Passive data

Passive data refers to data generated without the active participation of the subject. This includes data from global positioning systems and accelerometers or metadata on phone call and text activity. Although the potential healthcare applications are far-reaching, passive data raises numerous ethical challenges.

Maher et al. performed a systematic review to identify all ethical concerns, normative standpoints, and underlying arguments related to the use of passive data in healthcare.

Among the various challenges discussed in the ethical literature, informational privacy, informed consent, and data security were the primary focus of the current debate. Other topics of discussion were the evaluation and regulation of products, equity in access, vulnerable patient groups, ownership, and secondary use.

No clear ethical framework has been established that stimulates passive data-driven innovation while protecting patient integrity. The consensus in the ethical literature, as well as the parallels with similar concerns and solutions in other fields, can lay a foundation for the construction of an ethical framework. The future debate should focus on conflicts between two or more ethical, technical, or clinical values to ensure a safe and effective implementation of passive data in healthcare [1].

[1]

Maher NA, Senders JT, Hulsbergen AFC, Lamba N, Parker M, Onnela JP, Bredenoord AL, Smith TR, Broekman MLD. Passive data collection and use in healthcare: A systematic review of ethical issues. Int J Med Inform. 2019 Jun 22;129:242-247. doi: 10.1016/j.ijmedinf.2019.06.015. [Epub ahead of print] Review. PubMed PMID: 31445262.

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