-hacking scandal of Facebook in 2018 ('hitting 87m users', BBC 2018), scholars expected its implementation into universities to be rigorous and to affect the basis of the organisation of research ethics (Humphris 2018). Many academics have feared that data-protection would further curtail the work of researchers using ethnographic research methods, by adding a burden of bureaucratic formality to them, and also thwart the protection of research materials, as explained below. However, we need to be aware that the amended justification for doing scientific research may actually facilitate a more adequate ethics review process for the social sciences, as well as enhance the protection of personal data.

When funding agencies and research councils in the UK first introduced a requirement for ethical review, social science researchers had little say in its institutionalisation (Dingwall 2012). There were no major obstacles created against the treatment of social-science research ethics by the Data Protection Act (DPA 1998) as 'research' (Sleeboom-Faulkner et al 2017). This meant that social-science research ethics was modelled on biomedicine, which is largely characterised by detailed procedural study design with a focus on contractual rights and obligations of informed consent. Anthropology, which is more explorative in nature and does not follow strict operational guidelines, currently faces major challenges when undergoing ethics review: first, studying across cultural boundaries, the ethics of ethnographic research needs to be - and is - negotiated over time on the basis of standards appropriate to this negotiation and the ethics valid in other cultures. This process is complicated, if not thwarted, by ethics review, which determines what is ethical in advance of encounters with other cultural groups. Second, research involving vulnerable populations entails ethical issues and risks of which researchers new to a subject and/or area (including REC members) may be little aware. For instance, the vulnerabilities of ethnic minorities who engage in clandestine activities of resistance can only become clear during the research itself. In such cases, formal ethics review is at best, inappropriate and, at worst, clashes with the kind of ethics students/researchers need to consider and develop in the course of their research. And, third, research on powerful actors involved in the exploitation of vulnerable groups or in disputable practices investigated through covert anthropological fieldwork constitutes a fast-growing part of the social sciences. Here, notions used in formal ethics review can be unhelpful, obstructive and even damaging. For example, formal ethics review is unsuitable for research among unauthorised therapy providers in global networks. Issues include the difficulty of receiving institutional permission for conducting research beforehand; specification of the locality of interviews; the design of information sheets; and the signing of informed consent forms (also, Alvesalo-Kuusi and Whyte 2018)

Since the introduction of formalised ethics review, social science researchers have needed to 'translate' social-science research plans to fit a paradigm taken from the world of biomedical research ethics (cf Lederman 2016). The informal chats so characteristic of fieldwork, for example, anthropologists now had to plan and categorise under the heading of 'semi-structured interviews with oral consent'. A major two-fold concern about the digital, standardised nature of formalised research ethics, which first arose in the first decade of this

century, was reflected in the comments found in idea boxes and aired at meetings at the University of Sussex (*Have We become too Ethical?* November 2015) and Durham (*How Can We Become More Ethical?* August 2016): while some anthropologists experience the process of filling out formalised ethics forms as intimidating, especially due to its jargon and alienating language use, others experience it as a meaningless chore, encouraging box-ticking and hindering genuine reflection on ethical issues. It seems, then, that the method used to conduct ethics review in anthropology is not in agreement with the kind of critical self-reflection and embedded ethics (Meskell & Pels 2005) that anthropological methodology requires.

The stark variety in the administrative organisation of Research Ethics Committees (RECs) attests to various modes of organising ethics review among different universities in the UK. Exploratory internet research of one hundred and seventeen RECs in the UK by the authors shows a great diversity in organisational hierarchy. Working on the basis of publicly-available documentation (which excluded a small number of institutions from the survey), we separated degree-awarding institutions into four categories, excluding technical, musical, veterinary and other institutions which could not be anticipated to undertake (or judge the ethics of) ethnographic work. These categories were: universities which devolved ethics review to the subject level; those which devolved it to groups of similar subject areas; those which aggregated broad swathes of disparate subjects (such as social sciences with mathematics); and those which centralised all ethics review. Inevitably, the distinction between similar and dissimilar subjects was to some degree arbitrary: social sciences were, for example, grouped together but distinguished from the arts and humanities. Ninety percent of institutions aggregated different subjects to some degree, with almost a third centralising ethics review entirely.

The importance of such aggregation is apparent in the complaints formulated in the idea boxes and discussions referred to above, whereby disciplinary distance and the level of administration played a major role. Thus, most of the complaints related to communication (the intimidating style of forms; the facelessness of email; and the helplessness of being at the mercy of an unaccountable ethics committee), the inadequacy of expertise of ethics committees (unawareness of methodological requirements, such as covert research and participant observation and ethical procedures in other cultures) and unrealistic methodological requirements (anticipatory research plans for research that is exploratory in nature and whose specific questions and research locations may be multiple and interdependent and only arise in the course of the research).

Amongst the examined institutions, twenty-nine taught social or cultural anthropology in 2017, either discretely or as part of joint honours (as recorded by the Universities and Colleges Admissions Service (UCAS 2017)). The general trends shown across universities were largely replicated across this group. The bulk (~75%) of anthropology-teaching institutions aggregated subjects for ethics review to some degree, including around a third that centralised such review. However, the remaining quarter devolved ethics review to the subject level – this is over twice the proportion of institutions devolved to this level in the wider survey.

Twenty-four of these anthropology-teaching institutions were ranked in terms of their research output in the Times Higher Education (THE) 2017 Social Science scores. Comparison of these scores with degrees of aggregation for ethics review revealed stark differences between categories. The top three scoring institutions all performed ethics review at the subject level,

whilst the five lowest performing institutions aggregated dissimilar subjects together. On average, institutions that grouped similar subjects together scored more poorly than those that devolved ethics review to the subject level but better than those which aggregated dissimilar subject areas. Whilst institutions with centralised ethical review in many cases scored higher than those which devolved it to various degrees, this group includes a number of institutions that are already specialised to some degree, including London School of Economics (LSE), Goldsmiths, and SOAS.

Whilst these correlations can be explained variously, they are suggestive regarding the extent to which some anthropology departments are able to deal with or to avoid having to deal with the complications that tend to occur in highly centralised systems of ethics review. In light of the reported difficulties with ethics committees that lack the necessary expertise to appreciate the methodological necessities of anthropological fieldwork, or that inappropriately attempt to apply standard practices and norms from other disciplines, it is unsurprising that institutions that avoid such obstacles should perform better; increased restrictions and obstacles to research must be expected to be reflected in the range and quality of research produced. Further, given that academics are well aware of these issues, delegation of ethics review to the subject level may be indicative of environments in which they are empowered to prioritise quality research.

The recent introduction of the GDPR provides an opportunity for social science and humanities departments to review both the organisation of RECs and formalised ethics review (EU-GDPR 2016). It is important for anthropology departments to be aware of institutional changes related to ethics review and ethnographic fieldwork, especially as the ethics and data requirements have real consequences for the epistemology of anthropological research. In other words, the rationale of conducting activities such as ‘hanging out’, ‘chatting with folks’, ‘roaming the field’ now carries the extra weight of formalised ethics review and data protection. This affects the ways in which anthropologists are required to do research: informal relationships and casual conversation – the bread and butter of participant observation – are now loaded with bureaucratic processes around consent and intellectual property. Research funders, which have been gathering insights into these issues are aware of this, and have been fighting our corner in the context of the introduction of the GDPR.

A Joint Submission from the Economic and Social Research Council (ESRC), the British Academy, Wellcome Trust and other research organisations has pointed out that the GDPR is more prescriptive than the 1998 DPR (Joint-Submission 2017). It states, for instance, that ‘*Valid consent for taking data needs to be clear and affirmative (it cannot be silent or ‘inferred’ by inactivity)*’. Adopting this requirement would restrict or de-capacitate much social-science research. For this reason, the Joint-Submission *urges universities to make full use of the derogations specified by the UK government*.³ This is facilitated by the GDPR’s redefinition of the social sciences on a par with journalism, characterising their activities as in the public interest and their pursuits in themselves valuable as academic knowledge (see Article 85 of the GDPR (2018)). Thus, research results are to be processed as ‘special personal data’, but are safeguarded on the same basis to other forms of special expression including journalism.

³ For a list of the intended GDPR derogations by the UK government: <https://www.openrightsgroup.org/assets/files/pdfs/dcms/Summary%20of%20GDPR%20derogations%20in%20Data%20Protection%20Bill.pdf>

It is 'necessary to reconcile the right to the protection of personal data within the freedom of expression and information'.⁴ Furthermore, the Joint Submission recognizes that the adoption of the biomedical model has led relatively 'risk averse institutions', such as anthropology, to adopt unnecessarily restrictive procedures:

- Requirements for detailed *ex ante* or anticipatory protocols - problematic since social investigation often depends on informal 'soaking and poking' methodologies;
- Restrictions on the non-anonymous reporting of research results - problematic since identification is often critically linked to questions of agency and accountability in social investigation (e.g. in history, politics or law)
- Prohibitions on the use of deceptive and/or (semi-)covert methodologies - whilst deployment of such methodologies does require careful thought and justification, it remains essential for gathering information of manifest public importance including that related to discrimination, police malpractice, and the activities of far-right groupings (Joint-Submission 2017).

The Joint Submission states that 'these points were recognised during the drafting of GDPR resulting in "academic" expression being protected for the first time alongside and on an equal basis to other forms of special expression, namely journalism, art and literature, in Article 85'.

In brief, the implementation of the GDPR provides an opportunity for social scientists and humanities scholars to deal with both the level at which ethics review is being organised and the form it takes within their various disciplines. It is important that the professional organisations of the social sciences and humanities in the UK provide clear guidance for negotiating major issues around the implementation of the GDPR: the institutional level of review, the interpretation of the GDPR, and the review and teaching of research ethics itself.

Apart from learning how to negotiate formal guidelines and regulations with our respective university governance committees and management, we need to be prepared to conduct ethnographic research in a world where producing knowledge is understood and shaped in terms of rules for 'data management', engagement framed in terms of 'privacy protection and informed consent', and situated knowledge is expected to be 'shared' as data. Here we would like to draw attention to the teaching of research ethics and to the protection of the integrity of data gathering and management in ethnographic fieldwork.

For students, it can be puzzling to learn that until recently researchers could conduct research anywhere without having to apply for research ethics permission. This makes it necessary to create awareness of the role of ethics in the history of anthropology and ethnographic fieldwork. A second issue is that many students associated formalised research ethics with bureaucratic procedures, and therefore regard it as less important than 'the ethics of doing the research itself'. In the current world, ethics review has become a 'social fact'. This makes it important for students to become aware of the aims and rationale for ethics review and how it relates to their research aim. This brings us to the need to discuss with students how research ethics affects methodology and epistemology. As a step in this direction, Bob Simpson and Margaret Sleeboom-Faulker have put together an online tool - the EthNav, which provides guidance for students to orient themselves in the field of research ethics and ethics review. The EthNav is available on the website of the UK Association for Social Anthropology (EthNav 2019).

⁴ Article 89 EU GDPR, 'Safeguards and derogations relating to processing for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes'. Available at: (<https://www.privacy-regulation.eu/en/9.htm>)

The management of research data in data registers is not quite the same as the archiving of research materials, which has a long history in anthropology. The former is often organised by funding agencies or universities, who hope to store and share data to make investment into research pay off. Anthropologists do not usually think in terms of data units, a notion associated with commodified knowledge. It is better to speak of 'research materials', which have been co-created with the people that we engage in when we do research. As related above, there are many issues inherent to mechanisms for storing data, related to confidentiality and privacy, but also to politics and the ability to conduct ethnographic research with integrity. In the EU, many of these problems are shared, which is why we need to make a collective effort to develop ways of dealing with 'research materials' in the light of the GDPR. Some efforts in that direction have been initiated by Peter Pels (Pels et al 2018). One of the results are accessible guidelines (Dilger et al 2018; EASA 2018), which provide guidance on the ownership of research materials, archiving, consent, custodianship, embargo and public access. Both to protect our ability to conduct research in politically sensitive areas, and to protect the co-producers of our research materials from mandates for 'data archiving' and 'data sharing' by our governments, we all need to reflect on how to deal with the new regimes of information society.

References

Alvesalo-Kuusi, A. and Whyte, D., 2018. Researching the Powerful: A Call for the Reconstruction of Research Ethics. *Sociological Research Online*, 23(1), pp.136-152.

BBC 2018. BBC Facebook scandal 'hit 87 million users', 4 April. Available at: <https://www.bbc.co.uk/news/technology-43649018>

Caplan, P. 2003a. Introduction: anthropology and ethics. In *The ethics of anthropology: debates and dilemmas* (ed.) P. Caplan, 1-34. London: Routledge.

Dingwall, R. 2012. How did we ever get into this mess? The rise of ethical regulation in the social sciences. *Studies in Qualitative Methodology* 12: 3-26.

Dilger, H., Pels, P, and Sleeboom-Faulkner, M. 2018. Guidelines for data management and scientific integrity in ethnography, *Ethnography*, 20 (1). pp. 3-7. ISSN 1466- 1381

DPA, 1998. Data Protection Act 1998. Available at: <https://www.legislation.gov.uk/ukpga/1998/29/contents>

EASA. 2018. [EASA's Statement on Data Governance in Ethnographic Projects \[PDF\]](https://www.easaonline.org/)

EthNav. 2019. EthNav. [ONLINE] Available at: <https://www.theasa.org/ethics/ethnav.html>

EU-GDPR 2016/679. Available at: <https://www.privacy-regulation.eu/en/index.htm>

GDPR. 2016. General Data Protection Regulation. Intersoft Consulting. Available at: <https://gdpr-info.eu>

Hodge, D. 2013. The problems with Ethics. *PoLAR*, 36(2): 286-297.

Humphris, R. 2018. Is anthropology still legal? Notes on the impact of GDPR. *IRiS*.
<https://superdiversity.net/2018/05/16/is-anthropology-legal/>.

Joint Submission. 2017. Joint Submission to the DCMS. Available at:
<https://www.britac.ac.uk/sites/default/files/2017-05-10%20DCMS%20GDPR%20Derogations%20submission.pdf>

Lederman, R. 2016. Fieldwork double-bound in human research-ethics reviews: Disciplinary competence, or regulatory compliance and the muting of disciplinary values. In W. van den Hoonaard & A. Hamilton (eds) *The ethics rupture*. Toronto: University of Toronto Press.

Meskel, L. & P. Pels 2005. Introduction: Embedding ethics. In L. Meskel & P. Pels (eds) *Embedding Ethics*, 1-26. Oxford: Berg.

Pels, P. et al. 2018. Forum. Data management in anthropology: the next phase in ethics governance? *Social Anthropology*, 26(3), pp.391-413.

Rowley, H. 2014. Going beyond procedure: Engaging with the embedded complexities of being an embedded researcher. *Management in Education*, 28(1): 19-24.

Simpson, B. 2011. Ethical Moments: Future Directions in Ethical review for Ethnography. *Journal of the Royal Anthropological Institute* 17 (2): 377-393.

Simpson, E. 2016. Is Anthropology Legal? Earthquakes, Blitzkrieg, and Ethical Futures. *Focaal* 74: 113-128.

Sleeboom-Faulkner, Margaret, Simpson, Bob, Burgos-Martinez, Elena and McMurray, James (2017) The formalisation of social-science research ethics: How did we get there? *Journal of Ethnographic Theory*, 7 (1). ISSN 2049-1115

UCAS, 2017: Universities and Colleges Admissions Service. Available at:
<https://www.ucas.com/>

Van den Hoonaard, W. & A. Hamilton (eds) (2016) *The ethics rupture*. Toronto: University of Toronto Press.

Verhallen, T. (2016). Tuning to the Dance of Ethnography: Ethics during Situated Fieldwork in Single-Mother Child Protection Families. *Current Anthropology* 57(4): 452-473.