TRANSLATION FROM THE ORIGINAL SUMMARY IN SPANISH

Seminar 'Digital Footprint: Servitude or Service?'

Big Data in diagnosis and treatment of diseases

(Summary of the session of September 17, 2020)

The sixth session of the Permanent Seminar 'Digital Footprint: Servitude or Service?' took place on-line on September 17, 2020. Continuing with the analysis of Big Data and artificial intelligence (AI) in different sectors of activity, this session focused on the diagnosis and treatment of diseases and epidemiological management. In the background remains the moral question about the neutrality of algorithms, about the possibility of identifying people's behavior patterns, influencing, and even modifying them. The underlying idea is that we are witnessing an evolution of science and technology in which, more than causal explanations, significant correlations are sought.

The session had an initial presentation by José Ramón Amor Pan, Coordinator of the Bioethics Observatory of the Pablo VI Foundation, followed by comments from Alex Sánchez-Vivar, from NHS (National Health Services Scotland), and Cristóbal Belda Iniesta, Deputy Director of the Instituto de Salud Carlos III, both focused on the management and consequences of the Covid 19 pandemic.

Bioethical issues

When talking about Big Data analytics in the healthcare sector, one thing is clear: Big Data tools can bring enormous benefits to he diagnosis, treatment, and prevention of diseases. In this sense, not only are there many existing facts and achievements, but also a genuinely encouraging prospect of promises: thanks to AI, medical professionals can carry out more precise and detailed analyzes of the complex health data of their patients even before they fall ill and provide them with personalized preventive treatment. In the context of the aging European population, AI and robotics can be valuable tools to help caregivers and contribute to the care of the elderly and monitor patients' conditions in real time. Future scenarios include brain-computer interfaces, implants, exoskeletons, personalized and targeted drugs, embryo selection ... and dreams of super intelligence, super longevity, and super well-being.

Along with the facts and promises, ethical problems arise, and bioethical reflection turns necessary more than ever. The presentation identified at least five new bioethical problem areas:

- The previous selection of the data. Medical diagnosis and treatment need to consider objective data, but also a series of subjective parameters such as the patient's sensations or the variability due to

territory, an ethnic group, or a given population. In other words, when building an algorithm, it is necessary to take into account individual subjectivities that can directly influence the results.
- The doctor-patient relationship, that is, the impact of technologies such as AI and Big Data on the doctor's role and the level of humanization of healthcare.
- The concept of justice and the repercussions of Big Data on it (as in the issue of poverty).
- Nationalism and geostrategic issues that may be decisive, for example, in the development, testing, and distribution of vaccines.
- The reality and the illusions around "human enhancement."

Faced with these significant problems, however, the debate started from a conviction: the use of Big Data in health is, essentially, a moral imperative: it would be unethical not to use the potential of Big Data and AI models in medicine. The possible benefits of these tools to public health make their application a moral imperative. However, when addressing the above listed bioethical problems, utilitarianism is probably not the only (nor the best) ethical paradigm. There is a risk that the greatest good for the greatest number may, at times, lead decision-making scientists to affect the integrity of the individual directly.

Privacy vs. obligation to share data

Although data ownership is not the only problem from the bioethical point of view, it is an issue that focuses the attention of the debate: on the one hand, one can argue that health data are not personal, but rather the heritage of the humanity. But on the other, one can understand that obtaining and manipulating personal data could undermine the person's privacy and dignity.

The possibility of an obligation, or moral duty, to share health data derives from data's role in overcoming most diseases at a social level. For example, thanks to health data sharing throughout history, there is a cure for diabetes or leukemia conditions. In epidemiological surveillance, data are essential for the authorities' measures to control the pandemic and reduce mortality. Without data, it is impossible to detect outbreaks, identify the necessary control measures, or assess the pandemic's consequences. Thus surveillance models are essential because they allow acting quickly in pandemic times thanks to data processing technologies. These models also predict and alert the appearance of diseases, help to develop incidence maps; through AI they collaborate in diagnosis and treatment and allow tracking to prevent spread.

Covid 19: the dramatic absence of clinical data

Big data technologies in public health issues take on a new meaning in the Covid-19 pandemic context. In March 2020, the world stood still. In Spain, the health system collapsed in weeks, and the intensive care units were overwhelmed. Doctors and nursing teams faced a completely unknown disease; they did not have any

data but saw certain similarities between their patients and tried to connect them. However, without clinical information, they were unable to diagnose nor to treat patients.

During the first weeks of Covid-19, health workers struggled to save lives from a disease of which no one had experience or knowledge. Hence, there is an urgency to systematically use population data's enormous prediction capacity and do it until the benefit returns to society and to the individual; this is the goal of the "precision medicine" program that the Spanish government has just approved for its development at the Carlos III Institute. In other words, based on anonymized and globalized personal data, Big Data tools are intended to be capable of generating personal utility for the prevention or treatment of disease. From this point of view, a concept of the greater good to be protected emerges precisely when all the available data are required in a public health catastrophe such as the current one. Paradoxically, even those who refuse to share their health data will be diagnosed and treated with others' information.

From the collective to the individual

All this implies that the structured management of health data generates knowledge to the advantage of better treatments. The data coming from the individual feed the global population information under which public health decisions are made, but in the end, the center remains the person. In this sense, it is necessary to leave an abstract moral approach and consider the reality of clinical medicine to defend the usefulness of data in medicine. When speaking of a duty to share health data, one does not appeal to purely utilitarian ethics: in fact, utilitarianism and virtue ethics are seen here as complementarians.

Utilitarianism and virtue ethics appear as complementary if the ethical debate is not just about which principles are in conflict, but also about the general utility of sharing the data and the purpose sought: that the benefit of information from the data is ultimately seen on the individual. That is to say, questions about ownership and use of data can’t be answered without considering the purpose. In health data, algorithmic treatment and AI precisely allow to return from the collective to the individual. In this sense, their use is compatible with a definition of the common good as the conditions that allow everyone to participate in something good; in the specific case, the exploitation of health data, even though it is of a "utilitarian" nature, can respond to a vision that seeks not to forget anyone, nor to discard anyone.

Ethical propositions on the subject of Big Data management must have a universal aspiration and tendency. Currently, the data generated by an individual can reach companies' hands in different parts of the world. Hence, the need appears of a universalizable ethical thinking.

Public and private

In this field, it is also necessary to address the interaction between the public and private sectors. Some private companies control huge amounts of citizen data that they use for their benefit, and that can also be

useful for public health; for example, Facebook and Google accumulate a massive amount of lifestyle data that could be used for the benefit of public health. Public-private collaboration is seen as essential for those in charge of public health issues. That is because public health is linked not only to citizens' clinical history, but also to lifestyle habits, desires, vices, virtues, journeys and places visited, among others. Such cooperation can help build the complete picture needed to deal with certain diseases.

Of course, companies' interest is to obtain profits, but many believe there is a space for collaboration as long as Big Data tools are used responsibly. In this sense, the trend towards Big Data tools' democratization needs to be actively supported in order not to leave anyone behind. Responsibility is the linchpin in public-private collaboration.

Good work depends on the individual and collective responsibility, both public and private. But this requires monitoring and accountability to appropriate institutions. It is necessary to advance in multilateral cooperation, for which it will be necessary to adapt existing international institutions. On the political issue, understood as the capacity of larger and smaller units to undertake collective action, collective action in global instances is required. It is necessary to think about how international cooperation can be reactivated to address Big Data management issues in public health, globally and for the benefit of all.

Attendees:

1. **Alex Sánchez-Vivar**, , Epidemiologist – Guidance Scientifc Team Lead – Scottish Health Protection Network (SHPN) Guidance Team, Public Health Scotland
2. **Alfonso Carcasona**, CEO, AC Camerfirma
3. **Alfredo Marcos Martínez**, Professor of Philosophy of Science, Universidad de Valladolid
4. **Ángel Gómez de Agreda,** Colonel Chief, Geopolitical Analisis Area, DICOES/ SEGENPOL
5. **Ángel González Ferrer**, Executive Director, Digital Pontificial Council for Culture
6. **Arcadi Navarro**, Research Professor ICREA, Universidad Pompeu Fabra
7. **Carolina Villegas**, Researcher, Iberdrola Financial and Business Ethics Chair, Universidad Pontificia de Comillas
8. **Cristobal Belda Iniesta,** Deputy Director General del Instituto de Salud Carlos III
9. **David Roch Dupré**, Researcher, Instituto de Investigación Tecnológica
10. **Diego Bodas**, Lead Data Scientist Mapfre
11. **Domingo Sugranyes**, Director, Seminario de Huella Digital

12. **Esther de la Torre**, Responsible Digital Banking Manager, BBVA
13. **Francisco Javier López Martín**, Former Secretary-General, CCOO Madrid
14. **Gloria Sánchez Soriano**, Transformation Director, Legal Department, Banco Santander
15. **Guillermo Monroy Pérez**, Professor, Instituto de Estudios Bursátiles
16. **Idoia Salazar**, AI ethics expert, Universidad CEU San Pablo
17. **Javier Prades**, Dean, Universidad Eclesiástica San Dámaso
18. **Jesús Avezuela**, General Director of the Pablo VI Foundation
19. **Jesús Sánchez Camacho**, Professor, Faculty of Theology, Universidad Pontificia Comillas
20. **José Luis Calvo**, AI Director. SNGULAR
21. **José Manuel González-Páramo**, Former Executive Director, BBVA
22. **José Ramón Amor,** Coordinator, Bioethics Observatory of the Pablo VI Foundation
23. **Juan Benavides**, Professor of Communications, Universidad Complutense de Madrid
24. **Juan José Laborda**, Director of the Parliamentary Monarchy Chair, URJC
25. **Raúl González Fabre**, Professor, Universidad Pontificia de Comillas
26. **Richard Benjamins**, Chief AI & Data Strategist, Telefónica
27. **Victoria Camps**, Permanent Councilor. Consejo de Estado