10 principles to guide digital health and protect privacy - By Joseph Goedert

Now more than ever, consumers are using a variety of digital tools and applications that involve their health and their health information. As a result, it is crucial that healthcare organizations be transparent about how they use consumer data, following ethical principles that everyone understands. Current technology thus raises the questions of ethics—how far can medicine can go in dictating patient adherence to treatment? That's why Proteus, a vendor of drugs that communicate, has worked with Michael Keller, vice provost of the Academic Council at Stanford University Libraries, as well as more than 30 other health leaders, to develop a guiding set of principles to navigate potential conflicts between individuals' need for privacy and society's need for protecting public health. The health leaders have created a set of 10 ethical principles to guide the health digital future.

Principle 1: Products should always work in patients' interests - Digital health companies should work with providers, insurers, regulators and government to ensure products enable effective and affordable access to quality care. They must never be used to discriminate or deny necessary care.

Principle 2: Digital information sharing should seek to aid outcomes - Sharing digital health should always have the purpose of improving a patient's outcomes and those of others. Companies get consent from patients for information to be shared and should recognize that consent represents only a broad statement of trust by the patient. Providers should acknowledge their duty of care with respect to use of patient information.

Principle 3: Information should be shared only improve health and care - "Do no harm" should apply to the use and sharing of all digital health information. Digital health vendors should be alert to malicious use of health information and unintended consequences of well-intentioned users by adopting safeguards to anticipate and mitigate risks.

Principle 4: Patients should not be forced to use digital products - Patients should have the final say in what types of treatment they receive, particularly regarding the use of digital health products. Use of patient data should be voluntary with a positive mindset.

Principle 5: Patients should decide on where their info winds up - Patients should have the final decision on whether their information is shared, and they have a right to know how the company uses the data to generate revenue. Patients should know their information will be used for many purposes, know who is responsible to care for the information and how the organization gets paid when it uses the information.

Principle 6: Digital health information should be accurate - *Products should maintain high standards of data quality, reproducibility and integrity. Validation methods should be auditable and transparent.*

Principle 7: Digital health information should be vigorously protected - Those entities entrusted with patients' digital health information should use strong security tools. The products should meet state-of-the-art security standards, and patients should know how the companies perform against standards.

Principle 8: Security violations should be reported promptly - *If security lapses occur, patients may bear significant consequences. Entities that suffer security breaches must let consumers know of the event, along with what is being done to fix them.* As a general rule, within 10 business days of detection, companies should inform patients of any breach and potential consequences, and steps taken to mitigate risk.

Principle 9: Digital products should facilitate caregiver interaction - As organizations make decisions on deploying digital health tools, they need to factor in how these tools will enable patients to be more connected to their caregivers. Information created by products should strengthen the voice of patients and families in care decisions, by educating patients and improving communication and trust with providers.

Principle 10. Patients should be actively engaged - Because digital health tools can have such a significant impact on patients' health, they should be involved in the community that is shaping digital health products. Companies should give patients tools to express opinions, provide feedback and communicate their needs in a timely and professional manner.

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