

## Health equity and health data protection related to telemedicine amid the COVID-19 pandemic

The correlation between health equity and health data protection in the area of telemedicine has been put into relief during the COVID-19 pandemic. Indeed, the right to health data protection is not only a personal right but also a human right. Health equity cannot be maintained without an adequately functioning system of health data protection in telemedicine, yet, in many countries, health equity remains a mere dream. The United States and the European Union are the flagships of both health equity and health data protection, with HIPAA (in the US) and the GDPR (in the EU); however, some gaps do exist, as demonstrated by the practice of telemedicine during the COVID-19 pandemic. While US and EU regulations on telemedicine do provide legal certainty, fighting the COVID-19 pandemic has created a new legal climate, with new priorities superseding health data protection, which had been paramount beforehand.

**Keywords:** *telemedicine, health equity, health data protection, COVID-19 pandemic, human rights, personal rights.*

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## 1. Introduction

Health equity and health data protection are strongly correlated in the area of telemedicine. The quality of health equity in telemedicine is largely affected by the observation of data protection rules and principles. There is no legal certainty without ethics, and ethics are reflected in the law in effect. Ethical norms orientate not only lawmakers but also legal practitioners.

Health equity can be made a reality not only if a legal foundation is established but also if there is wide acceptance of the laws in society. Health equity should be guaranteed for all – the poor as well as the better-off. If there is a social discrepancy, health equity cannot be maintained. Health equity presupposes data protection being respected by all. When certain social actors erode data protection for their own purposes, other groups of people will suffer abuse of their rights. Where rights tied to health data are abused because of deficiencies in telemedicine, health inequity comes about.

The ethical ‘good’ is not necessarily identical to the notion of ‘lawfulness’. A derogation from the basic international principles of health data protection may be justified either by laws related to the COVID-19 pandemic or by social ethics. It is not only health equity that requires social coherence. The law on health data protection also demands it. Strictly abiding by the laws is not always ethical: *summum jus = summa injuria*. However, when the social actors are inclined to obey the laws and to respect the health data protection regulations, there is a great chance to create a society with immanent health equity.

It is important to protect all patients’ health data; no one is entitled to a higher level of protection by law than others. A right to health data protection is a personal right enjoyed by a living patient that vanishes after death. According to Hungarian court practice, if a patient has initiated a civil lawsuit for infringement of their right to health data protection, their heirs may continue the legal procedure after the patient’s death. This suggests that health equity presupposes a state of law where health data protection is guaranteed by the telemedicine system and also by the judiciary as a last resort.

## 2. Health equity and telemedicine in light of the COVID-19 pandemic

Authors from the United States have underlined the following problem: ‘economically disadvantaged Americans have the greatest need to take advantage of telemedicine to minimise unneeded contact for medical care as they are already in high-risk groups on a number of other fronts. Regarding work, they are more likely to work in essential public services’ (Khilnani, Schulz and Robinson 2020, 399). This sort of problem arises in every country in the world, and it is one of the main sources of health inequity amid the COVID-19 pandemic.

Recent research conducted in Canada has demonstrated that western rural Canadians prefer in-person medical consultations to telemedicine. This is the case even though most western rural Canadians enjoy access to telemedicine (Rush et al. 2021, 10).

A similar problem arises in other countries as well, including Hungary. Most rural Hungarians today, as before the pandemic, will take a coach to meet their physician personally rather than enjoying the advantages of telemedicine. In countries where telemedicine is not accessible to all, the hardship is even greater. The Canadian phenomenon is observed in various societies and cultures.

There is a certain level of intrinsic inequality in the information positions of the physicians and patients. The patients find themselves in a vulnerable situation when disclosing their health data. The physicians' responsibility for data protection is not merely of a legal but also of an ethical character. The physician's duty to protect other people, who are in contact with the contagious patient, may overwrite the patient's right to health data protection.

Recently, US authors have emphasised the importance of health equity in connection with telemedicine during the COVID-19 pandemic. Access to broadband Internet, the ability to pay for telemedicine and many other factors have been determining health equity during the pandemic (Ortega et al. 2020a, 369). Other US authors have argued that '[t]he COVID-19 pandemic has exposed the magnitude of US health inequities – which the World Health Organization defines as “avoidable, unfair, or remediable differences” in health' (Berkowitz, Cene and Chatterjee 2020). Lynch has observed that '[t]he COVID-19 pandemic has revealed starkly and publicly the close interconnections between social and economic equality, health equity, and population health' (Lynch 2020, 983).

In China, from July 2018, the government has introduced regulations on telemedicine (Iong 2020, 595) and it is now free of charge. In the US, Medicare reimburses the costs of healthcare provided through telemedicine (Ortega et al. 2020a, 369). Other countries, such as the UK, Germany, Canada, India and Hungary, also promote it in light of the COVID-19 pandemic. Hopefully, these developments will be upheld after the current situation.

In relation to the COVID-19 pandemic, authors from all over the world have pointed to the 'loss of health insurance, jobs and homes, which increases risk for mental and physical morbidity and all-cause mortality' (Shadmi et al. 2020, 2). All that harms health equity in various ways in the countries under examination. For example, in this study, the co-authors from Brazil state that rich white people have imported SARS-CoV-2 from abroad and then infected less well-off Black workers in Brazil (Shadmi et al. 2020, 3). The Chinese co-author is satisfied with the health measures taken by the Chinese government. The US co-author stresses the problem of uninsured homeless people and that of the prison population of 2.3 million because the prison healthcare system is 'understaffed and ill-equipped' (Shadmi et al. 2020, 10), and the co-author from Colombia focusses on the relevance of 'telemedicine for higher-risk groups, with the aim of reducing their unnecessary contact with the health system' (Shadmi et al. 2020, 13).

In Hungary, health equity is by and large ensured by the state. All the relevant human rights documents are in effect in the country. Nevertheless, there are ethnic minorities (e.g. the Roma), jobless people, underpaid employees, retirees with a small income and other social groups who have never enjoyed full health equity during the recent history of Hungary. Telemedicine is not accessible to these people

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or at least not fully accessible. The lack of access to broadband Internet is one of the disadvantaging factors. In Hungary, an unusual number of healthcare services are free; however, it is in private healthcare that a truly standard level of care is provided. After healthcare professionals' salaries were raised in 2021, they had to decide whether to work exclusively in the public or in the private healthcare sector because it was not permitted to work in both. Those who have chosen the public healthcare sector earn a considerable salary, while Hungarian patients who use private healthcare are those that can well afford it. Most socially vulnerable patients turn to public healthcare providers, thus enlarging the gap between the level of healthcare for the rich and that for the less well-off.

Telemedicine has been vital during the COVID-19 pandemic; however, health illiteracy and digital illiteracy mean that it is rather available to better-off and younger social groups (Julesz 2020, 29; Pikó and Kiss 2019, 108). Health inequity arises from this phenomenon, and it is not the only factor at play. In Hungary, it is mostly baby boomers who suffer from digital illiteracy. Those of advanced age hardly ever use the Internet. Their main means of telecommunication with their doctor is the telephone, though this is often insufficient for telemedicine. Spanish authors have concluded that '[i]f face-to-face care cannot be offered, telehealth interventions should be guaranteed, whenever possible facilitating contact by video call rather than by telephone' (Sanchez-Guarnido et al. 2021, 9). This assertion was made in connection with occupational therapy for mental health; however, it applies to a variety of areas of medicine, except for such interventions as surgery or other cases of physical intervention. Gyórfy et al. point out that quite a few patients conceal or exaggerate symptoms. This can be better recognised through a video connection than via telephone (Gyórfy et al. 2020, 989). Balogh et al. argue that telemedicine has become common in primary healthcare during the COVID-19 pandemic and that its advantages should be maintained after the pandemic but that the length of consultations via telephone ought to be reasonably limited (Balogh, Diós and Papp 2020, 1431).

In the US, authors have argued that 'those groups most vulnerable during the COVID-19 pandemic – older adults and those with pre-existing conditions – are also two groups that have historically been more likely to suffer from digital inequalities' (Khilnani, Schulz and Robinson 2020, 398). Other authors from the US have arrived at the result that during a major increase of telemedicine visits in March and April 2020 in the US, it was mainly patients aged 20 to 44 years who used telemedicine, particularly for urgent care (Mann et al. 2020, 1132). The COVID-19 pandemic makes telemedicine necessary to guarantee equal access to healthcare for all. However, health equity for the elderly and the poor exists on the whole in the law but not in reality. Those who cannot purchase the required technology cannot enjoy the advantages of telemedicine. They have to appear in person and expose themselves to potential infection. The waiting lists are long, and telemedicine can only cut them short for those experienced in the digital world. The tendency detected in the US applies in Hungary as well, though the living standards and the quality of the healthcare provided are not comparable.

According to Ortega et al., '[l]inguistic barriers are a recognized source of health inequities for ethnic minority communities whose health communication needs

cannot be adequately met in the majority language' (Ortega et al. 2020b, 1530). In Hungary, this sort of problem did not arise during the COVID-19 pandemic because ethnic minorities in Hungary generally (also) speak Hungarian. Nevertheless, these communities are legally permitted to use their first language in healthcare. However, in practice, they do not. In telemedicine, members of these groups intending to use their first language would certainly meet difficulties due to the lack of health professionals who speak minority languages.

In many countries, health inequity is produced by the scarcity of medical practitioners in the face of a growing population, among other factors. This sort of health inequity can be surmounted by training residents via telemedicine platforms, among other solutions. This is a great opportunity to teach them how to perform medical interventions and observe social distancing at the same time. For example, in Peru, ophthalmology residents have successfully been taught how to do cataract surgery via Cybersight, Orbis International's telemedicine platform (Geary et al. 2021, 8). Although the authors give an account of a success story, I believe that in-person resident–patient contact needs to be ensured to train future medical practitioners even during the COVID-19 pandemic. In the case of undergraduate medical students, e-education may be a way out because of the huge number of students concerned. In Hungary, medical students who enjoyed online education during the worst times of the COVID-19 pandemic have since had the opportunity to make up the leeway and take practical classes in the summer.

### 3. Telemedicine and health data protection

Telemedicine has gained in importance due to COVID-19. The pandemic prompted lawmakers to regulate the legal and professional ethical framework for telehealth. In Hungary, a large number of legal norms have been put in place to keep telemedicine within the borders of the state of law. The protection of sensitive health data and the special legal features of the doctor–patient relationship make it important to meticulously regulate the functioning of telemedicine. The regulations follow the inter- and supranational legal norms in effect in Hungary.

As stipulated by section 52 of the Preamble of the General Data Protection Regulation of the European Union (GDPR): 'Derogating from the prohibition on processing special categories of personal data should be allowed when provided for in European Union or Member State law', especially for the purposes of 'prevention or control of communicable diseases and other serious threats to health'. This regulation offers a certain level of freedom to Member States, such as Hungary, to place public health before personal health data protection, on condition that it is necessary and proportional to prevent the spread of COVID-19. Becker et al. argue that '[i]n a pandemic, such regulations can derogate from data subjects' rights and provide a legal basis for processing beyond the existing legal framework' (Becker et al. 2020, 5).

The right to health data protection is a human right. According to Article 6 of the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data of the Council of Europe: 'personal data concerning health [inter alia]

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... may not be processed automatically unless domestic law provides appropriate safeguards'. Article 8 of the Charter of Fundamental Rights of the European Union declares: 'Everyone has the right to the protection of personal data concerning him or her. Such data must be processed fairly for specified purposes and on the basis of the consent of the person concerned or some other legitimate basis laid down by law.'

Telemedicine provides an ample source of health data. There is a fine line between a legally permitted derogation from data protection and a violation of law. In Hungary, health services provided through telemedicine should be properly documented in the Electronic Health Cooperation Service Space. This requirement is a *sine qua non* of health data protection. An illegal breach of the patient's right to health data protection may lead to both civil and criminal liabilities. The patient may seek damages and bring the case before a criminal court, although the establishment of criminal liability rarely occurs in Hungarian judicial practice. According to section 219 of the Hungarian Criminal Code: 'Any person who, in violation of the statutory provisions governing the protection and processing of personal data in Hungary or in the European Union, for profit or causing serious disadvantage: a) is engaged in the unauthorized and inappropriate processing of personal data or b) fails to take measures to ensure the security of data is guilty of a misdemeanour punishable by imprisonment not exceeding one year. ... Any misuse of personal data shall be punishable by imprisonment not exceeding two years if committed in connection with special data.'

Leite et al. are of the following opinion: 'Public administrations around the world, such as Australia, the USA and the UK, are investing in telemedicine to manage COVID-19, with the specific aim to reduce the volume of patients interacting with emergency departments' (Leite, Hodgkinson and Gruber 2020, 484). The same authors underline the importance of data privacy and protection (Leite, Hodgkinson and Gruber 2020, 483). The Hungarian Act on Health Data Protection is in harmony with the GDPR (EU). The constitutional 'state of danger' in effect in Hungary narrows patients' right to health data protection with regard to COVID-19, though this is proportional and necessary in the time of a pandemic. In Hungary, there are limitations to how the health data obtained from the Electronic Health Cooperation Service Space can be used. Unnecessary and disproportional use of health data is strictly forbidden. The constitutional 'state of danger' is not an excuse for the Hungarian state to abuse patients' health data, and this is so in other countries as well.

Abeler et al. believe that '[w]eakening data protection might be preferable to the far-reaching restrictions of personal freedom and to the economic costs of the current lockdown' (Abeler et al. 2020, 1). The authors consider that a contact tracing system would be useful to warn a person who has been in contact with an infected person to self-quarantine. The authors find it secure because 'the necessary data could be processed in a way that would effectively preclude the central server from identifying users' (Abeler et al. 2020, 2). Bradford et al. argue that 'exposure tracing and notification is a proportionate response to the coronavirus public health threat that justifies some intrusion on the privacy rights of individuals' (Bradford, Aboy and Liddell 2020, 21). In my view, data collection does not run counter to the GDPR



(EU) if it happens with the intention of containing the COVID-19 pandemic. In the European Union, the national regulations on data protection may differ from each other on the condition that they do not violate the common basic EU principles of data protection.

Those basic EU principles of data protection are as follows: the health data must be processed lawfully and transparently; there is no room for data processing without a specific purpose; and only health data necessary for this specific purpose should be processed. Further, the health data should be protected against unlawful, unauthorised and unnecessary data processing. The Hungarian app has been criticised in relation to the aspect of data protection, mainly by party politicians; however, I believe that the basic principles of data protection have not been infringed in practice. Detailing the technological conditions of telemedicine is not a goal of this article.

In the US, the Health Insurance Portability and Accountability Act of 1996 (HIPAA) regulates the processing of information related to healthcare. While the US Department of Health and Human Services (HHS) Office for Civil Rights and healthcare providers found public video call platforms insecure for telehealth before the outbreak of the COVID-19 pandemic, the COVID-19 era has changed that office's opinion, and, as a consequence, healthcare providers have also changed their position. Skype, Zoom, GoToMeeting and many other platforms may now be used (Pool, Akhlaghpour and Fatehi 2021, 74). However, in terms of health data protection, some other public video platforms are still considered to be insecure and are not authorised by the Office for Civil Rights as a telehealth platform (Pool, Akhlaghpour and Fatehi 2021, 75). Bassan is of the opinion that '[h]ealth information accumulated in time of pandemic is highly valuable for those who profit based on it: health providers, health and medical device vendors, health insurance companies, health devices manufacturers, pharmaceutical companies, telecommunication and technology companies whose products may be used to provide telehealth, and advertisers' (Bassan 2020, 7). Bassan points out that 'privacy policies' and 'terms of conduct' set up by companies not covered by HIPAA but still providing platforms for telehealth do not guarantee health data protection (Bassan 2020, 7). In the US, management of electronic protected health information is regulated by HIPAA. Other US authors have concluded that '[w]ith the transition to a postpandemic phase, the key transformation of telehealth systems is to shift from crisis mode (where the use of stopgap or unproven technologies has been permitted) to sustainable, secure systems that properly preserve data security and patient privacy' (Wosik et al. 2020, 961).

Bhardwaj has pointed to the following problem: 'In the telemedicine framework, a standout among the most significant issues is the exchange of electronic patient information (EPI) between patient and a doctor that are remotely connected. A minute change to EPI may result in a wrong diagnosis for the patient' (Bhardwaj 2021, 2915). This is why new methods need to be developed.

From the perspective of scientific researchers, US authors have reasoned that 'we can imagine a unifying multinational COVID-19 electronic health record waiting for global researchers to apply their methodological and domain expertise' (Cosgriff, Ebner and Celi 2020, e224). Another US author has argued: 'HHS should encour-

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age health researchers to use the increased data provided by telehealth services to train AI [artificial intelligence] software that can further improve not only the telehealth services, but also other clinical care, healthcare operations, and research' (Hoffman 2020, 15; see also Héder 2020). In my opinion, health data protection, as a general rule, outweighs scientific aims; however, if those data could help contain the COVID-19 pandemic, a proper anonymisation would counterbalance derogation from general data protection rules. Section 4 paragraph 2(d) of the Hungarian Act on Health Data Protection allows data processing for scientific purposes. Section 4 paragraph 4 makes it legal only if justifiably necessary for the purposes of scientific research. Nevertheless, health data processing is always legal when the patient concerned or the patient's legal representative gives informed consent. In light of the COVID-19 pandemic, the last point is an exception, since masses of patients are concerned, and a great many of them are not in a state to exercise their right to self-determination.

The COVID-19 era has brought significant changes to the social, economic and scientific functioning of all countries. Nevertheless, the political functioning has not changed radically. In Hungary, data protection had become a battleground between civil society and government long before the outbreak of the COVID-19 pandemic. The pandemic put health data protection into relief, and it further increased the debate between civil society and government. In the list of the deceased due to COVID-19 published online by the government, it has been possible to link certain data to a specific person, though the rule of law has been observed. In some of those cases, concurrent information retrieved from tabloids have aided in this recognition.

#### **4. Pros and cons of telemedicine**

Telemedicine is largely based on legal and ethical cooperation between healthcare providers and patients. Telemedicine has not only primary advantages (e.g. social distancing) but also secondary ones (e.g. avoidance of informal payments). When I take into account the advantages of telemedicine, I arrive at the conclusion that, for various reasons, the secondary advantages prevail over the primary ones.

The primary advantages are that:

- the doctor–patient relationship does not always necessitate physical contact between doctor and patient;
- the cost of healthcare provided through telemedicine is usually lower because there are no additional expenditures, such as the cost of travel, meals and accommodation;
- telemedicine can reach rural areas that have previously fallen outside the scope of healthcare; and
- telemedicine makes it possible for physicians who are on sick leave because of COVID-19 to continue working from home.

There are also certain secondary advantages, namely that:

- telemedicine forwards new technologies and promotes digital literacy;
- digital nomads can enjoy a higher level of occupational health;



- the Internet of Things is an unavoidable step on the path of human digital evolution;
- the distance between doctor and patient mostly excludes informal patient payments, which are illegal in Hungary;
- patients will spend more money on necessary and useful healthcare devices than on purchasing legal gifts for physicians;
- patients become educated in healthcare to a certain degree, for example learning how to take blood pressure and how to measure oxygen saturation;
- both patients and doctors save precious time by curtailing futile chatting, although the doctor does still need to talk to the patient in order to establish the diagnosis and, in terms of health psychology, it is also important to inform and comfort the patient;
- the general health culture of society will be improved because of patients' increased personal involvement in caring for themselves; and
- timeworn medical practices will be more or less replaced by millennial physicians' digital response to current problems.

Besides the pros, however, cons also emerge, such as that:

- patients may be objectified;
- digital connections may replace interpersonal relationships;
- doctors' altruism and empathy towards patients may be diminished;
- only well experienced physicians will be able to offer medical advice via telemedicine, with fresh doctors needing to wait and learn despite having little opportunity to gain physical experience; and
- a generation gap between older and younger physicians might hinder the efficacy of healthcare provision.

## 5. Conclusion

Western-type health equity and health data protection are fairly new phenomena in Hungary. Both were imported from the European and American legal cultures. A Western type of health data protection was incorporated into the Hungarian legal system in the second half of the 1990s. Health equity is still under development in Hungary. The right to health data protection is a personal right of the patient, which may be overwritten by the healthcare provider's duty to protect others. Health equity and health data protection have been going hand in hand in the field of telemedicine during the COVID-19 pandemic. The digital illiteracy of the elderly might hinder the use of telemedicine, which is of high importance and not only during the pandemic. Regardless of party politics, the steps made by the Hungarian lawmakers during the COVID-19 pandemic have promoted the use of telemedicine, ameliorated the level of health equity and, meanwhile, protected the citizens' health data.

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