

Big data and the emerging ethical challenges

Mohammed Saqr

Department of Medicine, College of Medicine, Qassim University, Qassim, Kingdom of Saudi Arabia

Address for correspondence:

Mohammed Saqr,
Department of Medicine, College of Medicine, Qassim University,
P.O. Box: 6655, Qassim 51452, Kingdom of Saudi Arabia.
Phone: +966-16-3800050. Ext.: 2012.
Fax: +966-16-3801228.
E-mail: saqr@qumed.edu.sa

WEBSITE: ijhs.org.sa

ISSN: 1658-3639

PUBLISHER: Qassim University

The concept of big data refers to the capture and storage of large amounts about users and their usage behaviors for the purpose of offering personalized services based on predictions. Big data usage spans a wide array of fields that ranges from biomedical data, government usage, online commerce, education, research, and politics, just to mention a few. The ever-growing scope of big data presents new challenges that the current methods of privacy self-management are failing to adequately deal with. This tremendous growth of data is creating opportunities as well as new challenges unknown to the medical community before.¹⁻⁴

Few years before, it was unimaginable that one can wear a device that records his heart rate, rhythm, temperature, tremor frequency, physical activity, and sleep rhythm. Combining these data with the medical records, with the travel records, with the data of social networks, with the purchases history as well as with many other services that record our interaction with the technology is not difficult but is actually happening. The future promises even more sources of data and sensors that can record innumerable functions. Unfortunately, the rapid pace of development in data science is not met with due understanding of the legal, ethical, and cultural issues associated with collection, storage, and studying these data.^{2,3} When it comes to studying medicine, there are well-established guidelines and organizations that govern this issue such as Ethical National Committee of BioEthics (NCBE) on living creature and good research practice in Saudi Arabia, Data Protection Act in the United Kingdom, and EU Directive 95/46/EC in Europe. These guidelines are always used as the basis for granting ethical approvals for studies working with these types of data. However, there are many sides of data usage that are beyond these guidelines.

Privacy self-management (notice and consent) gives users the option to control their data by allowing or revoking access to their data by opting in or out. However, this is not always the

reality, because personal data are always collected, used, and analyzed and at times shared or abused. Consent is always not read, and if read not always completely understood, and if not accepted by the user he might have no access to a certain service, or choose an inappropriate alternative, or sometimes the lack of an alternatives, this makes agreeing to the terms obligatory and no more of an option. The failure of consent has been widely discussed and acknowledged.⁵

In an ideal world, transparency should be applied to all stages of working with data. The stakeholder groups should be adequately informed about purposes of the data captured, how it is collected, stored, transferred, or processed. They should also be informed about the way data will be analyzed if any third parties or companies will participate in data processing. Users should be given clear guarantees that data will not be sold or transferred to other institutions or legal entities without proper consent. However, reality is far more complex, the data collected today might be useful 5 years later when a new algorithm is discovered that can use the data for a certain prediction, at that time we cannot get back to the users and tell them what their data are being used for. Which calls for new ways that can guarantee users rights, enable research, define what the future data usage can be and how the whole process can be governed and supervised, and cases of abuse are identified and properly handled.¹⁻⁴

The rapid growth of biomedical information necessitates the orchestrated efforts of all parties involved in research to understand the legal, ethical, and cultural challenges facing us. The old rules do not help solve the emerging problems. We need new policies that are crafted – not just for the current challenges – but with the future in mind.

References

1. Varley-Winter O, Shah H. The opportunities and ethics of big data: Practical priorities for a National Council of Data Ethics. *Philos Trans*

1. R Soc Math Eng Sci 2016;374:20160116.
2. Mittelstadt BD, Floridi L. The ethics of big data: Current and foreseeable issues in biomedical contexts. *Sci Eng Ethics* 2016;22:303-41.
3. Larson EB. Building trust in the power of 'big data' research to serve the public good. *JAMA* 2013;309:2443.
4. Schneeweiss S. Learning from big health care data. *N Engl J Med* 2014;370:2161-3.
5. Mantelero A. The future of consumer data protection in the E.U. Rethinking the 'notice and consent' paradigm in the new era of predictive analytics. *Comput Law Secur Rev* 2014;30:643-60.