

ABSTRACT

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PATIENT CONFIDENTIALITY AND ETHICAL EPIDEMIOLOGICAL RESEARCH THROUGH CONTACT TRACING APPS AND SOCIAL MEDIA HEALTH SURVEYS?

Epidemiological measures implemented to address the COVID-19 pandemic, have emphasised the complex legal and ethical issues involved, when attempting to make use of information technology and internet intermediaries, to achieve public health goals. For individuals, their right to privacy and rules regarding patient confidentiality may be undergoing subtle modifications, due to the manner in which information technology has been deployed to manage the pandemic. The use of social networking platforms as gateways to health surveys, and the launch of contact tracing applications, present challenges for patient confidentiality, in addition to ethical regulation of epidemiological and medical research. A key question for many European countries, is whether the GDPR adequately addresses data privacy in the context of internet enabled health research and health care? The legal impact for both individuals and society is partially dependent on whether private or public entities have direct legal responsibility, for the development and management of contact tracing apps, in addition to other internet enabled, health policy solutions. Legal concerns also extend to the structure of public-private collaboration in this sphere, and how contracts regulating these relationships, apportion legal responsibility for ethics, oversight and confidentiality. In Switzerland, government higher education institutions, EPF Lausanne and ETH Zurich have been given the task of developing the contact tracing app DP-3T, for the country. The result of this fully public sector approach means that legal responsibility is clear, and the applicable regulation is equally so; the Human Research Act and attendant ordinances, including the Swiss Federal Act on Data Protection, in case of private sector collaborations. This contrasts with the “private sector but government - supported” approach in the United States, along with variable regulation on data privacy and health research across several U.S. States. Whatever the approach taken by countries, it is useful to deconstruct the possible ways in which contact tracing apps, could leave lasting changes to patient confidentiality and data privacy regulation.ⁱ

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