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A fair balance: health data protection and the promotion of health data use for clinical and research purposes

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Propositions as part of the dissertation written by Irith Rolinka Kist

Title: *A fair balance: health data protection and the promotion of health data use for clinical and research purposes*

A. Four propositions on the subject of the dissertation

1. It is a common misconception to believe that individuals can exercise full control over their personal health data.
2. The individual expression of explicit consent is not, and should not be, the only realization to protect the individual's human dignity, self-determination and autonomy.
3. Consent is but one legal ground in the GDPR and often not necessarily the most appropriate in health care and health research.
4. Data processing in health care and research requires balancing the individual interest *of* the patient with the societal interest *for* all patients.

B. Four propositions on the scientific discipline of the dissertation

1. A balanced approach between individual data protection rights or interests on the one hand and the free flow of data on the other promotes the quality of health care and research.
2. A risk-based approach by monitoring and supervisory authorities serves data protection compliance in health.
3. A comprehensive interpretation of EU law, whilst both considering the wording and the context, serves both the spirit and the letter of the law.
4. The EHDS provides an opportunity to further shape data sharing for clinical and research purposes in addition to the general framework of the GDPR.

C. Propositions on societal developments

1. The predominant focus on individual data protection rights and interests in health care and research negates the significance of the principles of solidarity and reciprocity in society.
2. The data controller is responsible for the lawful, fair and transparent data processing. The patient's trust in the data processing and the transparent communication by the data controller are crucial elements for the exchange of data [Recital 58 and 60 GDPR; article 5 (1) (a) GDPR].
3. The use of health data for secondary research purposes is best achieved in a governance structure *of* the people, *by* the people, and *for* the people [Based on President Abraham Lincoln's Speech The Gettysburg Address, 1863].