

Data protection in a global economy

Éditorial

Marie-Laure Denis, State Councillor, President of the CNIL

Introduction

What kind of world do we want? How far can and should we go?

Dr Laure Tabouy, PhD, Neuroscientist and ethicist, Ethics and Epistemology team, CESP-INSERM U1018, Espace éthique APHP, Université de Paris-Saclay

1 – Data use: private companies and academic research, together for a more responsible future of data management

In a world that is both connected and in tension, what are the challenges and approaches to ensure the value and protection of data?

Jérôme Andres, Secure Information and Communication Systems, Thales Group

Digital revolution has induced massive economical transformations, since the last thirty years. Data exchange, thanks to the Internet has been cornerstone to this revolution, enhanced by their valuation in all domains: science, health, society, politics, arts, entertainment... Information and knowledge they produce become actual assets, to protect for their own value, as well as for consequences they can cause, directly or indirectly. Data emergence is not neutral, like other aspects of Digital and any innovation: as much a cure as a poison, they can lead to both risks and opportunities. Cybersecurity is a practice and an industrial sector that can allow gauging and marshalling such routes. In this context, political regulation and balances are needed, at both national and international.

Targeting, through data, the breaks in the healthcare pathways: an opportunity for patients and innovators

Marco Fiorini, Director of the "Artificial Intelligence and Cancer" project of the strategic contract for the healthcare industries and technologies, **Stéphanie Kervestin**, General Delegate of Ariis (Alliance for Research and Innovation in the Healthcare Industry), and **Virginie Lasserre**, Director of External Affairs at Janssen France, co-leader of the "AI and

Care Pathways" axis of the strategic contract for the healthcare industries and technologies sector

In this article, we put forward the idea that the pharmaceutical, medical device design, diagnostics and digital health industries have distinct histories and technologies.

In contrast, the production of health data by each of these industries creates a common breeding ground for innovation. This breeding ground is particularly fertile when it focuses on the description of patients' health care pathways, which cover the prevention, diagnosis, treatment and follow-up phases. This "patient perspective" is the one served by all these sectors and, beyond the private sector, the one that is the subject of public policy.

We describe here how, within a strategic contract for the health industries and technologies, the ability of these industries to work with the State to develop a common semantic for the description of health care pathways makes it possible to consider a method for quantifying the disruptions that occur within these pathways, which are as much a loss of opportunity for the patients.

The aim here is to objectively assess their importance in order to prioritize them with regard to the technologies available in France.

Towards a right of ownership of personal data

Alain Bensoussan, Attorney at Law, Lexing Alain Bensoussan Avocats

The challenges linked to "the permanent emergence of new technologies and the omnipresence of personal data processing in all areas of life", as recently underlined by the president of the CNIL, Mrs. Marie-Laure Denis, place data more than ever at the center of all attention, and with it, the question of the ownership of personal data, their patrimonialization and the right of everyone to monetize their own information.

What rights for data in a data-centric economy?

Bertrand Warusfel, Professor at University of Paris 8, member of the Paris Bar (FWPA)

In an economy whose innovations and productivity are largely based on the production, exchange and processing of digitized information, data is acquiring increasing economic, social and political value. But the corollary of this statement is that, like any value, "data" is subject to extreme competition and provokes both litigation and a demand for European, or even international, regulation.

We are therefore seeing the gradual emergence of a data law, which we would like to summarize here. This legal framework remains rather heterogeneous and very partial. But the very important (and no doubt quite disturbing) effects of the exploitation and algorithmic processing of data in the years to come should serve to accelerate the structuring of this law, provided that clear political choices are made to specify the essential values that a digitized economy must respect.

Data-driven and AI in healthcare: bringing the "Human Guarantee" MedTech and HealthTech ecosystem to life!

David Gruson, Director of the Luminess Health Program and co-founder of Ethik-IA

PariSanté Campus is the new major ecosystem of digital health in France and internationally. Its priority orientations include the development of a strong Healthtech and Medtech sector, focused on data-driven management and artificial intelligence (AI) in healthcare. The attractiveness of France and Europe will depend not only on the deployment of innovative technologies and methodologies in these areas, but also on a strong commitment to positive ethical regulation centered on the new principle of the "Human Guarantee" of AI.

People in the Sun: light up your data

Charles Huot, People in the Sun Company

It is nowadays a truism to say that data is one of the essential drivers of the economy. Digital is present at all levels of society and one of its physical expression is the growing increase (+50% per year) of data production and storage capacities. Data is born and grows over and over again; it never dies; and the more we consume it, the richer it becomes. Unlike our natural resources, data is an inexhaustible resource that irrigates the world's communication networks under water, on land, in the air and in space. We should perhaps replace the verb "to irrigate" with the verb "to flood" or "to submerge" because the volume of data is so overwhelming our information systems. We can even talk about digital bulimia.

At People in the Sun, we accompany organizations in their reflections on the use of data. The questions are multiple and cover technological, economic and legal fields, but also ethical ones. Each of these fields deals with a particular aspect of data.

Valorization of human health research and data protection in the digital age

Frédérique Lesaulnier, Doctor of Law, Data Protection Officer of the Brain Institute

Human health research is undergoing a digital revolution due to the huge amounts of data available, which are collected in multiple environments, and the possibility of extracting knowledge and correlations from them thanks to technologies that increase storage and processing capacities. At a time of open science

grand challenges, the GDPR is leading to a refocusing of the data protection organization on the organizations that process it. Compliance with the regulation must be integrated into a global approach to data governance and requires the involvement of the people who generate the data. We will present here a few avenues of reflection and action developed by research actors for an ethical and responsible use of personal health data.

International research and data protection

Gaëlle Bujan, Data Protection Officer, CNRS

Research is evolving on a global scale in terms of its foundations, its values and its networks of experts. In the digital age, the acceleration of exchanges and research perspectives accompany the dissemination of knowledge, the limits of which are constantly being pushed back. At the same time, the risks are new and multiplied; they are associated with the imperatives of integrity, ethics and respect for people. Regulations are adapting to this movement: they aim to make the players more responsible, to contribute to society's confidence in research and are becoming increasingly protective of rights and individuals.

In this evolving and seemingly restrictive environment, research organizations have put in place policies that promote a culture of data protection and the achievement of their objectives on an international scale. International research and data protection regulation are not mutually exclusive.

Aligning access to microbiome data and privacy considerations for better solutions for health and wellbeing of society and environments

Frederik Coppens, VIB-UGent, ELIXIR Belgium, Gent, Belgium, **Lene Lange**, BioEconomy Research & Advisory, Copenhagen, Denmark, and **Kathleen D'Hondt**, Department Economy, Science and Innovation, Flemish Government, Brussels, Belgium

There is a growing body of evidence that underpins the importance of microbiomes in biology. Understanding the functioning of microbiomes and their interaction with the environments will allow to develop novel interventions to support human, animal, and plant health as well as the environment. The potential that microbiomes can have to prevent the onset of non-communicable diseases is huge. This can only be developed when studying the impact of lifestyle, nutrition and environment in the context of the genetic content. As human microbiomes have been shown to be stable over time and can allow to identify the 'carrier' of the microbiome, access to microbiome data has been questioned in the light of privacy protection and the General Data Protection Regulation. In this paper we discuss the potential of microbiomes in different areas and how microbiome data may be shared to support the concept of doing good.

2 – The data economy: what uses for data at the heart of collaborations, partnerships or collaborative platforms. What data to share? Who should have access to it?

Epistemological issues in data science

Jean-Gabriel Ganascia, Specialist in artificial intelligence

After recalling the singularity of "masses of data", which is not only due to their volume, but also to their evolutivity and variability, we will show that both their accumulation and their exploitation have proved necessary for the major players of the Web and that this is due to three reasons linked to the specificity of digital industries. We will then reflect on data science and on the opposition between, on the one hand, those who claim that correlations are now sufficient and, on the other hand, those who still insist on the use of models and on the key epistemological function they play in the scientific process. We will conclude on the current lack of a mathematical theoretical framework for data science, while evoking the old theories, those that existed in the 1990s, and opening up to progress in this direction.

Encryption, or the contribution of cryptology to the security of data storage, transmission and processing

Louis Goubin, Professor at the University of Versailles Saint-Quentin-en-Yvelines – Université Paris-Saclay, director of the "Cryptology and Information Security" research group at the LMV laboratory (UMR CNRS 8100)

The development of techniques for the storage, transmission and processing of digital data creates an increasingly acute need for securing this data. Cryptology, which is often called the science of secrecy, provides solid answers, often with mathematical proofs, to the question of data confidentiality, and thereby to the protection of privacy. We propose here an excursion through the problem of data encryption, from basic cryptographic principles to more complex applications requiring the ability to perform calculations on encrypted data. New perspectives are opening up thanks to recent techniques, one of the challenges being to articulate security and regulatory compliance, when it comes, for example, to supply chains in industry or platforms implementing a sometimes worrying analysis of the users' personal data.

Helping researchers better manage their research data: the data librarian profession

Laetitia Bracco, Curator of libraries at the University of Lorraine

Research data are progressively considered as scientific productions of their own, in all disciplines. In the context of Open Science, more and more requirements are made by funders and by public policies in general to

better produce, structure, preserve and open these data. Access to the data underlying publications is also increasingly requested by scientific journals, as part of their commitment to integrity and transparency. Scientific and technical information staff, in university libraries as well as in other structures, are thus required to support and train researchers in all these issues. To carry out this mission, it is necessary to increase the skills and develop new activities for those who hold the emerging position of data librarian.

The Health Data Hub, a lever for the valorisation of health data

Stéphanie Combes, Director of the Health Data Hub (HDH)

By seeking to mobilize the full potential of health data to improve the health system, the Health Data Hub is at the crest of the innovation wave.

Its objective is to enable and simplify access to health databases (mainly the *Système national des données de santé* (SNDS), the French national health insurance database) in order to reuse them for research purposes.

Faced with the many issues raised, the platform has taken the decision to include its ecosystem and citizens in its project, as well as to open up to an international perspective: to be able to align the Health Data Hub with all the actors involved and future prospects.

Data science in health and data protection of Metavers

Adel Mebarki, Co-founder and CEO of Kap Code

The use of social networks in healthcare is constantly growing within an increasingly connected society. These platforms have become real tools in patients' pathways. From searching for information to building communities, social networks are becoming a permanent part of the "digital care pathway" for patients and healthcare stakeholders. This spontaneous generation of real-life data is the subject of multiple research projects for public health purposes. However, with the advent of the Metavers, several ethical and societal issues arise around the use of these sensitive data.

The challenges of Metaverse in terms of personal data protection

Thomas Fauré, President and founder of Whaller

The metaverse announced by Mark Zuckerberg will be a universe beyond the one we know in which "you will be able to do almost anything you imagine: work, learn, play, buy, create (...)". Cut off from the physical world, the "metanaut" will be totally immersed in a new digital world. With no limits, the metaverse will have major anthropological consequences. At the same time, the amount of personal data produced will be exponential, as will the difficulties of protecting it. Everything the user does can be exploited for or against him. "Augmented data", biometric and behavioral, will make it possible to offer even more targeted advertising than today. GAFAMs are already filing patents for their collection

and potential exploitation. In this new world, where current regulations will quickly become outdated, it is important to think about the future protection of each person's fundamental rights.

3 – Humanities and data: the challenges of changing societies through data. Trust in the digital age

A decade and a half of OECD action on data governance policy-making

Elettra Ronchi, Senior Policy Consultant on Data Governance and Digital Health WHO/Europe; former Head of the Data Governance and Privacy Unit in the Division for Digital Economy Policy at the OECD, and **Christian Reimsbach-Kounatze**, Information Economist and Policy Analyst in the Division for Digital Economy Policy at the OECD

The OECD has long recognized the need to better understand how to reconcile the risks and benefits of data access and sharing to help governments reap the benefits of data-driven innovation. To guide policy-making, the OECD has produced over the last decade and a half a significant body of analytical work and legal instruments setting out principles and best practices to address sector- or domain-specific challenges in the governance of data. These Recommendations include: the Recommendation concerning Access to Research Data from Public Funding ; the Recommendation for Enhanced Access and More Effective Use of Public Sector Information ; and the Recommendation on Health Data Governance . In what appears to be the latest strong demonstration of its commitment to the issue, the OECD Council adopted in 2021, the Recommendation on Enhancing Access to and Sharing of Data (EASD Recommendation). Differently from the preceding ones, the EASD Recommendation provides an overarching set of principles and policy guidance to help governments reconcile potential risks and benefits and unlock the re-use of all types of data across and within sectors, jurisdictions, organisations, and communities. The aim of this paper is to put in context this significant body of work and set out the main policy issues addressed by these OECD Recommendations.

The CNIL faces the challenges of building a trusted digital society

Étienne Maury, CNIL

For the CNIL, ensuring trust in the digital age responds to legal and regulatory issues, but also ethical, technological, economic and societal ones. Its action and its role are evolving and face multiple challenges, which are not only national but also European and international, given the geography of the globalized digital economy. The apprehension of these challenges constitutes the framework in which the CNIL places

its strategy to respond to current and future matters. In addition to the need to guarantee the effectiveness of the fundamental right to the protection of personal data, there are also issues related and intrinsic to the evolution of the digital ecosystem, whether in terms of support and innovation but also legislative and regulatory developments at European level.

Data altruism: how can data be used to serve the general interest?

Éric Salobir, President of the executive committee of the Human Technology Foundation and founder of OPTIC

The volume of data continues to grow, yet it is largely underutilized. This paradox is a major obstacle to initiatives that benefit the general interest. Data altruism, an innovation in data sharing theorized by the European Commission, could be a solution to this problem by removing the mistrust that hinders such sharing. In the report "Data altruism: a European initiative, data for the public good", the Human Technology Foundation and the Sopra Steria Next Exploratory set out to show how the still theoretical concept of Data altruism can become a reality. In this article, we detail the major proposals of this report and show that it is possible to build a system that greatly facilitates the provision of data to help initiatives working in favor of the general interest.

Has data become the primary issue in cybercrime?

Éric Freyssinet, General officer of the Gendarmerie

Data is at the heart of cybersecurity issues, as the main target of cybercriminals, as a tool for the same, but also as a tool for information systems defenders. This concerns both personal data and all sensitive data of organizations. And the risks are not only related to the famous ransomware, even if it is the most dynamic threat.

The challenge of data for cyber defense

Didier Danet, Lecturer (HDR) at the University of Rennes 1

The digital space is a field of conflict, where the control of data is an issue of growing importance. Indeed, contrary to a widespread vision, cyber defense is not only interested in the protection of interconnected information systems (the container), but also in the protection of information content, of which data is the raw material. However, if the control of data is becoming a central issue in cyber defense, it is rendered almost illusory, notably because of the "datafication" of the world, the digital revolution at work, and new social practices that weaken the capacity of states to control the production and circulation of data. In this article, we suggest exploring two avenues of reflection: the first aims to better protect the stocks of data in the possession of civilian and military institutions, and the second to make actors responsible for generating data flows.

4 – What does the data say about humans?

Accountability at the heart of data protection: what data says about the human being

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The acceleration of innovations makes it essential to reflect on the societal, ethical and legal issues related to the use of data, in particular on the notion of responsibility. The design of interdisciplinary safeguards and evaluation and monitoring systems, as well as the definition of governance adapted to the sociological, ethical and legal values of different countries, are currently emerging worldwide. It is around the need to agree on the notion of social responsibility that, for example, the neuroethics called for by the OECD Council through its recommendation n°0457 of 2019 on responsible innovation in neurotechnologies is being built. In the reflection on the notion of responsibility, the philosopher can bring an important light on this question. It is therefore by summoning Hans Jonas and Hannah Arendt, but also by using research ethics and neuroethics as well as existing laws and recommendations, that this work around social responsibility concerning data has taken shape.

Concluding Remarks

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Miscellany

Experiences with passive or positive energy buildings

Pascal Gontier, Professor at the École nationale supérieure d'architecture de Nantes and member of the Académie d'architecture

From the end of the 1990s onwards, the subject of energy savings has been gaining ground in the architectural debate, and requirement levels are gradually evolving. Those requirements which were focused on heat consumption at first are now extending to energy consumption as a whole and are taking carbon consumption into account.

My architecture practice has been environmentally committed since its very beginning, and this commitment has always been taking us forward, by anticipating changes when possible and going beyond regulatory or programmatic requirements. We are convinced that the twofold challenge that is energy consumption and environmental issues cannot be fulfilled through simple normative and technical solutions only.

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