EXPANDING ELGA IN A REFLECTIVE WAY

IN BRIEF

- Electronic health record systems allow for patient health data to be digitally stored and retrieved.
- These systems continuously expand the type and scope of patient data stored.
- In Austria, patient data for approximately 96% of the population can currently be accessed through the national electronic health record system ELGA.
- As new features and uses are added to the system, benefits and risks need to be assessed in an open and comprehensive manner.

WHAT IS IT ABOUT?

There are many positive examples of innovations concerning the storage, retrieval, and management of patient data in the health sector. These include computerised management in doctors' surgeries, electronic patient ID cards, and the digital exchange of diagnostic reports and images, all of which have often contributed to smoother workflows and services. However, the ongoing expansion of the types of data stored, the newly enabled features and connections created raises some crucial questions: How are the data used? Who has access? What are the risks of adding new features to the system, such as recording vaccinations? How can decision-making structures be adapted to meet the new need for knowledge to anticipate risks and benefits? Crises such as the Covid-19 pandemic require the collection and analysis of more and more data to track the spread of diseases. But decisions about what data to store, for how long and by whom are often opaque or even arbitrary.

In short, the governing structures for digital health records no longer fit the knowledge requirements of the technology-related risks and benefits. It is therefore time to introduce a governance model for patient data that reflects the complexity of the issues at stake. As more and more people are affected in different and new ways, people with different competencies, skills, and knowledge need to be continuously involved in the evaluation of the decisions made.
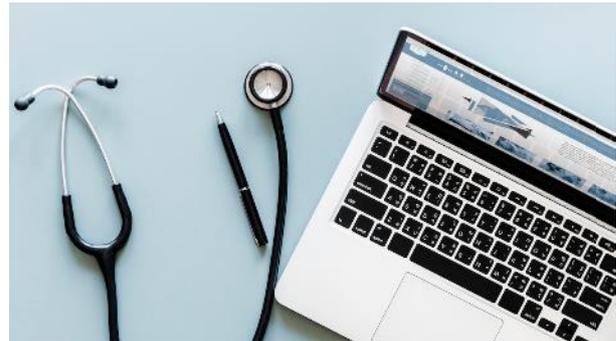
Photo: rawbixel / Unsplash

Public e-health applications are continuously being expanded

Responsible Research and Innovation (RRI) is an approach to technology governance implemented by the European Commission to reduce uncertainty in scientific discovery and technological innovation. Governance principles such as anticipation, reflexivity, inclusion, and responsiveness are used to guide innovation step by step. Variations of these principles have long been used in the implementation of health technologies at national levels in Europe, but their interpretations by decision-makers and regulators remain relatively informal, unsystematic, and implicit. This makes it all the more important to define RRI at national level.

BASIC DATA

Project title: SmartCare – Smart City hypothesis and ICTs use and governance in the healthcare sector in the City of Vienna
Project team: Sinozic, T., Rose, G.
Duration: 08/2018 – 01/2020
Funded by: City of Vienna Magistrate 7

KEY RESULTS

Austria's national health record system ELGA is considered a successful infrastructure which has been efficiently implemented when compared with similar digital patient record systems in other European countries such as the UK and Germany. Based on interviews with the main actors involved in the implementation of ELGA, the SmartCare project identified four main factors underlying its success: (1) an existing network of health sector actors as well as formal and informal regulators who were supportive of the system; (2) the timely creation of a regulatory authority that had financial and political support from the federal government, the federal states, and the social security system; (3) the stability of the original objectives (exchange of health data) during the implementation process; and (4) the attention to public acceptance by introducing the opt-out option. Different stakeholders such as doctors and patients were involved in the design of the system to varying degrees.
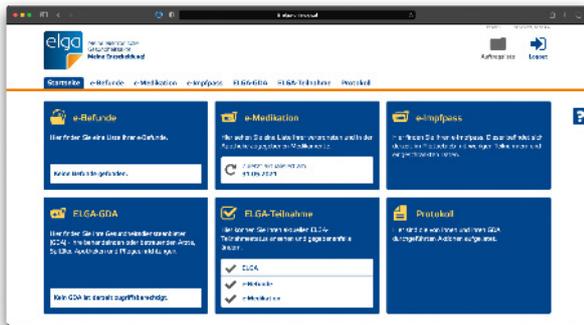
Patients can view their medical ELGA data

These inclusive elements, which occurred only selectively throughout the process, led to the decentralisation of data collection and storage across federal states, the requirement that the data are not to be used for research, and the opt-out option. However, the system faces requirements that are highly dynamic and the rules change according to the circumstances. For example, some ELGA data are now made available for research after all. Whilst the opt-out option was initially a suitable option to preserve individual freedom of choice and privacy, it led to discrimination during the Corona crisis: those who opted out of ELGA did not receive free Covid-19 test kits. Such discriminatory steps undermine public trust and need to be openly discussed.

WHAT TO DO?

Features of electronic health records, such as their functions, rules, and contexts, are constantly challenged over time and called into questioned because of changing circumstances and requirements.
These systems need to be regulated in a way to allow them to maintain and strengthen societal values rather than undermine them.

- The process of assessing the benefits and consequences of new digital innovations in healthcare services, such as the introduction and expansion of electronic health record systems, needs to be systematic and open, and the processes need to be repeated every time there is a significant change to the system (e.g. a new function/feature, rule or link/connection that affects the population).

- Current decision-making structures and processes for publicly funded comprehensive patient information systems need to be continuously evaluated for their ability to solve social problems and meet societal needs. These include free will, fairness, privacy and autonomy in the storage and retrieval of digitised patient information, in addition to improving patient care.

- It is particularly important to openly and systematically evaluate and re-evaluate the protection and safeguarding of societal values with experts and lay people as conditions change and demands on data increase.

FURTHER READING

Iakovleva, T., Oftedal, E. M. and Bessant, J., (2019) (eds) *Responsible Innovation in Digital Health: Empowering the Patient*, Cheltenham, Edward Elgar.
e-elgar.com/shop/gbp/responsible-innovation-in-digital-health-9781788975056.html

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