

Online platforms, digital tools, and ethics in Biomedical research

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Research opportunities have been expanded and the feasibility of doing research and accessibility to data has been increased over the past few decades with the development of online platforms and digital tools. The use of the online platform to collect data has become a popular mode recently with the COVID-19 pandemic. The researchers and ethics review committees both need to be aware of the measures to be taken to implement ethically sound online research. Moreover, researchers need to understand that though the data collection is done differently, basic ethical principles (autonomy, justice, beneficence and non-maleficence) apply to any research endeavour (WMA, 2013).

Researchers need to pay special attention to the privacy risk and the issues related to consent. If the researcher intends to use publicly available data in a website, permission from the website owners is required and is obliged to abide by their terms and conditions. In such situation application for ethical approval is necessary. However, it may fall in the category of exemption from the ethical review. Consultation of institutional policies, updated guidelines by the regulatory bodies on the privacy and security measures in online research is essential for ethics review committee members during the review process.

According to the Council for International Organizations of Medical Sciences guidelines (CIOMS, 2016), the researchers are expected to pay attention to the followings:

- Providing adequate details mainly in the context of the purpose of the research and the intended use of data to the participants. This is a short introduction which is more or less similar to the description present in the information sheet (eg: aims, methods, benefits, risks, discomforts, voluntary participation, freedom to withdraw irrespective of the consent given, post-study provisions, ethical approval, contact details of the investigators and the ethics review committee). The information sheet is given to the participants in onsite research while this appears before the consent form and questionnaire/digital app in online research.
- Obtaining voluntary consent before embarking on the survey/research. This is done using a standard format after the introduction part. It is essential to obtain consent for the research, making that step compulsory allowing to proceed only when the participant agreed.
- Informing the presence of privacy risk and the privacy-security measures to be followed to protect their data. If personal information and identification details are collected researcher needs to justify the collection of such information and elaborate how privacy and confidentiality are maintained especially when the data sets are shared or published online.
- Notifying the potential limitations on the security measures on privacy-protection despite the safeguards put in place. The traditional de-identification techniques (deduction of name, postal address, and other contact details) notably have limitations and may still expose the individual's identity. The use of different online platforms and digital tools or mobile devices/apps have their

limitations related to privacy characteristics. Therefore, the researcher needs to be aware of the features of the devices and the mitigation measures.

In the future, internet and technology-driven research will move forward, and is of critical importance to keep the research going even during a pandemic like this. Hence, defining the firm ethical boundaries would promote ethically sound online research with digital tools, while encouraging flexibility and situation-based ethical decision making especially in ethically grey areas.

References

Council for International Organizations of Medical Sciences (CIOMS) in collaboration with the World Health Organization (WHO) International Ethical Guidelines for Health-related Research Involving Humans, (2016).

World Medical Association, Declaration of Helsinki – ethical principles for medical research involving human subjects, (2013).