Appendix: Summary of Best Papers Selected for the IMIA Yearbook 2023, Section on Human Factors and Organizational Issues (HFOI)

Roschka S, Leddig T, Bullerjahn M, Richter G, Liedtke W, Langanke M, Hoffmann W

Data routinely collected in healthcare delivery have immense potential for reuse in research, quality improvement, and optimization of services. In general, patients support the idea of secondary use of their data to advance medical science and to improve healthcare services. It is desirable—and sometimes legally necessary—that such reuse be made only with the patient's (or a proxy's) informed consent. A similar need arises in relation to residual biospecimens. This work answered the question: How do patients and their caretakers like to be informed and to provide consent? In this well-designed study, acceptability of the consent process was assessed in a comparison between two groups, one consented on admission and the other having to meet someone separately to provide consent. Both groups reported no pressure to provide consent. All who were consented immediately were informed before providing consent. About half of those who had to meet separately provided their consent without attending the informative meeting. The paper is notable for the rigor of the study and its implications for many types of patient data consent processes.

Turner JA, Calhoun VD, Thompson PM, Jahanshad N, Ching CRK, Thomopoulos SI, Verner E, Strauss GP, Ahmed AO, Turner MD, Basodi S, Ford JM, Mathalon DH, Preda A, Belger A, Mueller BA, Lim KO, van Erp TGM

With increasing emphasis on the learning health system (LHS), research is seeking to translate "real-world data" into "real-world evidence". The FAIR principles characterize data that are available for such use: they must be Findable, Accessible, Interoperable, and Reusable. The goal is computable biomedical knowledge (CBK) in the form of "machine-actionable data objects." Exemplars of systems that build on existing applications by integrating the FAIR principles provide evidence for the viability of the concepts of LHS and CBK. Here we have a description of a platform that combines the virtues of decentralized analysis and trustworthy data sharing. COINSTAC allows for secure distributed analysis of neuroimaging data. ENIGMA is a very large consortium that integrates data and coordinates large-scale analyses of brain imaging, genetic, clinical, and behavioral data. Their combined approach was demonstrated through a complex meta-analysis of sex differences in symptom severity in individuals with schizophrenia. The paper contributes to the advancement of FAIR principles in complex datasets.