Ethical and legal issues involved in conducting studies on mental health using social media data. Examples from the M-HEALTH project: Abstract for LESSON 2019 – Zurich, October 2019

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ABSTRACT

Research with large datasets of social media data poses several ethical challenges, particularly in relation to issues such as privacy, consent, security, and intellectual property. However, to our knowledge no efforts have been made to consider the ethical and legal challenges (e.g.: to secure ethical approval) of conducting public mental health research with geo-referenced (or spatial) social media data. The goal of this study is to take this challenge by exploring the main ethical and legal issues involved in conducting such a type of study (the MHEALTH study) and to offer a tangible solution to researchers and stakeholders alike on how to tackle them. Driven by these and other questions and committed to ensure the strictest compliance with current ethical, legal and security requirements, we worked to ensure the M-HEALTH study, aimed at analysing geo-referenced Twitter data for mental health research purposes, building up on a solid ethical infrastructure. To do this, we followed different steps: first, we reviewed the literature on the ethical and legal implications of doing research with big data, in general, and with social media data, in particular; next, we screened the most common and conventional approaches for addressing the main ethical and legal issues of collecting and analysing personal/health data; we then engaged with two stakeholders in data protection within the University of Zurich and the Cantonal Government of Zurich, respectively; finally, we adapted different approaches to the peculiarity of our study design and data (geo-referenced social media data) into the study protocol, the data management plan and the data sharing and confidentiality agreement for subsequent ethical approval. This presentation will highlight the main ethical challenges that emerged when planning to set up a repository with the enriched geo-referenced social media data and the strategies we intend to pursue to limit any possible risks for the users involved. The talk will be enriched with information that emerged from our team's collaboration with the delegate for data protection at the University of Zurich and the data protection officer of the Canton of Zurich between May and June 2019. Our goal is to offer practical advice on how to secure ethical approval for thematically and methodologically analogue studies while contributing to the current debate on the ethical, legal and social implications of research with georeferenced social media and big data.