BIG DATA FOR PUBLIC HEALTH: DOES THE DATA PROMISE A BETTER QUALITY OF LIFE?

By: Martyna Giedrojc and Roger Lim

Summary: Public health in the 21st century brings all stakeholders together in an organised effort to ensure the safe use of their data in a digital world. Big data holds the potential to transform and benefit public health and could lead to improved quality of life. It could open the door for more research and bring effective and tailored treatments for patients. It is no longer only about providing access to health care services and medication, but also about assuring a whole range of other factors, such as a stable social and economic situation, climate, as well as good housing and workplace conditions.

Keywords: Big Data, Public Health, Quality of Life, Privacy, Digital Future

Europe’s digital challenges and public health transformation

The notion of what is considered public health has been changing. Previously, it primarily focused on addressing the need for sanitary conditions and the fight against infectious diseases. The next public health revolution was focused on changing individual behaviours contributing to non-communicable diseases and premature death. At present, public health is emphasising health as a key factor of quality of life. It means that future health moves beyond a focus on individual behaviour towards recognising the influence of a very broad range of determinants on health such as climate, social and economic development, culture, housing and workplace conditions.

In line with that, European society has embraced new technology by transforming the ways in which we pay, shop, dine and travel. The use of digital technology in our daily lives has led us to generate massive amounts of data, which in the majority of cases are unstructured. Only recently have we been able to understand and have the means to use this data for health purposes. The current “big data revolution” has the potential to transform our health systems and change the way in which we receive treatment. Big data could lead to improved quality of life for people by providing them with crucial information about their future health and enabling them to take the necessary steps to prevent the onset of illness and thus stimulate behavioural change. As global society is becoming more digital, there are many challenges that need to be solved to ensure that Europe does not lag behind. Digital technology can enrich public health and care provision, thus allowing citizens to live longer and enjoy more healthy life years.
What kind of data is desirable?

On the other hand, the notion of sharing personal data between people, facilities and companies for purposes other than treating the patient has raised many concerns regarding data privacy. Personal health data has become of great value for organisations and institutions which use it for research purposes. The list of companies interested in big data includes major pharmaceutical and medical devices players who use these data to tailor their health care products to the needs and demands of patients. In recent years, technology giants have been showing greater interest in providing health care solutions and have become large actors in the health care sector. These companies offer solutions for storing data in their clouds and they invest heavily in the development of artificial intelligence (AI) for health care. But the digital footprints of every click leave traces on the Internet: every piece of information has a value and by extension it also has a price on the health care market.

The health care sector is a data-intensive industry collecting information, such as clinical, genetic, behavioural and environmental data from an array of devices including electronic health records (EHRs), genome sequencing machines, patient registries, social networks and smartphone applications that monitor health. Gathering this wealth of information by tapping into different data repositories and being able to analyse it provides immense potential for improving the effectiveness and quality of health care for patients, possibilities for disease prevention, by identifying risk factors at population, subpopulation and individual level and improve medicine monitoring and patient safety. Big data for public health purposes could also encompass information from Internet clicks, queries in search engines, social media information, home monitoring, mobile transactions and socioeconomic indicators. Such data can be analysed and linked with health data to create new datasets for analytical purposes. On the one hand, this can foster innovation and create patterns for new insights, but on the other hand it can be an assumption based only on data comparison. This assumption can be wrong as it does not take into account the behavioural aspect of collected data. The major concerns of big data for society are a decline of universal access to health care, growing inequalities and patients and health professionals’ exclusion from the product development process, for the benefit of business development.

The people behind big data

The term big data is already well known and frequently used in scientific, political and corporate discussions at the European level. For example, its importance has been acknowledged by the European Commission in the “Study on Big Data in Public Health, Telemedicine and Health care”:

“Big Data in Health refers to large routinely or automatically collected datasets, which are electronically captured and stored. It is reusable in the sense of multipurpose data and comprises the fusion and connection of existing databases for the purpose of improving health and health systems performance. It does not refer to data collected for specific study.”

The study, prepared by Gesundheit Österreich Forschungs – und Planungs GmbH and commissioned by Directorate General Health and Food Safety (DG SANTE), highlights the need to communicate a positive picture of big data in health and to encourage people to get involved in the discussion. The Commission has also outlined the next steps towards a data-driven economy, by making sure that all citizens have a sufficient level of digital skills. This includes not only patients, health professionals, academics and medical industries, but the whole of society.

The use of big data in health is a new science full of promising case examples, but arguably there are still many obstacles that need to be overcome. While the use of big data for public health holds enormous promise, there are numbers of practical and legal hurdles that need to be worked out, such as data privacy and citizen’s awareness of its ownership. The lack of transparency, uneven access to information and, unfair and discriminatory conclusions based on comparisons of data blocks with no specific questions in mind, feature among the key concerns, which could led to social and cultural segregation.

Better use of data for health systems

The needs of our society are growing and citizens are becoming more demanding, therefore European health systems need to start adjusting to the new situation. Concerns about deteriorating health access are well-founded and the quality of health care affects public health in general. In practice, public health expenditure has been decreasing steadily since the onset of the financial crisis and patients’ out of pocket expenditure has increased.

Some countries monitor and measure their health systems by using the Health System Performance Assessment (HSPA), a tool to collect information and data to identify areas where health systems need improvements. The assessment captures and takes into account all aspects of health systems, especially indicators on workforce, health information systems, health determinants and, socio-economic and environmental factors in order to have a complete picture of health systems performance. The feasibility and effectiveness of HSPA depends on the existence of extensive comparable and reliable data sources, collected on a consistent basis in each country and the ability to compare the results amongst many other countries as possible. The EU could focus on improving availability of indicators and making better use of those data that could be translated into comparable knowledge.

The advent of big data has important implications on further measuring the accessibility, effectiveness, efficiency and safety of health systems. Healthy life years and access to high-quality health care for those in need should be
the principles of every HSPA process. One of the difficulties is that national governments have the liberty to determine their own way of applying HSPA, for which there is no single accepted template at the European level yet. This creates challenges for the comparability of indicators between EU Member States.

Outbreak control in favour of epidemiology

The process of providing an overview of the national legislation on electronic health records within the EU Member States and the introduction of the legal requirements for electronic health records implementation remains one of the most important priorities of DG SANTE.

The information for epidemiological purposes could be used to plan and evaluate future strategies to prevent illness and study the distribution of diseases among populations. As can be expected, only through access to reliable information can epidemiologists predict actions and create guidelines for the management of patients who already have existing health conditions. With high quality data sources, tracking disease outbreaks can be simpler and faster, but a closer look at the source of the data is needed.

Business innovation result in better treatment

Big data could open the door for more effective and tailored treatments for patients. That brings an opportunity for the development of new pharmaceuticals that respond to different patients individually, albeit coming at great financial cost. For example, innovation in the pharmaceutical field in view of the digital agenda and eHealth could be a key driver to safeguard the health, well being and lives of European citizens. It is likely to uncover unknown links between diseases, which can lead to medical recommendations based on new information. Big data can accelerate the development of new drugs and repurpose existing ones in order to tailor them to the needs of patients. It also fosters the creation of new data-focused businesses and health analytics.

While it brings a lot of opportunities, big data also raises some important concerns about its impact on the rights and freedoms of people, including their right to privacy. There is not enough transparency about the risk of constant monitoring of people’s daily activities and about the logic of profiling, which could be used for marketing unhealthy products and behaviours, or even abused by unauthorised persons.

Data translated into quality of life

Big data presents a formidable opportunity and sizeable challenge to the development of digital health. The EU bolsters data-driven innovation and growth and in 2014, the European Commission launched its strategy on big data, which, according to the Vice President for the Digital Single Market will bring opportunities to more traditional sectors such as health care.

To obtain a complete picture of data-driven health care, it is crucial to have a regulated and safe free flow of data between countries. Reliable data flow also involves cross-border health care, where information can be collected, exchanged or shared. The European Commission DG SANTE has been working closely with the eHealth Network, established under Article 14 of the Directive on the application of patients’ rights in cross-border health care. It has created a voluntary network of national authorities responsible for eHealth, whose main activity is to improve eHealth interoperability, allowing data to travel smoothly between health systems. eHealth interoperability creates added value by linking up various data repositories in the EU, which could be tapped into for the purpose of research.

In the next few years, the eHealth Network’s work on big data will focus on the real importance of public health and how data could contribute to the quality of life for all people living in Europe. For example, it could be used to create a better understanding of the causes of people’s bad eating and drinking habits, lifestyle factors and stress, all of which exert a negative effect on physical and mental health.

Health in the 21st century ensures public health in a digital world

People tend to forget that technology is only a means to an end on the path to success in achieving better public health. In order to make the best use of digital technology for health we need to ensure that it is used for the purposes of all people. It will not be possible to create effective, accessible and resilient health systems
and sustainable economies whilst dealing with a population that is increasingly unhealthy. Health, as one of the key preconditions for economic growth, has to be strengthened using many measures including healthy housing and workplace conditions and improving lifestyles, as well as maintaining good air quality.

In the end, public health policy as such is not something that needs to be implemented only by public health authorities. To advance on health in the 21st century, all stakeholders should be aware and involved in an organised effort to ensure safe use of data in a digital world. Big data holds the potential to transform and benefit public health in the future, but it will be no longer only about providing access to health care services, institutions and medication, but about the bigger picture in which society understands digital technology, also taking into account the socio-behavioural aspects that influence quality of life.

References

- Harford T. Big data: are we making a big mistake? *Financial Times* 28 March 2014. Available at: https://www.ft.com/content/21a6e7d8-b479-11e3-a59a-00144feabdc0
- Tackling Meat Production and Consumption, the *European Health Parliament* 2016. Available at: http://www.healthparliament.eu/documents/10184/0/TEHP_PAPERS_2016_ClimateChangeAndHealth_SCHERM_v_20141118_co07b_0d853e4-ac5f-4bc7-be34-6642035ff7f0
- Portugal

**Portugal: health system review**

**By:** J Simões, GF Augusto, I Fronteira & C Hernández-Quevedo

**Copenhagen:** World Health Organization 2017 (on behalf of the Observatory)

**Number of pages:** 184 pages; **ISSN:** 1817-6127

**Freely available to download at:** http://www.euro.who.int/__data/assets/pdf_file/0007/337471/HiT-Portugal.pdf?ua=1

Since the financial crisis, health sector reforms in Portugal have been guided by the Memorandum of Understanding that was signed between the Portuguese Government and three international institutions (the European Commission, the European Central Bank and the International Monetary Fund) in exchange for a €78 billion loan. Measures were implemented to contain costs, improve efficiency and increase regulation. Still, financial sustainability of the Portuguese health system remains a challenge. Due to cuts in public workers’ salaries the increasing migration of health care workers risks to negatively affect the quality and accessibility of care. While several reforms are aimed at improving coordinated care and developing the use of Health Technology Assessment, there is still scope for increasing efficiency in the health system.

While overall health indicators for Portugal have notably improved in recent years, they still hide significant health inequalities, which are mostly related to health determinants, such as child poverty, mental health and quality of life.

Even though the Portuguese National Health Service (NHS) is universal, comprehensive and almost free at point of delivery, there are also inequities in access to health care, mostly related to geography, income and health literacy. The so-called health subsystems, the special health insurance schemes for particular professions or companies that exist next to the NHS, as well as private voluntary health insurance, provide easier access for certain groups.