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## **Is it time to re-evaluate the ethical governance of social media research?**

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Last month, a group of UK researchers came together to hold a workshop on social media (SM) research ethics to explore current thinking in the field. The workshop brought together researchers, research ethics committee (REC; IRB in the US) members, and research institution representatives. The panel of 10 expert speakers from both health and non-health related disciplines<sup>1</sup> discussed their research within the context of how understandings of SM research ethics have changed and are progressing. Discussions at the workshop emphasised a need to shift how we think about SM research ethics, from considering only specific ethical issues, to including ethics along the entirety of the research process [1], thinking about issues (and solutions) in combination, as well as including broader questions about ethical governance.

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<sup>1</sup> 1 The boundaries between health-related and other data are breaking down, and the ethical governance of health data is not, cannot, and should not be distinguished or separated from data governance in general (<http://www.who.int/bulletin/volumes/96/1/17-197426/en/>). The governance of health-related SM research needs to fall under the broader category of ethical governance in general.

It is well understood that SM research blurs the boundaries around traditional ethical notions of human participant research. Much discussion has focused on questions relating to, for example, whether SM data is human participant research, and in turn, whether we need to receive consent from SM users to use SM data; and whether SM data should be viewed as publically accessible or a private space, and what this means in terms of harnessing, analysing, and presenting the data [2, 3]. The new and fast-developing nature of SM; the variety of unique SM platforms; and the diversity of disciplinary methodologies used to analyse SM data, has led to the realisation that there can be no blanket answers to these questions. Rather, any ethical approach to SM research must be context specific, requiring deep thought by scholars embarking on their work about how best to approach their research ethically [1]. This seems justifiable, but raises the question of how we can govern ethical decision-making if SM researchers are making individual case-based ethical decisions during their research. Indeed, our own research has identified a ‘personal ethics’ culture for SM research, in which SM researchers monitor their own (often different) decisions about how best to act ethically [4]. This has, in some instances, led to a potentially problematic ‘cafeteria ethics’, in which researchers pick and choose which ethical perspective to adhere to based on their own ethical principles and viewpoint.

Discussions at the workshop enabled the start of a conversation about what ethical governance structures could look like as we move to address some of the issues above, and in particular pointed to the need to consider ethics along the whole SM research process. From these discussions we make two recommendations, which we explore below.

First, during the day it became increasingly apparent that the question of whether SM research should be classified as human participant versus other research may have little value in this field. Journal editors and REC members often ask this question to determine whether ethical approval and/or consent is required for a specific research project. However, workshop speakers provided strong case examples of researchers who classified SM data as ‘text’ due to disciplinary norms, but at the same time came to the realisation that receiving consent is ethical best practice [5]. This was not a unique example, but something that is becoming increasingly common in the field. As such, the language at the workshop was not centred around notions of ‘human participants’, rather workshop speakers spoke about the absolute requirement that all researchers – no matter which data was being analysed or how - should consider SM users’ perspectives [6]. If we can neither accurately classify SM research as human participant research or text-based research, our recommendation is for RECs and journal editors to incorporate the additional term ‘data subject

research' in their ethical governance documents to encapsulate data from this field. Ethical governance of 'data subject research' can be aligned with key principles of SM research ethics, which may differ from human participant or non-human participant research. We heard at the workshop that some UK RECs have started to move towards this approach, though we understand that practice is still very inconsistent.

Second, workshop speakers emphasised the necessity to view ethics as much broader than through the lens of binary decisions around consent and anonymisation, as is currently typical in a lot of SM research ethics, and to view research ethics as more complex and at all stages of the research process – from the research question stage through to publication and aftercare [1]. Moreover, it was stressed that the data collection stage – the stage most focused on by RECs/IRBs - may account for only a minor aspect of a SM research project. It was also stressed that whilst this may also be the case for other research fields, it is particularly relevant to SM research given the abundance and permanency of online data. For instance, when choosing a research question, the speakers explained the need to be aware that 'just because it [the social media data] is there, doesn't mean we should use it' [7], rather we must ensure that if we are using SM data, that the research question we are asking the data has some form of public value. Whilst this seems obvious, it is important to stress this, because the nature and accessibility of SM data could mean that this could otherwise be overlooked. Speakers also stressed that at the dissemination stage, and especially when applying quantitative methodologies, it is imperative to include transparent explanations of analytical methods/algorithms used to analyse SM data so as to ensure findings are not interpreted as the whole 'truth' but one version dependent on the opacity of the processes through which the data passes as well as researcher biases [8]. And finally, the importance of considering aftercare was noted [1]– specifically that researchers remain contactable in years to come. This was viewed as particularly important to safeguard those participants who have previously consented to data being available on SM platforms in the form of raw or interpreted data, but who later wish to remove this (the example was given of a photograph of a participant conducting a specific activity which they later wanted removed because they were looking for employment).

We argue that the above points are examples of the types of issues we need to consider in more depth when thinking about how to develop a SM research ethical governance structure. Therefore, our recommendation is that, when developing such an ethical governance structure, we use the opportunity to re-evaluate the REC's role in reviewing SM research, and how it can best accommodate this broader view of ethics. The current REC structure - inherited from the biomedical field – may be inadequate, and we must urgently start a conversation about how the

REC role can incorporate a longitudinal perspective of ‘ethics as a process’ over the entirety of the SM research process and beyond.

In order to start this conversation, and to explore issues surrounding social media research ethics and governance more broadly, The *Journal of Empirical Research on Human Research Ethics (JERHRE)* invites contributions to a forthcoming **special issue** on **Ethical Issues in Social Media Research** Guest Edited by Gabrielle Samuel PhD (King’s College London) and Elizabeth Buchanan, PhD (University of Wisconsin-Stout). The special issue aims to publish articles which:

1. explore the perspectives of researchers, research ethics committee/institutional review board chairs and members, research institutions and affiliated bodies, the public and/or social media users about social media research;
2. explore questions around best practices in terms of the ethical review of social media research;
3. explore, report and/or critically examine different ethical issues which have emerged from social media research, particularly novel issues arising from under explored social media platforms; and
4. explore stakeholder perspectives on recent social media scandals, such as that of Cambridge Analytica/Facebook.

Abstract submission for the Special issue: 15<sup>th</sup> September 2018; submission of full manuscripts: 15<sup>th</sup> January 2019; target publication date: August 2019. More details can be found [**insert link**].

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