



European Medical Students' Association

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Data Usage in Healthcare: Electronic Health Records

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The European Medical Students' Association (EMSA) represents medical students across Europe. We envision a healthy and solidary Europe in which medical students actively promote health. EMSA empowers medical students to advocate health in all policies, excellence in medical research, interprofessional healthcare education and the protection of human rights across Europe.

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Executive Summary

Unlocking the power of Big Data technology in healthcare could have a huge impact on research and patient care through supporting evidence-based medicine, value-based healthcare and a patient centred approach. However, the healthcare industry is lagging behind other sectors due to challenges such as privacy and security of health data, siloed data and budget constraints.

An EU-wide infrastructure for the centralisation of Electronic Health Record Data would ease European healthcare towards data usage, thus supporting its benefits. Alongside, the EU needs to develop a legislative framework ensuring the patients' benefit being prioritised over financial interests.

Problem statement

EMSA's policy paper "Digital Health in the Medical Curriculum: Addressing the Needs of the Future Health Workforce" (Mosch, 2019) from 2019 noted the healthcare sector as being one of the most far-behind industries regarding digitisation and called on the implementation of digital health education into the medical curricula to prepare future healthcare professionals for a transformed healthcare sector. More recently, a survey showed that in 2020 approximately 85% of students in European medical universities wished for more digital health training (Machleid, 2020). In 2022, after the COVID19 pandemic urged a broad variety of sectors to adapt to digital formats, the healthcare sector was no exception and there was a significant increase in data usage, namely through virtual appointments.

Throughout this policy paper, we aim to address how centralisation of Electronic Health Records could enable digital transformation in healthcare and we further stress the importance of integrating this topic into the medical curricula. The impact on the healthcare system is not directly caused by digitisation itself, but rather by the new possibilities in generating, accessing and analysing health data as well as new ways of patient-doctor-communication.

Generating and storing data

Data of high volume, variable structure and high velocity is referred to as "Big Data". Because of those characteristics, traditional databases fail to be of any help in managing Big Data. Traditional databases are designed to serve specific purposes and have a predefined data structure to do that. Because data needs to be cleaned, enriched and transformed to be integrated, these databases are limited to certain sources of data and can answer only the predefined questions.

In opposition, 'Data Lakes' allow for the integration of data from various sources and are not limited to a predefined purpose. Raw data from individual patients (e.g. wearable devices, Internet of Medical Things (IoMT), medical imaging, Electronic Health Record (EHR), genomic data) and data on a populational level (e.g. pharmaceutical research, search engine data, public records, genetic databases, insurance records) can be connected.

Accessing Data

As Data Lakes allow for storing data from various sources, they provide an infrastructure for digitisation of all kinds of health data, such as EHR. The transformation from physical to digitised health data makes it possible to share data between healthcare stakeholders, thereby enabling clinicians to access a patient's whole medical history and for researchers to access huge cohorts.

Analysing Data

In 2001, the field of molecular biology and genetics was transformed by the Human Genome Project. It marked the beginning of the 'post-genomics' era characterised by the availability of large-scale data sets. This in turn led to a shift from a hypothesis-driven methodology to "unbiased data-driven approaches, sometimes called '-omics' studies" (Read and Sharma, 2021). One example of these "hypothesis-free" correlation studies are the genome-wide association studies (GWAS), which identify certain genetic variants as risk factors for diseases. As health data from different sources will be stored in the same data lakes, these correlational approaches will not stay limited to inheritable biomolecular data. The integration of EHRs, diagnostic data, lifestyle data, genetic data and many more will enable research to identify risk factors and disease modifying factors which are behavioural and thus modifiable, paving the way for targeted prevention.

Big data analytics in medicine and healthcare "enables analysis of the large datasets from thousands of patients, identifying clusters and correlation between datasets, as well as developing predictive models using data mining techniques" (Risteveski and Chen, 2018). Medical knowledge platforms like 'Pathway Medical' will be able to support clinical decision making in diagnostics and therapy as well as providing more individualised prognosis, thereby driving evidence-based medicine.

Value-based healthcare

Big data is pushing the movement towards value-based healthcare and is opening the door to remarkable advancements, even while reducing costs. The trend of Value Based Healthcare describes the move from a pay-for-service model, which financially rewards caregivers for performing procedures, to a value-based care model, which rewards them based on the health of their patient populations. Non-communicable diseases (NCDs) are on the rise and cause 71% of deaths globally. Preventive measures are crucial in tackling NCDs and value-based healthcare provides a framework that incentivises prevention over treatment. Healthcare data analytics will make tracking population health possible, thereby enabling this switch.

Data in Patient Centred Care (PCC)

Patient centred care is one way of supporting value-based healthcare. It is the equivalent of customer orientation in other industries. Mainly it describes aiming not only for statistical improvements on a population level, but to deliver real world benefits for the patient by "understanding the patient as a whole person, building relational connections between the clinician and patient, and supporting patients in health self-management" (Butler, 2020). Literature shows great benefits in a patient centred approach (Little, 2001) and data can be a great ally to healthcare professionals in delivering this approach, whether it's through prevention or treatment focused wearables and apps or through the development of health literacy platforms designed for patients. Implementation of electronic

health records (EHR) can support patient centred care. However, since most EHR systems currently in use were designed for medical professionals and profit purposes, they often undermine the patient-physician relationship during examination (Rathert, 2016). Furthermore, the lack of interinstitutional EHR accessibility (often referred to as “data silos”) complicates collaboration in managing chronic diseases in a patient centred manner.

Centralisation of Electronic Health Record Data

In today’s world we still encounter many countries with no Electronic Health Records (EHR) and in those where EHR are used, data isn’t usually shared between different stakeholders due to legal difficulties and lack of incentives. Promoting the merger of EHR databases associated with different healthcare settings would contribute to a database that could have a significant impact in both patient care as well as research. For example, the European Medical Information Network (EMIF) aims to improve access to health data derived from the electronic health records of around 50 million Europeans, as well as cohort datasets from participating research communities. Nevertheless, the comprehensible reason for healthcare being far behind other industries in data management is the obvious sensitivity of patients’ health data. Healthcare providers and researchers must keep the respect for patient’s data in mind, as stated in the Declaration of Tapei on ethical considerations regarding health databases and biobanks as well as in the World Medical Association’s Declaration of Helsinki, namely in article 9: “It is the duty of physicians who are involved in medical research to protect the life, health, dignity, integrity, right to self-determination, privacy, and confidentiality of personal information of research subjects”.

Not having access to centralised EHR leads to a less efficient and less broad approach to patient treatment, due to a lack of a complete and coherent medical history. It is important to note, however, that the centralisation of EHR requires financial investment by all parties involved and the implementation of platforms that allow for safe and practical interoperability.

All of this should be implemented alongside the European Parliament’s General Data Protection Regulation (GDPR) regulation regarding data protection, but the current GDPR regulation still allows for a lot of derogations regarding data privacy (Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016). This incentivises companies to take advantage of those shortcomings in favour of more profound data analytics.

Lastly but just as important, a problem we encounter according to a survey published by EMSA (Machleid, 2020) is that education on eHealth including EHR data usage isn’t delivered to medical students, leading to a decreased motivation in adapting to new electronic approaches.

Our view. Aim

The 2020s are expected to bring unprecedented innovations in health. New technologies enable us to use healthcare data in new ways, thereby holding the potential to transform structures of our healthcare systems. Advanced analytics and Big Data technologies can act as catalysts for this transformation, including the movement toward evidence-based medicine, value-based payments and a patient centred approach.

In theory, healthcare practitioners and patients alike should be preparing to not just adopt - but embrace - these futuristic solutions. However, while technology can ease the path to wellbeing for both doctor and patient, the healthcare sector has been relatively slow to adopt new ways of working compared to other business sectors. Even though there are valid reasons for the healthcare sector to be conservative in this regard, we, as medical students often feel frustrated by those many missed chances. We as EMSA urge the medical community to discuss future scenarios and proactively shape the healthcare of tomorrow with the possibilities of data usage. To our great concern, the EMSA survey on the implementation of eHealth in the medical curriculum from 2019 showed that most medical students will leave university without being part of academic discussion in this field. This is why we, as EMSA, are driven to foster interest about information technology in the medical community.

Data in Patient Centred Care

As stated before, focusing on a patient centred approach alongside the development of data in healthcare can uphold many benefits. Ideas such as the 'Personal Medical Record' focus on the accessibility of health data for patients and thereby integrate the patient in the management of their own health. Further benefits for the patient include: improving coordination and continuity of care among providers, decreasing the frequency of medical errors, and reducing or eliminating medication and drug errors through e-prescriptions. We believe that besides medical professionals and healthcare investors, the patient should also be regarded as a stakeholder when developing EHR systems by integrating functions supporting PCC (Butler, 2020), thus enabling patient participation and true longitudinal patient care.

Centralisation of Electronic Health Records

Using EHR leads to higher amounts of quickly accessible data, which in turn improves clinical decision making and patient outcomes, leading to a more efficient health system (Kruse, 2018). For example, a study shows that after implementing EHR in a surgical intensive care unit, there was a decrease in the rate of central line bloodstream infections by 85% and a decrease of 28% in overall mortality (Flatow, 2015).

Centralising EHR leads to a higher amount of more accessible patient information, which can allow for more effective public health measures. Broader correlational research identifying risk factors of complex diseases can help targeting prevention and screening programmes more precisely. Bigger data pools can promote the development of treatment focused research regarding drug interactions and adverse reactions, which can help decrease the amount of hospitalizations associated with the misuse of medication (Dechanont, 2014).

Some aspects that limit the centralisation of EHR are financial investments in technology interfaces, system errors in healthcare being potentially fatal, patient dissatisfaction with healthcare professionals that are less attentive while taking notes on the system (Al-Jafar, 2013) as well as the need for interoperability. This last factor needs to take into account whom to share the data with (public and governmental sources or private companies), how much to share and how to guarantee confidentiality and data privacy.

Regarding data privacy, substantial legal and ethical risks associated with the management of personal health data need to be considered. Although centralising this information electronically carries many benefits, it also poses risks such as the discrimination based on ethnicity, gender, class or health status (Ienca, 2018) which can be misused by insurance companies, governments and other stakeholders involved. In order to minimise this risk, regulations such as the EU's Data Privacy Regulation (2016/679) or the "Guidelines on the protection of individuals with regard to the processing of personal data in a world of Big Data", written by the Consultative Committee of the Council of Europe's data protection convention (Pastorino, 2019) have risen to assure that data is being protected while still being used for scientific progress. Despite this, the Regulation (EU) 2016/679 on the protection of personal data, adopted by the EU in 2016, still allows for derogations regarding safety and confidentiality, addressed by the European Patients Forum. For research, among other areas, this regulation allows for many situations where the European Union or Member states can overlook data subjects' rights.

We urge each country's policymakers to further implement specific, targeted and coherent policies that take into account the aforementioned regulations and that aim to protect the privacy and confidentiality of personal health data, using it only when absolutely necessary and beneficial. There are already solutions for ensuring health data security: An option adopted for the maintenance of data privacy by research and healthcare professionals is attributing a number to each individual (tokenization) and using that number instead of the name or other characteristics of the individual. This practice is already adopted on a national level in Sweden and Finland.

In what concerns interoperability, the European Commission is currently working with Member States on implementing an European Health Data Space built upon characteristics such as a strong system of data governance and rules for data exchange, data quality and a strong infrastructure and interoperability. The EU needs to either create a governmental infrastructure or a gapless legislative framework to allow for companies to do so.

Recommendations

EMSA calls the healthcare professionals to:

- Educate themselves as well as their patients on data privacy and data privacy regulations;
- Collaborate with companies in developing wearables and apps that aid in prevention;
- Collaborate with companies in developing data platforms that contribute to health literacy for patients;
- Collaborate with the pharmaceutical industry and data companies to develop new treatment technologies that can be personalised to the patient. These upcoming technologies should also be equipped with an educational setting to better prepare patients for it.
- Consider telehealth as a tool complementing today's physical appointments by providing the ability for low cost and efficient follow up appointments. It can be especially useful in the management of chronic diseases.

EMSA calls the European Commission and European Union Member States to:

- Respect EU's Regulation 2016/679 on the protection of personal data and to only apply derogations to individual's rights when absolutely necessary.
- Prioritise the discussion about creating a EU-wide centralised Electronic Health Record infrastructure (EHDS) via the creation of a governmental infrastructure or to close current gaps in privacy regulation of company-created infrastructure.
- Develop effective measures that promote the access to internet and telehealth devices, as well as education on how to use them, to everyone, regardless of geographical position or socioeconomical aspects.

EMSA calls the healthcare facilities to:

- Subsidise the switch to digital infrastructure that will allow healthcare professionals to adopt telehealth as well as to be able to use Electronic Health Records that allow interoperability
- Provide education on the usage of EHR and telemedicine as well as on matters concerning data privacy.
- Request patient centred care functionalities in new EHR systems.

EMSA calls the companies to:

- Make sure their regulations associated with the protection of clients data are in accordance with the EU's GDPR Regulation.
- Not discriminate against clients based on their personal health information;
- Further prioritise clients' mental and physical health over profit as well as not to use clients' health data and data from correlation studies against individuals.

EMSA calls the Medical Faculties to:

- Prioritise education on data privacy and on the usage of EHR.

EMSA calls the EMSA and EMSA's members to:

- Organise webinars with experts on data privacy and on the usage of EHR.

Abbreviations

EU - European Union

IoMT - Internet of Medical Things

EHR - Electronic Health Record

GWAS - Genome-wide association studies

NCDs - Non-communicable diseases

EMIF - European Medical Information Network

GDPR - General Data Protection Regulation

EHDS - EU-wide centralised Electronic Health Record infrastructure

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