

Digital medicine can only find sufficient trust with effective data protection

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Data protection does not prevent optimal patient care. Nor is this the case with regard to research. The discrediting of data protection by the German Society for Internal Medicine (DGIM) harms the digitization of medicine.

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In a press release on its 128th congress, the DGIM denounced the data protection practiced in Germany. Excessive data protection is a risk to the health of many people and even endangers human lives. The Hessian Commissioner for Data Protection and Freedom of Information (HBDI) Prof. Dr. Alexander Roßnagel was surprised by the view and the statements contained there in relation to data protection. They discredited data protection in the context of patient treatment and research, thereby harming medical work. In the field of digitization, this is dependent on the trust of patients that their highly sensitive data is handled responsibly. In addition, according to the HBDI, the DGIM is torpedoing Prof. Dr. Alexander Roßnagel describes the previous efforts of the HBDI and other supervisory authorities to ensure an interest-based balance with such exaggerated statements.

The HBDI comments in detail on the central statements of the DGIM as follows:

The DGIM fails to recognize that point 26 of the current orientation guide for hospital information systems (OH KIS) states that if a patient is treated again after the access restriction has taken effect, the restriction on access to data from previous treatment cases is lifted may be. Against this background, the following assertion by the DGIM is incomprehensible: "Data protection can mean that a doctor in the emergency room cannot see the treatment of the same patient by the specialist due to a technical access block, since the emergency doctor is not involved in the original treatment was."

In the area of the emergency room, it is also permissible under data protection law to grant emergency access. Both the alleged "access blockade" and suboptimal patient care caused by data protection are therefore not evident. The announcement by the DGIM causes uncertainty and the misconception among patients that data protection is an obstacle to emergency treatment

Unfortunately, untenable theses are also being put forward for the area of research.

It is correct that the principle of data minimization should also be taken into account in research. If a lot of highly sensitive data

is stored about a person, this is always associated with a risk of social discrimination against people.

Restricting data processing of personal data to what is necessary for research is a viable means of limiting this risk and still enabling medical research. If altruistic data donations are desired, data protection is even a prerequisite for research. Only he can create the necessary trust and willingness to donate data.

When researching with anonymous data, the principle of data economy does not impede in any way. In no research project to date have the researchers had to do without data that is necessary to achieve the research purpose for reasons of data protection.

In this context, the HBDI draws attention to the recent resolution of the Conference of Independent Data Protection Officers on Scientific Research and Data Protection of March 23, 2022, which emphasizes the support of research, especially medical research, by the data protection supervisory authorities.

The secondary use of data that has already been collected is now also extensively permitted in many regulations, such as Section 75 SGB X.

Against this background, the following passage from the DGIM press release is also viewed critically:

"Another data protection principle and its implementation in Germany is becoming a problem, especially for gaining medical knowledge: "Data economy" means asking for and documenting only the personal data and information that is immediately necessary. "This may make sense in order to curb the collecting mania of Internet companies - but this principle is completely counterproductive when it comes to clinical data from individual patients or medical data from clinical studies, in disease registers or in population-based epidemiological studies," says Lerch. "The more comprehensive the data included, the higher the probability of uncovering previously unknown connections: between drugs and their side effects or unexpected health effects, between laboratory parameters, biomarkers or environmental influences and the development of diseases." According to the DGIM chairman, it would be an enormous waste of scientific, human and economic resources to be evaluated for other purposes than the original questions, or even to have to be destroyed after a certain period of time. Adjustments in this regard are highly urgent."

When the DGIM claims that one of the most urgent areas on the way to the digitization of the healthcare system is the handling of "data and the General Data Protection Regulation (GDPR) in the healthcare sector at the legal level – a regulation that applies throughout Europe, but especially in Germany, is interpreted in a way that sometimes endangers the life and limb of

patients.", then this is a statement that is in no way substantiated and also does not correspond to the truth. The most important regulations of the GDPR are specified by the European Data Protection Committee and adopted by the German supervisory authorities. In this context, it is often misunderstood that the essential statements of the GDPR were also valid in Germany before the GDPR came into force.

The "demonization" of the GDPR and data protection is not new. Already in the course of the pandemic, the statement was made in isolated cases that data protection had cost human lives. However, the way in which the fundamental rights of the persons concerned (contact tracing, data storage by employers, data processing by health authorities, restriction of the rights of those affected) could be restricted during the pandemic shows that combating COVID-19 is only possible and possible through the GDPR was not prevented by them.

The HBDI has submitted an offer to talk to the DGIM based in Hesse. The HBDI Prof. Dr. Roßnagel on this: "Dialogue is important to me, and should there still be points in the area of treatment, research or digitization from the point of view of the DGIM where data protection prevents solutions, my employees and I would be happy to exchange ideas to disposal."

In the consulting practice of the HBDI, it is always important to point out data protection-compliant solutions and options and not to limit oneself to the rejection of existing concepts.

Sources: Press release of the German Society for Internal Medicine Resolution of the data protection conference: Scientific research - of course with data protection

Contact for press representatives
Press spokeswoman: Ms. Maria Christina Rost
Press and public relations: Telephone: +49 611 1408 119
The Hessian Commissioner for Data Protection and Freedom of Information
P.O. Box 316365021 Wiesbaden
Print
Send as email