

Project Visualization of Privacy Path in eHealth & m-health: Regulatory & Policy Frameworks

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Acronym: VPPEM

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Privacy is a fundamental principle underpinning quality healthcare. Consumer's trust in the appropriate handling of personal health information must be maintained as the health sector moves to adopt and implement new technologies. Visualisation will provide a clear identification of the explicit structure of patient's record data. Adopting new, tech-enabled health care approaches which can deliver high quality, patient-centric, healthcare to EU citizens requires trust and assurance in the system. The medical sector, policy makers and patients will also be hesitant to discard the traditional system that has worked well in the past to and embrace the digital revolution.

The overall goal of the study is to contribute to: (1) a safe and secure handling of the patient's data through identification of vulnerabilities that can lead to non-compliance of privacy and data protection laws in the EU (2) a visualisation of the private information flow to assist in the drafting of regulatory and policy framework to accelerate eHealth solutions for more efficient health services (3) an illustration of relationship and significance (transactions and interactions) across the internet –some of them originating from the assignments to users of inappropriate permissions on sensitive data, thus recognising as early as possible the risk deriving by inappropriate access right management and to identify the solutions that they need to prevent such risks and 4) visualisation of the technical interoperability of eHealth applications upon the normative framework at both EU and national level and assess the urgency of fostering the adoption of information security and data privacy enhancing measures, in particular through the incentive of the law, in parallel to the promotion of technical interoperability. A review of the current Data Protection Directive 95/46 and the Proposed Data Protection Regulation show that they do not always lend themselves to congruous and seamless amalgamation. This has resulted in various interpretation and a times, legal gymnastics on the of medical practitioners, data officers and lawyers resulting in deprivation of the rights of privacy for the deceased and important medical information to relatives of the deceased , which could offer valuable support for to the preventive care. Diagnosis and treatment plans. The laws regulating medical records and other related legal issues need to be reviewed and are not dealt the current data protection law and proposed regulation.

Professor Kierkegaard gave a speech discussing new developments in Privacy and data protection laws in EU, such as data retention, right to be forgotten, e-health, sensitive data and security. It was well attended by professors in the medical field, lawyers and PhD students. The talk shed some light on post-mortem privacy, a phenomenon rather neglected in the legal literature. Acknowledging the quite controversial nature of the phenomenon and certain policy and legal arguments pro and contra, the speech explores the data protection (informational privacy) aspect of the issue. More precisely, the focus is on the distinction between the current and the newly proposed data protection regime in the European Union (EU), assessing how these regimes are susceptible to protecting the deceased's personal data.

The remainder of the visit was devoted to visualisation of the possible legal issues arising from the right of access to the sensitive data and access to records of the deceased, especially Human rights. The visualisation provided clear representation of the process and will be of great help to all stakeholders in understanding the relevant issues.