Big Data in Healthcare

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Collection, storage and analysis of health data have been, are and will be one of the fundamentals to provide efficient healthcare services and its importance is only increasing considering the growing amount of health data collected every day. The situation gets even more complicated because relevant health information does not only come from traditional interviews and medical tests in a hospital or outpatient clinic, but it involves data that patients collect themselves using wearables for telemonitoring and data that healthy people collect using a wide variety of health and wellbeing apps. According to the Ericsson Mobility Report of 2015 there were at the end of 2015 around 7.3 billion mobile subscriptions i.e., there are as many mobile subscriptions as there are people on this planet and all of them create every day new and valuable data about health and wellbeing. In addition, thanks to new technologies there is more data collected in clinical settings in addition to genetic information which itself is already big data by volume. Combined this information allows better understanding health patterns and can be used not only for curing diseases but also for preventing them, improving patient safety and preserving quality of life i.e., it improves overall health outcome and reduces healthcare spending. Furthermore, information, that is, originally collected for a completely different purpose may also give an important insight to a disease i.e., information from social media, from loyalty cards of shops, use of public transport and business transactions may improve our understanding of trends in shopping/cooking/eating habits together with trends in physical activity in different age and social groups. In other words, we are talking about Big Data in healthcare and for public health policy making [1].

Of course, information about a patient alone gives a good overview of the condition of this patient, improvement as well as worsening of a condition, but even with a complete overview of this patient it is still about one patient only. For one doctor it may be an overview of a few thousands with additional input from literature, yet it is a very small universe compared to what technology could allow today.

There is a huge potential in ICT to utilise Big Data, the Cloud and High Performance Computing for health systems and health research although managing it all is a real challenge.

Data protection concerns everybody. Today, there is insufficient awareness, loss of control and trust, particularly in the online environment. This is demonstrated by 81% of respondents in the 2015 Eurobarometer [2] saying that they have only partial or no control of their data online. 2 out of 3 citizens say they are concerned about this. According to Article 8 of the EU Charter of Fundamental Rights 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. Furthermore, everyone has the right of access to data which have been collected concerning him or her, and the right to have it rectified. The new Data Protection Regulation maintains the objectives of the Data Protection Directive to safeguard the right to personal data protection and guarantee the free flow of personal data between Member States. It puts individuals in control of their data through easier access to personal data and individuals will have more information on how their data is processed; enhanced "right to be forgotten"; a right to know when one's data has been hacked.

It is important that there is the right balance between data protection rights and the need to support public health and medical research objectives. For that the Regulation establishes a privacy friendly environment with legal rules in place so that individuals can trust that the use made of their data will not turn against them. Work at the technical level to implement privacy guarantees by approaches such as privacy by design and privacy by default will be continued.

As data from mobile health and wellbeing apps make an outstanding contribution to health, it is important to carefully address data protection aspects in this field. Therefore, in line with both the Data Protection Directive and Regulation, the Commission is facilitating the preparation of the Code of Conduct on mHealth apps covering privacy and security principles for

app developers to be followed when designing these apps [3]. A draft of this Code is already publicly available and has been submitted to the Working Group (WP29) of the Member States' data protection authorities for review in June.

The Commission is also looking into other areas of data protection relevant to eHealth and whether there is a need for specific guidelines as indicated in the eHealth Action Plan 2012–2020.

Collecting and Sharing Health Data

An important step towards the use of Big Data in healthcare is an effective implementation of electronic health records. Indeed, our studies on the use of eHealth among general practitioners and hospitals have demonstrated that almost all hospitals [4] and general practitioners [5] in the EU are using computers. However, data sharing is not so common and one of the main reasons for it is lack of interoperability.

The European Commission has already put in place several activities to improve the situation. First of all, eHealth interoperability is one of the 16 key actions under three pillars of the Digital Single Market Strategy [6] and it is also part of the "EU eGovernment Action Plan 2016–2020 - Accelerating the digital transformation of government" [7] that supports Member States in the development of eHealth services that also enable cross-border exchange of patient data based on the guidelines adopted by the eHealth Network [8].

Interoperability has a prominent role in the eHealth Action Plan 2012–2020 [9] in which one of the four areas of actions is dedicated to addressing technical, semantic, legal and organisational issues. As a result, the Commission, with the endorsement of the eHealth Network, proposed the Refined Health Interoperability Framework based on the results of studies, pilots and research projects. In addition, on July 28, 2015 the Commission has adopted the Decision on the identification of 'Integrating the Healthcare Enterprise' profiles for referencing in public procurement.

Furthermore, during the period 2012–2020 research and innovation funding is foreseen from the EU Framework Programme for Research and Innovation Horizon 2020. Indirect effect on achieving interoperability is also expected through increasing awareness of the benefits of eHealth in general as well as from a better understanding of the importance of data sharing and cross-border cooperation to achieve better health outcomes. Finally, interoperability is one of the three areas of the Memorandum of understanding signed by the representatives of the EU and US in 2010.

It should be underlined that in addition to the activities listed above, interoperability is closely linked to many other documents such as the EU Regulation 910/2014 on electronic identification and trust services for electronic transactions in the internal market and the political agreement on the Network and Information Security (NIS) directive. The European 'Free flow of data' initiative tackles restrictions on the free movement of data for reasons other than the protection of personal data within the EU and unjustified restrictions on the location of data for storage or processing purposes. Because of the exponential volume in health data, the speed of technological change, the need for continuous re-investment, the huge growth in storage requirements as resource-intensive applications such as 3D-imaging and genomics and the pressures on recruitment and retention of skilled staff, the need to provide cross-sectorial healthcare services to tailor the healthcare needs of patients (integrated care), are all good reasons for seeking a Cloud Services who can ensure reliable, scalable services. The European Cloud Initiative aims to offer to the researcher better access to supercomputing, data storage, analysis and re-use by using a European Open Science Cloud and a high-performance European Data Infrastructure.

Data Usage

Data analytics are very important to turn Big Data into value and bringing benefits to society and citizen in all application sectors, by leading to more efficient or accurate processes. Equally important is the methodology for data collection which is also user friendly and does not become an additional burden for doctors and nurses. Today, we are not effectively using all already existing data for health. Some of our H2020 projects are helping to get there. For example the project P-MEDICINE funded from the EU 7th Framework Programme brings together the top knowledge in healthcare, basic science, IT, law and ethics around a common objective: accelerating individual diagnostic and treatment by means of a large database where patient-related information can easily be accessed. The project was clinically driven right from the beginning, meaning that relevant clinical questions were posed and answered right from the start.

The EU research projects are also looking into the use of Big Data for addressing population health and making effective health policies.

Conclusion

Big Data is very important for making personalised medicine a reality. As top-level science cannot today happen in isolation, health data have a limited impact if stored and used within an isolated computer by one doctor. The real benefits come from data sharing and access to data, with full respect of all data protection mechanisms. With it we can make a real difference in health and care for everybody.

References

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