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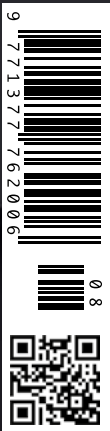
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Patient Trust Needed for Healthcare Data Success

Summary: Health data holds the promise of healing a plethora of healthcare operational woes. Saluscoop looks at how we can make data work for provider and patient.

More and More Data for a Healthier Society

We are experiencing a period of data explosion: the digitalisation of health records, the increasing use of smartphones, portable devices, sensorisation and genome sequencing exponentially increase the quantity and quality of personal data related to health.

The health sector is one of those that generates great volumes of data, whether related to health or the lifestyles of citizens. Data, from multiple sources, is recorded through different devices and systems, such as Electronic Health Record (EHR) systems, Apps, Social Networks, Personal Health Records Systems (PHR), Hospital Information Systems (HIS), Laboratory Systems (LIS) and Radiological Information Systems (RIS-PACS).

The increasing computational capacity of computer systems allows processing a large amount of data, which becomes increasingly useful and valuable information. This data is of enormous value for companies and institutions to the point that to obtain our data they offer services at low cost or free in exchange for accepting legal agreements that tend to be very extensive and difficult to understand. This competition for our data means that they are in silos and that they are not readily available or accessible, hindering and slowing down any investigation. Even so, the trend, owing to social changes and mentality, is that the citizen, the owner of personal information and his/her own health history, can increasingly access health information from anywhere at any time.

The future of medical research lies in the possibility of combining and integrating all these sources of data, from medical, genetic records to data from social networks. The knowledge generated by combining and analysing the large volumes of existing information (our clinical data, habits, lifestyles and

circumstances, genetic profile) will represent a qualitative leap in the knowledge of diseases. The benefits of using data in research are tangible and significant: if the paradigm of scarcity were changed to the abundance of data, it would undoubtedly be a great opportunity, a great accelerator for research. The potential improvement in the provision of services is also significant: not only will it help us to define more personalised and effective treatments, in addition, the resource allows for the possibility of overcoming physical barriers and providing healthcare to groups and areas with less accessibility.

Property and Availability of "My Data"

But this new panorama raises some questions that we must consider, make decisions about and legislate on. The first question is whose data is it? If a patient is x-rayed, is that person the owner of the data obtained or is the public hospital, which, paid with our taxes, could make use of it and use it in an investigation that would benefit everyone? Citizens are the holders of personal data. Since May 2018, European citizens, under the General Data Protection Regulation (GDPR), and as holders of data have the right to access and to obtain a copy of it in a common format (eg PDF). We also have the right to the portability of our data (if we change company, we can request that our data be passed to the new company, through a mechanism similar to what happens when we change telephone operator and keep the number). This includes the availability of our health records for research.

Salus: Citizen Cooperative of Health Data for Research

Saluscoop wants to contribute to accelerate the development of research in the field of health by making more and more diverse data available to more



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researchers in more accessible conditions. For this Saluscoop aims to provide citizens with the possibility of setting the conditions under which they make the data relevant to their health, clinical, lifestyle and socio-demographic available to researchers.

In this way, the citizens can exercise their management rights over the data and influence the research agenda. Saluscoop can only contribute to fulfilling its mission to generate an abundance of data for health research if it is capable of attracting a critical mass of citizens and a sufficient diversity of data to become a relevant player in this environment.

The advantageous position of Saluscoop in the data market for health research should be based on the following factors:

- Cost of access to data is zero through donation of citizens.
- Data diversity: clinical, habits for a holistic view of health.
- "Light" technological development that does not store data for management of data access keys.
- Non-profit so all surpluses are reinvested.

The way to achieve this critical mass and to finance the technological developments and human resources needed to achieve it are the most important critical decisions of the Saluscoop development plan. Saluscoop is a citizen cooperative of health data for research. Its objective is to help citizens to manage their health data and to share them for scientific research projects that are of interest to them. Cooperatives and data donors will not receive personal financial compensation for the use of their data. The surpluses of the cooperative will be used to finance research projects and services for members.

The last contribution of Saluscoop is SALUS Common Good License trying to introduce a citizen-led license to manage health data.

How can citizens take ownership of their data and have an active role in medical research? In order to provide an answer to this question, Saluscoop, citizen cooperative of health data, introduced this year the Salus Common Good License for medical research. Based on an open study (TRIEM) to find out under what conditions citizens would be willing to donate their health data, this license provides a tool to advance management of data in medical research and improve collective health.

The five guarantees of the Salus Common Good License for medical research are:

- Only health: your data will only be used for research of any disease, especially chronic and rare illnesses

- Non-commercial: research projects will be promoted by entities that support general interest such as public institutions, universities and foundations.
- Shared results: results of the research will be accessible at no cost.
- Maximum privacy: all data will be anonymised prior to use.
- Complete control: you will be able to cancel or change the conditions under which your data can be accessed at any time.

Conditional Donation: Consent and Anonymisation

Through the sharing or donation of data we are facing a great opportunity, but not without problems, dilemmas and risks that we must understand and discuss. Patients are usually very generous with their data when it comes to helping clinical research, but they, rightly, promote the protection of their privacy. On the other hand, there is an atmosphere of opacity that leads companies to make unethical uses of the data, generating distrust in the citizens who decide not to share their data with those who could contribute to generating a significant collective return - for example, in the discovery of new treatments. It seems indisputable that the patient should give an informed consent for the use of their data, similar to that required for other less sensitive services than the health service. However, it is not clear what the scope of that consent is, and the question is whether it could be used in any type of investigation of any disease, in any circumstance. Probably the answer would be no, but it is also unreasonable to limit the scope of consent so much that it makes future research unfeasible. The data related to health is of maximum sensitivity, may contain information about the most intimate aspects of our life and may expose us to multiple risks, for example, the risk of being discriminated against or even manipulated.

Consent, then, on its own, isn't enough. It is necessary that the privacy of patients is also protected with the anonymisation of the data, that is, the elimination of any data that allows identifying the person. This process raises a new debate: who should be the guardian and with what guarantees? How can citizens make informed decisions about the conditions of sharing and use of their data? The decision to share our data requires balancing many risks, including privacy and security and possible misuse of data, in relation to the enormous potential value of accelerating innovation in medicine and even improving the

planning and provision of public services. Only citizens can make those decisions, considering their beliefs, their fears and motivations. The more knowledge they have about the nature of the data and the technological operations that allow them to extract value from them, the more capable they will be of making decisions that minimise the risks and increase the collective return. We have to give an express consent to donate our data to third parties. In this consent, it must be detailed under what conditions and for what purposes the cession of data takes place. If third parties use our data, they should treat only those that are relevant to the purpose of the analysis and, when possible, dissociate them from our personal data.

“DATA IS THE GOLD OF OUR TIME, A GIGANTIC BUSINESS FOR THOSE WHO KNOW HOW TO TAKE ADVANTAGE OF IT”

Conditions for the Use of Medical Information for Research Purposes

What we understand as "health data" is changing and will continue to change significantly. What it increasingly means is integration and linking to a particular person, information as diverse as patient medical records, data generated by patients, biological data of portable monitors, fitness, mood and symptom tracking data, video data and sensors of people, genome data. Data is the gold of our time, a gigantic business for those who know how to take advantage of it. And just as public health systems collect the vast majority of our health data, the private sector wants to access it to carry out clinical research. Although it may be a beneficial relationship for both, it is evident that only the public sector will put the citizen at the head of the priorities of that investigation. All these issues should be addressed for the design of genuine health data governance. The benefits that digitalisation will bring to the health sector are indisputable and should not hinder clinical research. But it is essential that public and private systems are custodians and guarantors of our health data. In reality, administration and private companies are failing in the attempt to protect the privacy of the individual. It looks like they care very little. But to develop better and fairer health services, to improve and make universal health services free of charge, organisations and researchers need to have quality, representative information about patients.

The use of Big Data and the revolution that will result in more effective, better quality and completely personalised health services, is also an opportunity to ensure the sustainability of public systems if the return on public investment is guaranteed. The data can be used to heal if it is well used. We must therefore overcome the current crisis of confidence in relation to the use of personal health data. The only way to move towards a better health system is by having people control their health data. Citizens could easily access and share their health data in a standardised and real-time format with specific research projects and studies that work on a large or small scale by organisations of all types, including communities of people engaged in particular conditions.

The next step would be to make these large and varied datasets useful for people and professionals in the health system. It consists of using new tools and skills to analyse large amounts of data, interpret them at the individual level, through the development of continuous learning algorithms, fed by millions of historical health data and advance new research for a better understanding of diseases and health. All these attempts to increase, from our data, the knowledge of what is health and how to achieve a healthier life requires that citizens feel comfortable with the use made of their data. Health services should move gradually from the medical care of diseases to actions that improve the health of the population. Providers should be rewarded based on the results of the care they provide and on whether they help citizens live well and stay healthy. Universal and free health services should not discriminate based on whether citizens share their data as well as not discriminate against certain unhealthy behaviors. The sector has to maintain trust and clearly explain the benefits of sharing.

The health system must work to extract the full potential of health data, be more transparent about what happens with health data, how it is processed and what the results are, generating confidence that the data will not fall wrong hands and will not be used without the citizen's permission. ■

KEY POINTS



- Citizens are the holders of their personal data
- Consent and anonymity should be mandatory when it comes to protecting patients' data
- Data generated by patients is invaluable to the public and private healthcare sectors
- Saluscoop aims to give citizens management rights over how their data is used by researchers