

ERA OF DIGITIZATION: RE-DESIGNING PRIVACY PROTECTION IN HEALTH CARE

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ABSTRACT

The paper examines the issue arising when delivering healthcare in the modern information society. Throughout the past decade, the Internet has seen a significant rise of the "Web 2.0" trend, which carried on its wings a health industry trend often referred to as "Health 2.0" or "Medicine 2.0". More recently, we have also witnessed the crowning of concepts such as Health Social Media, eHealth and mHealth. European Union as well as the national states develop strategies implementing new technologies for personal and medical data sharing, including the prescription of medicals as well as their validation through websites. Healthcare data privacy and security is one of the top challenges, healthcare providers face. The huge amount of data the medical care generates holds potential for researchers, providers, pharmaceutical companies as well as for doctors, who can use it to improve care or find new treatments and insights into disease. The key issue to examine is how to balance the competing interests of privacy and data-sharing and not exclude the patient as a holder and owner of the information. The paper addresses the issue of privacy protection in digitized healthcare, using the analysis of the legislation and case-law of the Czech Republic, stressing the demands for human rights and privacy protection of a member state of the European Union. The paper introduces several proposals for providers on how to re-design digital healthcare with respect to laws and patients' rights. The paper concludes that even modern and digitized medicine is based not only on evidence and modern technologies but also on human interaction and face-to-face approach and trust between the doctor and patient.

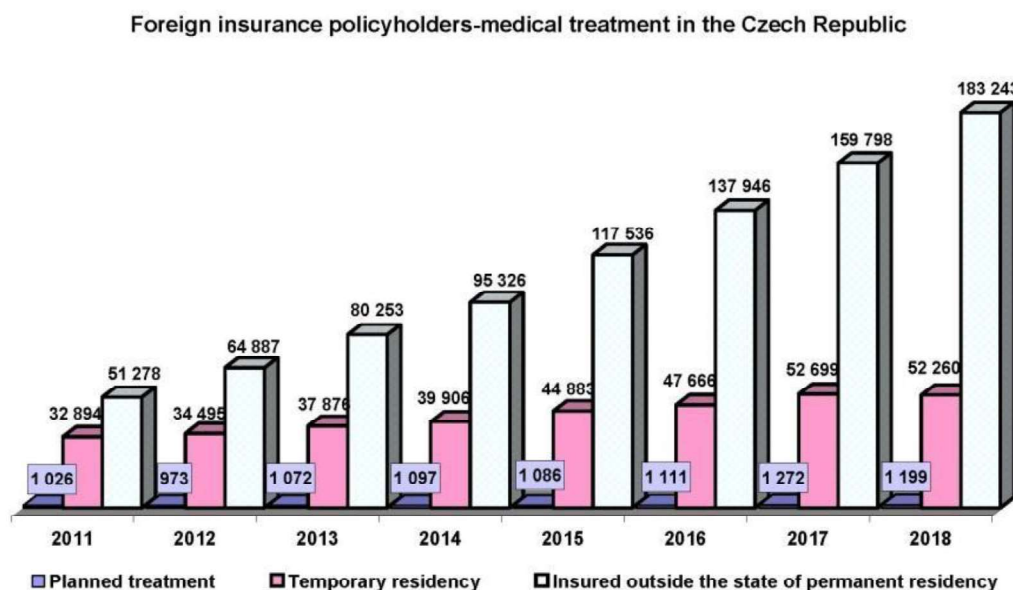
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INTRODUCTION

The European Union (EU) healthcare system is underpinned by the principles of solidarity and compulsory health insurance. The EU member states claim the basics of the welfare state, which means that most of the medical treatments and interventions are covered from public funds. Innovations in natural science, especially biotechnologies and informatics, brought substantial changes to healthcare. The main switch is connected with the introduction of artificial intelligence in daily practice, as contemporary society is based on technologies and knowledge. The use of modern technologies enables a much more patient-oriented approach and complete access to medical data sharing. But the healthcare systems, founded in the late fifties of the 20th century remain fragmented, oriented to provide acute, not chronic or long-term care. [1] The latest challenge is globalized healthcare as cross-border migration becomes very common in the (EU). The EU citizens and persons settled there move for studies and work, alone or with whole families. The most important documents of the primary EU law underline the right for the protection of public health, including medical research and accessible healthcare as one of the solidarity rights, but under the conditions of the of national laws. [2] The secondary EU law, the Regulation (EC) 883/04 on the coordination of social security systems and especially the Directive 2011/24/EU on the application of patients' rights in cross-border healthcare form the basis for cross-border healthcare and medical services to support both the freedoms of free movement and services and the possibility of enjoying the latest achievements of the medical

science. Graph No.1 indicates the steady increase of foreign patients seeking health care in the Czech Republic.

Graph 1



Source: Health Insurance Bureau, Statistical Yearbooks 2011 - 2018

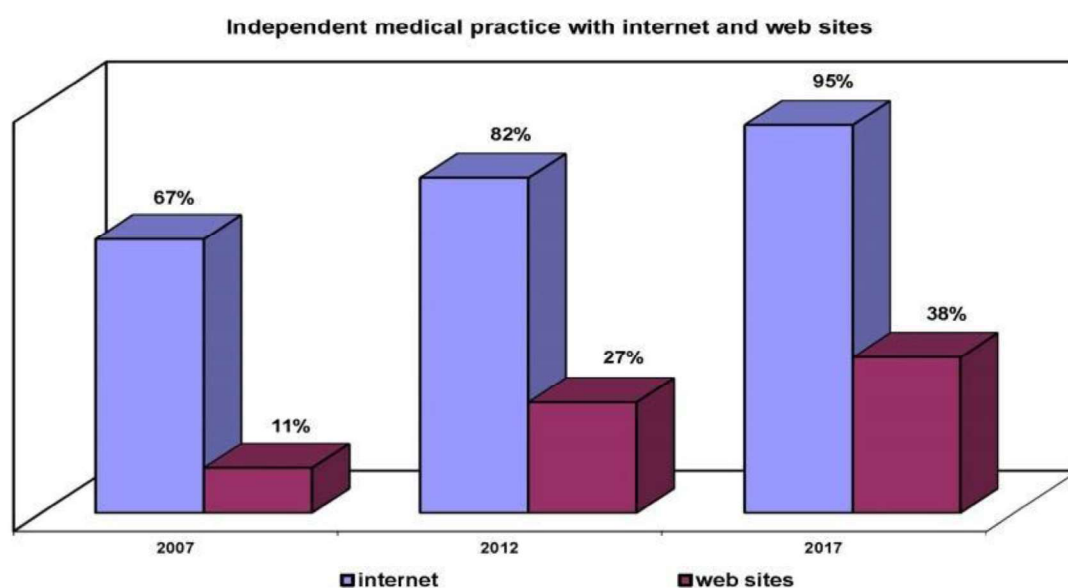
Due to the above mentioned, national systems of health care have to change and be re-designed. The main challenge is to keep in check the costs without hitting the quality and safety of healthcare. Artificial Intelligence (AI) and its widespread use are one of possible and essential resources for redesigning health care in post-industrial society. The paper aims to highlight the benefits and risks of modern technologies to patients' rights and security. The paper examines legal and managerial challenges and introduces some proposals. The Czech Republic, as a very well accessible Central European state, with an extensive network of public and private medical facilities, developed medical technologies and a very recent legal regulation of public and private legal issues in health care, is a sought for both planned and acute medical care, based on EU regulations. The analysis of the Czech laws, legal practice, and the experience of authors in public healthcare form the starting point to find out the appropriate methodology and proposals for re-designing the privacy protection in healthcare.

TOPICAL ISSUES

The possibilities of AI in medicine and health care are immense. But they are closely connected with technological development and digital infrastructure. The challenge and question to the next future are whether the right to access the internet belongs to human rights? The Resolution of the General Assembly of the United Nations on The Promotion, Protection, and Enjoyment of Human Rights on the Internet [3] considers that access to the Internet is one of the main tools for civil society and citizens to exercise their fundamental human rights. Indeed, without access to the Internet, people may be excluded from the community, the possibility of education and the freedom of exchanging ideas or expressing their opinion freely. Some authors argue that the Internet is only a technical means, which enables to realize the right, but it is not a human right in itself. Moreover, human rights and life within the society could be exercised through other technical types of equipment, for example, mobile phones or Bluetooth connections. [4]

Health is considered a fundamental human right that is the basis for the exercise of other human rights and is essential for a dignified life. Medical practices as well as patients seek on Internet the most important information and develop a relationship. EU adopted the strategy of the Digital Single Market. E-Health, as one of the policies, should assure personalised medicine throughout Europe and enable secure access to the relevant health data within the EU. [5] The Czech Republic adopted the National eHealth Strategy in 2016 (national strategy). According to the Action Plan for Years 2016-2020 the compulsory e-Prescription and the possibility of EMD have been regulated by law. E-health, telemedicine forms another part of the national strategy, using an exchange of information and health monitoring through mobile applications. Patients should consult with a specialist through various telemedicine platforms and media.

Graph No. 2 indicates the steadily growth of modern communication in medical practice.



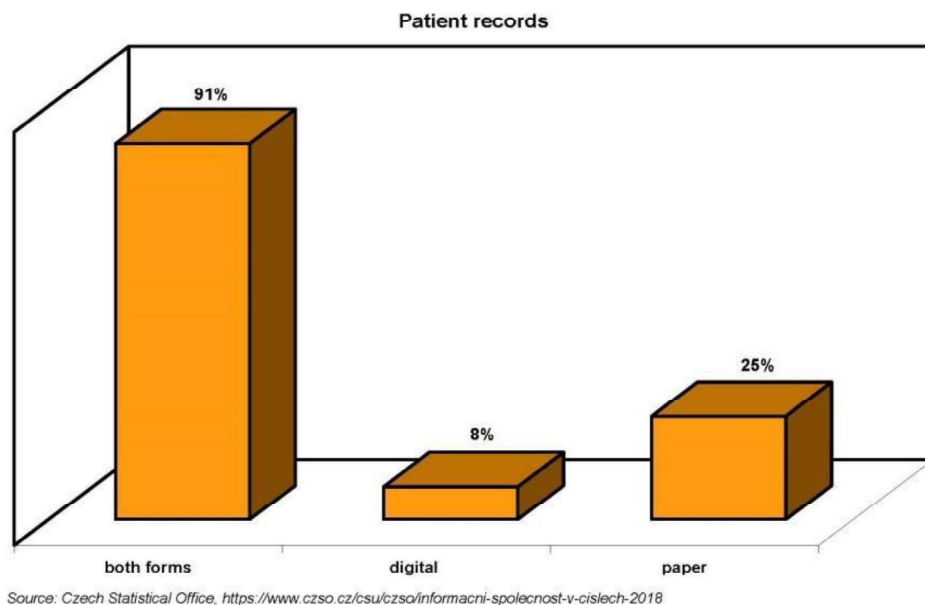
The most obvious risk for patients using modern technologies and especially social media for exchange medical information is confusion and misdiagnosis due to the consumption of low quality of information as many websites are very easily accessible. *"Medical information on social media may be unreferenced, incomplete, informal information that relies on anecdotal reports, unlike traditional medicine."* [6]

Another significant problem when sharing sensitive medical information is privacy protection as both with confidentiality form the key concepts and notions when providing health care. The right to privacy is one of the most important rights of an individual, which protects human dignity and other values, such as free interaction with others and the right to choose information, which an individual freely provides to the surroundings. Privacy is sometimes narrowed only to the protection of personal data in information systems. The notion of privacy, however, has a broader dimension both in general and during providing of health care. The medical and legal practice, as well as the theory practice-distinguish between "privacy" and "confidentiality". The area of privacy and its protection focuses on obtaining information, while confidentiality focuses on the communication of information. Both terms however complement each other and overlap not only while providing health care. [7]

One important question during providing health care is the protection of personal data and providing information about a medical condition. Data about health conditions are recorded in

medical documentation and are kept either in paper or electronic format. The most documentation keeping is through the combination of both these formats. Electronic files are used for sharing information among healthcare professionals and within large medical institutions. Daily care in smaller hospitals or private practice is recorded in both ways. The graph No. 3 confirms the above-mentioned, because 91% of Czech private medical practices kept patient files in a combined form in 2018.

Graph 3

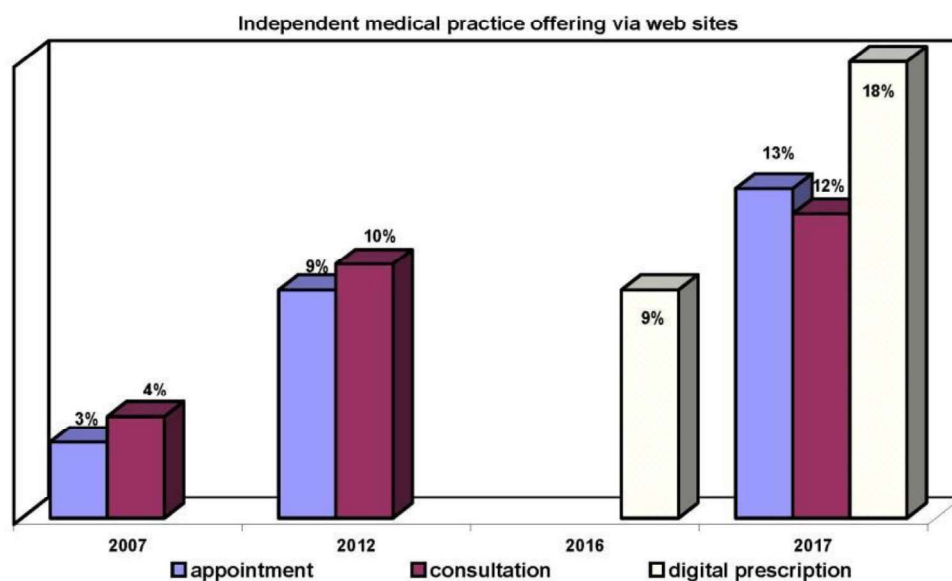


The protection of personal data and providing information about a medical condition forms one of the most important issues when providing healthcare. Data about health conditions are recorded in medical documentation and kept either in paper or electronic format. The documentation is mostly kept in both formats. Electronic files are used for sharing information among healthcare professionals and within large medical institutions. Daily care in smaller hospitals or private practice is recorded in both ways. The graph No. 3 confirms the above-mentioned, because 91% of Czech private medical practices kept patient files in a combined form. The information recorded in patients' files is owned neither by the healthcare provider, nor the patient. According to the Czech case-law, just the tangible medium belongs to the medical practice. The right of the patient to access the files applies to the content, ie. the information, not to the ownership of the medium. [8] Two problem areas appear when dealing with the information in files. One is privacy protection, covered with the duty of professional confidentiality. The second issue is the access to the documentation, which allows either the patient or the law. The Czech Constitutional Court ruled, that medical records are protected by the constitutional right for privacy protection. Just the prevailing public interest, for example in criminal proceedings, permits access without the consent or even knowledge of the patient. [9] The EU and national legislation and the case-law emphasize privacy and the information self-determination of a patient as a subject of the information. The AI enables any healthcare provider to compile, process and share enormous amounts of data (big data) and information quicker, in more detail and to a much greater extent than the man can do. These processes can be easily improved by learning of the machine itself. AI and digitization facilitate to keep of medical records in electronic form (EMD) and send them to any place of the world, for example data collected during clinical trials. In such a sensitive situation, the medical and legal practice should assess the legality, proportionality, and rationality of disclosing the information about the health

care and the health status of a patient without her consent. The breach of professional confidentiality and privacy protection is a professional or administrative offense. According to the Criminal Code of the Czech Republic, a person or legal entity could be held responsible for the crime of unauthorized use of personal data. This crime includes also the breach of professional confidentiality duty. The crime of violation of the confidentiality of conveyed messages stipulates for misuse or illegal download of stored or transferred data. The healthcare sector is viewed as a critical infrastructure not only because of a large amount of personal and sensitive data stored but also because of its irreplaceability in the daily life of communities and the whole civil society. Despite this vulnerability, the users – medical professionals, providers, and patients require immediate and quick access to the data and technologies. Any protection, which could make the admittance to the system a little bit difficult, is considered being an unnecessary barrier and obstacle of managers, not understanding the needs of contemporary medical care. The compulsory digitization of medical documentation and other data and their transfer via the Internet or cloud storage attract cybercrime. It is very difficult to disclose a computer crime, as it is always hidden and silent with no violence and the data could be sold anonymously through unidentifiable computers and banks in states, where no obligation to report money laundering exists.

Graph No. 4 shows the increasing offer of digital services in independent medical practices in the Czech Republic. In 2016 the e-prescription was launched; it became compulsory beginning the 1st January 2018.

Graph 4



Source: Czech Statistical Office, <https://www.czso.cz/csu/czso/informacni-spolecnost-v-cislech-2018>

RE-DESIGNING PRIVACY PROTECTION

The highlighted concerns and challenges require the re-designing and new, measures of privacy protection to make form AI in the healthcare sector a useful and secure tool, suitable not only for introducing new therapeutic methods, but also facilitating the daily care in every medical practice. The law falls behind new technologies and progression in medicine. That is why we underline, that both the theory and practice must be searched for solutions in joining managerial and legal approaches. Moreover, the combination of management and law will be operational and successful only in the case that all stakeholders will be involved in their own

accord. In the Czech Republic, patients and medical professionals were excited by the compulsory digitization in selected medical services, though they voluntarily use digital services and the Internet is a daily source of healthcare information (see graphs 2 and 4). Taking into account the interdisciplinarity of the medical law, the need to balance private and public interests, the interaction between state- and community-owned healthcare providers and private medical practices and providers, and also economic interests of public finance, covering the majority of healthcare costs, we suggest exploiting the theory of the new governance. This methodology enables new approaches both in law and healthcare, as it is based on collaboration, experiments, flexibility, adaptation, experimentation and has no coercive nature. The methodology accepts not to be the only way of solving public issues. New governance assists to create a basis for more effective forms of participation, enables coordinate administration on multiple levels, allows great flexibility and promotes innovative solutions. It is more than a set of managerial tools as it coordinates actions as well as produces and reproduces socio-cultural, economic and political relations and values, while at the same time impact upon, define, and determine the outcomes of such interactions. The scope is usually to achieve field-specific, practice-oriented goals—broadly and narrowly defined. [10] The theory and practice of new governance are closely connected with the new public management, which involves stakeholders, ie. patients, healthcare providers, and communities. The critics argue that the new governance may cause disorder and boundaries between and within public and private sectors become blurred. The essence of governance and its most troublesome aspect is a focus on mechanisms that do not rest on recourse to the authority and sanctions of government. If especially the practice remains aware of the mentioned challenges, this approach is, according to our experience, the most appropriate for re-designing healthcare from the legal and managerial point of view. The methodological emphasis on exploring local conditions and peculiarities is very significant from the perspective of the covered topic as because the solution is to be found in the community, The new governance theory emphasizes *„building on collaboration between state and non-state stakeholders to address public problems through experimental forms of decision making and policy implementation.”* [11] New governance methodology is suitable for exploration and re-designing questions of public interest as it comprises the complex mechanisms, processes, and institutions through which individuals and groups express their interests. They negotiate also about their differences and exercise their rights and obligations. [12] The healthcare law has to comply with the new requirements of the EU for the privacy protection, set down in the Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, (General Data Protection Regulation, GDPR). General legal awareness is concerned with the data and privacy protection and the second issue addressed-free movement of the data-remains unnoticed. But the provision of healthcare is just about the data sharing and movement, very often cross-border. AI and Radio Frequency Identification (RFID) technologies enabling store and communicate data significantly change the role of healthcare legal regulation, as it is necessary to enlarge and re-design traditional concepts of patients' security. The personal physical safety of patients is now assured in different ways, but in the context of global cyber risks, it is necessary to evaluate the adequacy of existing international and national standards of patients' safety in the virtual space.

CONCLUSION

An effective system of health care provision is a crucial institution within a society, one which carries the same significance as the justice and democratic political system. Whilst consideration of the right to health and the highest possible standard of health care services generally concern decisions regarding the provision of public resources, the fundamental human right to life and health remains an integral consideration within the legal doctrine and judicial practice in terms of assessments of liability for damage. Healthcare and medical law form an interdisciplinary field that can be defined as follows. [13] *"Certain regulations are compiled and issued for the sole purpose of securing, enhancing and protecting human health."* The right to health does not only concern the provision of health care, in the European context usually covered by public insurance, but also the human right when seeking health services not to become a mere faceless object within a system administered by the state or by other authorities. The digital era opens new challenges for solving managerial and legal issues when providing health care. In order to ensure the right to health under new technological and social conditions, we suggested how to identify the individual's subjective right to participate in the care of her health. It is necessary to discuss whether constitutionally legal dimensions of the right to health entails the right to participate in health care, or even the simultaneous right and duty to accept sole responsibility for deciding on one's health, because AI, Internet, and social networks enable to get relevant and up-to-date information. Security is of high value to society and individuals. Ensuring the safety and security of data and information sharing entails providing a stable institutional and legal framework by which individual needs for privacy protection can be satisfied. In today's globalized society, notably according to current EU standards, healthcare providers and medical professionals must meet standardized requirements, such as the protection of personal data, patient record keeping, accounting regarding health care provision, management as well as the archiving of documents related to their activities. In such situations, the legal entity or individual, who is also a business proprietor, is frequently in a wider conflict which usually takes the form of a clash of different, often conflicting, legal obligations. These divergences among competing responsibilities regularly have an impact on the protection of privacy and fulfilment of the duty of confidentiality. We argued and highlighted our findings of the new governance and new public management as the most appropriate methodology and practical approach to re-design the healthcare in the era of digitization. *"The essence of governance is its focus on mechanisms that do not rest on recourse to the authority and sanctions of government...Governance for (some) is about the potential for contracting, franchising and new forms of regulation. In short, it is about what (some) refer to as the new public management."* [11] All these understandings of the new governance carry the assumption that actors are embedded in, determined by and shape such structures and processes, too. The global industrial society and new technologies and digitization change all the relationships when delivering healthcare. Traditional approach, stressing the individual liability of a medical professional for the negligence and malpractice, became obsolete. Large groups of specialists, doctors, biochemists, biomedical and IT engineers, laboratory and nursing staff, provide for healthcare and health services. Healthcare is one of the weightiest of the world's problems, as the majority of healthcare difficulties and paradoxes have ethical and moral causes. The spectrum of illnesses has changed, the relationship between patient-doctor has lost its personal character and the financial burden of healthcare costs limits the use of modern technologies for all patients in need. [14] But the main values, when re-designing privacy protection and healthcare protection of human dignity, health, and life, remain.

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