Social (media) networks as a platform for health-related research: privacy challenges

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With advancements in information technologies, social media networks present numerous opportunities for health and public health researchers. Not only social media networks allow to reach out to populations and access research data that otherwise would have been challenging to obtain, they present innovative opportunities to examine the displayed online behaviors and beliefs in a context that is naturalistic, and provide possibilities to make various connections beyond those possible from the volunteered and observed data. While in the former case, social media networks serve as a recruitment tool and hence the user is only being reached out to, in the latter cases, the user-generated content in itself becomes a data pool for research without necessarily the user as a data subject being aware of that. This type of research can be done either by profit or by non-profit actors, and these data could be used for various purposes, for instance, advancing science and contributing to better understanding of human health and its determinants. They could also be used for purposes, such as profiling and automated decision-making concerning the data subjects.

In the absence of specific regulations targeting health related data mining for research purposes on social media networks, it remains unclear whether and how the rights and interests of data subjects are currently protected. In light of the foregoing, this contribution examines how GDPR responds to data mining from social media networks for health-related research, and consequently, to what extent, if at all, individual's privacy is safeguarded. It begins by unfolding the link between social media networks, data mining and privacy concerns. Thereafter, it reviews the GDPR approach to privacy protection, and analyses data mining practices under the GDPR. Finally, it reflects on the extent to which individual's privacy is safeguarded in social media network research, and accounting for different types of research, available technical measures and their limitations, and it identifies the concerns that remain and suggests ways forward. This contribution shows that personal data mining for healthrelated research purposes, in principle, falls within the scope of the GDPR, disregarding that data could be mined in a privacy-preserving way without identifying the data subject. Contrary to the reported claims on difficulty to apply GDPR to inferred health data, this contribution demonstrates the necessity to comply with the provisions attributable to processing special categories of data and, consequently, the degree of protection afforded to the data subjects. A distinction in regard to the data subject protection could be drawn depending on whether and how an EU Member State has acted in regard to Article 89 GDPR that permits derogations from the common EU standard for scientific research purposes. In those EU Member States that have foreseen derogations under Article 89 GDPR attributable to data mining, data subject's protection is considerably lower than in those states that have not foreseen the derogations or the derogations do not apply to data mining for research purposes. Nonetheless, as scientific research is usually subject to further requirements, oversight and enforcement could be more effective.