The Use of Big Data in Medicine and Public Health Policy-Making: Opportunities and Challenges

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Abstract. This paper presents the problem of small outcomes compared to the investment in large scale IT projects. Focus was given in the application of big data in health sector, where the new element, enhancing the problem, comes from the incorporation of new forms of patient generated data. Proposed were processes aiming on the one hand to underline that apart of the importance of patients' involvement, also important is the involvement of all the other stakeholders. This will both make data collection easier and better, and turn data into actionable information. Finally concrete interventions in the direction of Big Data usage in Health sector are here proposed, which will help in enabling new operating and business models.

Keywords: big data, public health policy-making.

1 Introduction

In many sectors, when implementing large scale IT projects, the outcomes seem small compared to the investments. It makes no difference in the health care sector. Medical professionals claim that with the currently used IT systems they are wasting their time, as they are hard to use and even more they interfere their interactions with patients. In addition, healthcare institutions get more losses than gains, as they have to deal with many issues when integrating new IT systems into their operations. Finally, any efforts in the direction of persuading health institutions to share information continue to lag, due to communication and compatibility issues, and legal limitations, resulting in data being useless for the public health policy-making.

Getting an inside look of the problem we may see that the currently used IT systems focus majorly on electronic registers, which can improve billing and reimbursement procedures [1]. Smaller part of the applications is focused on the improvement of the services provided to the patients, like the order entry – results provision cycle [2]. Even less applications, get deeper focusing on data analytics for medical professionals and public health decision makers [3, 4]. Therefore, we have improvements in the operations, at some level, but we do not get one level below to improve the processes [5].

However, we see some industries use technology better than others do, and labor productivity statistics reflect that. In the case of U.S., we see that the health care has been growing faster, as an industry, than the overall economy. However, since the number of health care workers has been rapidly increasing, and the use of information technology has lagged, productivity growth has been minimal [6].

The idea of this paper is to explore, whether big data can help in the direction of improving IT systems, and their use in the health sector, so they can better serve the medical professionals and more specific the public health policy makers. Even more to propose proper interventions, which can contribute in overcoming the current obstacles, and in introducing new business and operation models, including multidisciplinary knowledge and teams.

2 Big Data value in the health sector

However, let us first define the use of big data in the health care sector. Until now, the focus is on public health policy-making, clinical trials and research, and health services provision improvement. The data used for the purpose are electronic health records (EHRs), electronic patient reported outcomes (ePROs), genomics and imaging data. There are many examples of successfully implemented systems, but all of them are related to concrete institutions and deal with concrete medical cases [8, 10, 11].

Supporting the above, we may see [12] where the developments in the health care sector, majorly based on Big Data analytics are focused on improving the public health policies, the clinical research and the care provided to patients.

The difference comes since until recently data like EHRs, and ePROSs were included. The new element comes from the incorporation of new forms of patient generated data. These forms include both physiological but also psychometric data. Data collected real-time, and directly through sensor devices or data generated online, as patients' comments or posts in social networking tools online. We see mobile technologies and sensor devices facilitating the development of new models supporting online methods of health monitoring. The focus is on recording and analyzing big volumes of physiological and psychometric data, now directly collected from patients.

However, although we see many successful projects, applying different technologies in healthcare in analyzing Big Data, there is a lag between those projects and their real application in clinical practice. We have promising results in clinical research, as data-driven hypothesis generation and testing, or as identification of relationships and results based on heterogeneous data sets of genomic or environmental data and patient health records [13]. However, in the everyday clinical practice the overall result is becoming unclear. We have in place clinical decision support systems, and tools. We also have advanced diagnostic systems and tools

and other types of health information systems, which are improving the patients' experiences and the overall quality of the provided health and care services.

The aim of this paper was to review the Big Data and data-driven systems and tools targeting patients, doctors and public health policy makers as their immediate beneficiaries, and identify actions focused on how Big Data actually can help to improve the effectiveness of those tools and systems used for the promotion of health in primary and secondary healthcare.

3 Improving the processes

Having in mind the above, both as example of best practices, but also as divided opinion of the medical professionals, and health policy decision makers, regarding the effectiveness of big data in health care, we propose to get one level below and try to define the operations. Having the operations defined we may further propose interventions on a per-process basis.

The scope of the proposed processes is on the one hand to underline that apart of the importance of patients' involvement, it is also important the involvement of all the other stakeholders. They are all part of the big data value chain in medicine and public health policy-making. We need to include from the medical professionals to the public health policy-makers, but also IT and data specialists, the public administration, etc.

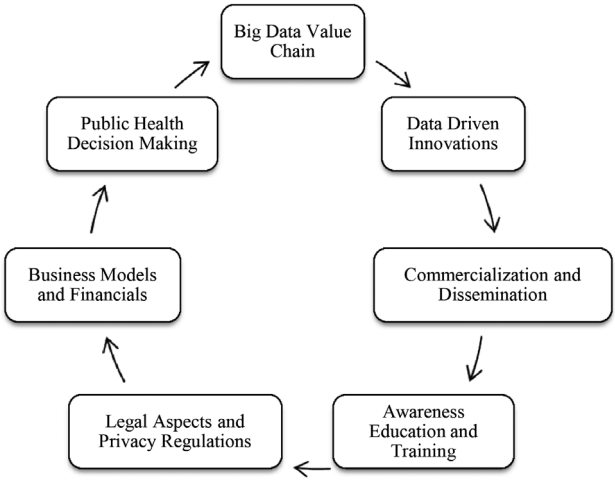

Figure 1: Health care sector processes, and fields of interventions.

The European Commission (EC), Directorate-General for Health and Food Safety, Directorate B — Health systems, medical products and innovation, Unit B.3 — Cross-border Healthcare, e-Health [7], has been active. It has presented policy recommendations in the respective Final Report as results for a Study on Big Data in Public Health, Telemedicine and Healthcare. Here we refine those recommendations as an actionable plan for the patients, doctors and public health policy makers, supported by IT and data specialists, the public administration.

The scope of the actionable plan is to provide with suggestions to the public health policy makers on how to:

- utilize the strengths and exploit the opportunities of Big Data for Public Health without compromising privacy or safety of citizens;
- use Big Data in Health not as a goal in itself, but as a tool to reach certain purposes that benefit the patient and the public;
- protect current ethical standards and not let be compromised for potential benefits of Big Data; and
- include as more as possible stakeholders in the implementation of the proposed recommendations and in the production of future recommendations on Big Data in Health.

4 Interventions

Concrete interventions in the direction of Big Data usage in Health sector are here proposed. They are formulated as recommendations in different aspects, which will enable new business models. The following list summarizes the interventions:

1. *raise awareness*: aiming in the development and the implementation of a communication strategy, which would help increasing the added value of Big Data in Health and encouraging a positive attitude towards Big Data in Health.
2. *provide education and training*: focus on the human capital and increase the workforce capabilities in utilizing the Big Data potential in Health. There is a huge need for increasing the digital literacy of the healthcare professionals.
3. *secure the data sources*: the quality and safety of the existing data sources is the first priority, but also the need of expansion, and identification of new data sources. An excellent example in this direction must be mentioned the experience, and best practice of the act on secondary use of health and social care data. This act opens up new possibilities and streamlines usage health and social care data. On March 13th 2019, after almost four years of preparatory work, the Finnish Parliament approved the Act on the Secondary Use of Health and Social Data [14].
4. *use open data, and promote sharing of data*: by promoting open use and sharing of Big Data, but always taking care not to compromise privacy and con-

fidentiality rights of the patients. Here we can mention as best practice the Global Alliance for Genomics and Health (GA4GH) white paper [15].

5. *focused on target-oriented Big Data application*: Big Data analytics in health should be based on concrete needs and interests of stakeholders for evidence-based decision-making [16]. The trustworthy and reliable information production needs to address the related to the application of Big Data in Health concerns. Best practice in this direction is the Ethics guidelines for trustworthy AI [17].
6. *improve data analysis methods*: by identifying potential for Big Data analysis and analytical methods improvements.
7. *develop standards*: helping to improve interoperability at all levels, and enhance Big Data applications in health.
8. *further support legal, and medical ethics initiatives*: by clarifying existing already regulations and legal frameworks, and by adopting new alignment instruments for medical ethics [18]. Best practice in this direction should be considered the GDPR, Regulation 2016/67915, which aims at strengthening the rights of natural persons, and represents the foundation for EU data protection rules.

5 Conclusions

The problem of small outcomes compared to the investment in large scale IT projects was presented as it appears in many sectors. Especially in the application of big data in health sector, the new element enhancing the problem comes from the incorporation of new forms of patient generated data. These forms include both physiological but also psychometric data. Data collected real-time, and directly through sensor devices or data generated online, as patients' comments or posts in social networking tools online. Proposed were processes aiming on the one hand to underline that apart of the importance of patients' involvement, it is also important the involvement of all the other stakeholders. This will both make data collection easier and better, and turn data into actionable information. Finally concrete interventions in the direction of Big Data usage in Health sector are here proposed, which will help in enabling new operating and business models.

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