Personalized Medicine and Data Technologies, Welfare System, and Ethical Issues

PersMed Lab

Thomas LEFEVRE

Sorbonne Paris Nord University, IRIS
Invited by the University of Tokyo

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Co-organised with the University of Tokyo, RIKEN and Keio University

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Programme

Health big data in France: about ten years of technical, organizational, and political developments

24 October 2023 | from 14:00 (Tokyo time)

At RIKEN: 2-1 Hirosawa, Wako, Saitama, 351-0198, Japan

In English

Abstract

In 2015, the French Ministry of Health and Social Affairs ordered an inventory and reflection on big data in health. At the same time, the French Prime Minister ordered a reflection and the establishment of an ambitious action plan relating to genomics for research and healthcare for 2025, aiming at building several platforms dedicated to genomic sequencing and high-dimensionality data analysis.

The first group, which I led and was constituted of public and private stakeholders, relied on a broad consultation within public and private institutions, research and industry, and the civil community. Our group's report and recommendations concerned 4 aspects: the technical, economic, legal and ethical, and social conditions of the development of big data in health in France. They served as a basis for initiating other structuring initiatives: the health section of the commission on Artificial Intelligence ("Villani" mission) in 2017-18, then the mission to prefigure the national data platform (also named Health data hub) in 2018, leading to the creation of this platform in 2020. The choice was made of a single and centralized architecture, the development of expertise in terms of large national and local databases linkage, and the promotion of the creation of hospital data warehouses. One of the missions of the Health data hub is to promote the reuse of health data for research and public health purposes, but also for the development by public or private actors of AI algorithms. At the same time, 4 interdisciplinary institutes in artificial intelligence were created in 2019 (3IA), as well as a priority equipment program for research in digital health in 2023. All of these initiatives raise a variety of technical, social and legal questions, which we will discuss during this lecture.

Health big data policy in France – a tentative micro socio-history approach

25 October 2023 | 18:00 - 20:00 (Tokyo time)

At Keio University: 35 Shinanomachi, Shinjuku-ku, Tokyo 160-8582, Japan

In English

Abstract

In 2015, the French Ministry of Health and Social Affairs ordered an inventory and reflection on big data in health. At the same time, the services of the French Prime Minister ordered a reflection and the establishment of an ambitious action plan relating to genomics for research and healthcare for 2025. While I was piloting the first group, and it seemed logical to consult with the second group, we were explicitly asked not to communicate with each other and to work separately. This astonishing duality of reflection and action well symbolizes the situation and the dynamic about digital health in France, where history, the relationships of public institutions with each other and towards citizens as well as the political dimension shape broadly the current landscape: to understand the expectations and current concerns in terms of big data and artificial intelligence in health in France, it is necessary to represent the main actors, from the 80s to today.

In this lecture, I will therefore present a brief socio-history of French public institutions which explains the current opportunities and obstacles in terms of big data in health; I will take stock of the situation in terms of systems and initiatives to promote a certain number of uses of big data and AI, as well as the relationships maintained between France and Europe, but also the United States on this issue, particularly in terms of regulation and data protection. I will draw the ecosystem of health data in France, highlighting the areas where the efforts of the different actors are concentrated, in what form, but also the areas of weakness or of lesser interest. Among other things, I will address these specific questions: What are the expectations and concerns in France regarding R&D and medical applications based on medical big data? How are stakeholder concerns being overcome?

Frontières et modes d'existence de la médecine personnalisée à l'ère du numérique

27 October 2023 | 15:00 - 17:00 (Tokyo time)

At The University of Tokyo: 7 Chome-3-1 Hongo, Bunkyo City, Tokyo 113-8654, Japon

In French and Japanese

>> MANDATORY REGISTRATION <<

Abstract

Le programme de la médecine s'est articulé depuis au moins l'Antiquité autour de ces 3 éléments : un sachant qui peut être aussi praticien, des savoirs concernant les affections et les moyens de s'en prémunir ou de s'en débarrasser, et une personne, un consultant, un « malade ». Ce programme inclut donc par nature, un caractère individuel et personnalisé.

Ces dix dernières années, le concept de médecine personnalisée, plus largement de médecine 4P (personnalisée, préventive, participative et prédictive), suscite un regain d'intérêt au sein du monde de la santé.

Que peut signifier, et impliquer, cette médecine personnalisée ? En sus des 3 éléments cités, la médecine 4P rend plus visible la participation d'autres éléments

clés : le développement technologique, et les acteurs qui promeuvent ce développement d'un point de vue idéologique et commercial.

La personnalisation mise en avant entend toucher au moins deux moments des pratiques en santé : la prévention et le curatif. Ces deux moments ont vu leurs moyens d'action augmenter grâce d'une part au développement d'un modèle biomédical de la santé prédominant, appuyé sur l'essor de l'evidence-based medicine mais aussi de l'épidémiologie et du concept de facteur de risque, et d'autre part des technologies comme celles de séquençage du génome et du numérique.

Aujourd'hui, la médecine personnalisée est à l'intersection du discours, du développement technologique et de ses potentiels apports à la santé. Ce discours est tenu par plusieurs acteurs, aux intérêts qui peuvent diverger et apportant autant de définitions de la médecine personnalisée : à partir d'une approche interdisciplinaire liant sociologie, épistémologie appliquée et sciences de la santé, nous proposons de discuter de la position de ces acteurs (professionnels de santé, entreprises technologiques, financeurs entre autres), des définitions qui en découlent ainsi que des implications actuelles ou possibles de ce discours sur les pratiques en santé et le système de soins en France. Enfin, nous reviendrons sur l'articulation entre social et individuel et les dimensions non technologiques de la personnalisation.

Speaker

Thomas LEFÈVRE (Sorbonne Paris Nord University, IRIS)

Thomas Lefèvre is Assistant Professor – healthcare practitioner in legal medicine and health law, at the Sorbonne Paris Nord University and at the J Verdier hospital, in the legal and social medicine department. He is a researcher at IRIS (CNRS-Inserm-EHESS-USPN). He is an engineer from the Institut Mines Telecom (2005), specialized in signal and information processing, obtained a PhD in applied mathematics and epistemology, and a ScD in social epidemiology. He is a medical doctor specialized in public health and forensic sciences. He holds the "habilitation à diriger les recherches" and supervises and co-supervises 6 doctoral students. One of his two main research themes focuses on the study and assessment of the impact of digital technology and AI on professional organizations at a micro-social scale, in health and in criminal law, which he explores using mixed methods and from an interdisciplinary perspective. For example, he led the interdisciplinary Big Data Drop IT project, completed in 2020, on the impact of predictive techniques in forensic medicine and criminal law. He led two national working groups, one for the French Ministry of Health (Big data and health, 2015-16), the other for the High Council for Public Health (National Strategy for Registries in the Age of digital, 2020-21). In 2017, he created the ORFeAD network – Tools and network for the federation, analysis and use of data in forensic medicine, making extensive use of different AI techniques to facilitate access and structuring of multicenter research. He is the author of more than thirty scientific articles, and recently contributed several chapters to the reference textbook *Artificial Intelligence in Medicine* (Springer Nature).

Personalized Medicine and Data Technologies, Welfare System, and Ethical Issues

(PersMed Lab)

GOALS

The PersMed lab raises three fundamental questions:

- **What are the respective benefits of home care and hospitalization?**
- **How personalized medicine can contribute to a public policy of prevention?**
- **How to conciliate the development of personal medicine and the protection of personal data?**

CONTEXT

During the last decades, tremendous progress has been achieved in the application of new technologies to health. In this context, there are rising expectations that major health issues can be technologically managed and that we will observe further increase of human longevity. In particular, it allows us ambitioning the development of personalized medicine, i.e. diagnosis and treatment that are tailor-made for each patient (Schleidgen et al., 2013). A key is the accumulation of data in order to increase our knowledge of each patient through the statistical management of individual heterogeneity.

In this context, the potentialities of data management by extended intelligence or by artificial intelligence (AI) have attracted a lot of attention (Morley&Floridi. 2020, 2019). It is considered as the most promising avenue in terms of innovation and transformation of our socio-economic systems but also of our intimate life (Lechevalier, 2019; Ema et al., 2016). To put it simply, AI in healthcare is an overarching term used to describe the use of AI to mimic human cognition in the analysis,

AI is considered as the most promising avenue of our socio-economic systems and our life.

presentation, and comprehension of complex medical, and health care data. Although the concrete applications of AI to healthcare are diverse (e.g. using AI to efficiently diagnose and reduce error; making more accurate and earlier cancer diagnosis with AI; developing new medicines with AI), it is possible to consider that the primary aim of health-related AI applications is to analyze relationships between prevention or treatment techniques and patient outcomes. At the same time, despite or because of all these promises, AI in healthcare raises several unprecedented ethical concerns related to its practice such as data privacy, automation of jobs, and representation biases (Lechevalier, 2019).

AI is just one example, among many others that deserve our close attention, as they have in common to mobilize personal data on health, with the goal of developing a personalized medicine, in the same spirit than what was allowed by past personal relationship between doctors and patients. The range of application is also very wide from delivery of oxygen at home for a patient suffering from various kind of respiratory problems to diagnosis of cancer or the conception of drugs. It concerns medical care in institutions (hospital, clinics) and at home.

These technological premises cannot be realized in putting aside the functioning of our health systems.

They also lead to several concerns that

AI in healthcare raises several unprecedented ethical concerns such as data privacy, automation of jobs, and representation biases.

are diverse in nature (Dalgarrondo&Hauray, 2018). First of all, the development of personalized medicine is at odds with the logic of health insurance systems that are build on a socialization of risks and on a normalization of diagnoses and treatments. At the same time, these socialization and normalization show some diversity across countries, for example from the US – where individual health insurance principles are still dominant and lead to health expenditures that are both diverse across income groups and among the most important in the world – to Scandinavian countries – where the principle of public health insurance is the strongest. Besides the insurance issue, which is a condition for the solvability of personalized medicine, the

organization of health systems themselves is an important factor

that may promote and impede the development of personalized medicine: it can be more or less decentralized, dominated by some groups (e.g. doctors) or others (e.g. institutions) and centered or not on public hospitals for example. Last but not least, the use of personal data raises ethical and political concerns. The access to and the use of these data are a condition for the development of personalized medicine. However, it lies on the consent of patient and is conditioned by a certain level of trust for the institutions in charge of storing, sharing, and using these data. Is it p o s s i b l e to give this

responsibility to the private sector? Is the leadership of public institutions the guarantee of the absence of any misuse or abuse?

The development of personalized medicine is at odds with the logic of health insurance systems that are build on a socialization of risks and on a normalization of diagnoses and treatments.

relies on estimations with different methodologies (e.g. economic methodology focusing more on efficiency and cost and sociological methodology focusing more on well-being) and a political economy perspective that takes into account the different vision of stakeholders (doctors, patients, health insurance, g o v e r n m e n t , etc.). Based on this preliminary investigation, it is then possible to discuss the limits of the mandatory health insurance in a context of personalized medicine. One polar position is to focus on public insurance, in this case, it is difficult to value the diversification of health services in order to take into account the heterogeneity of individuals, even if the quality of healthcare is taken into consideration. The other polar position is to consider that personalized medicine requires getting out the framework of public insurance. Between these two polar positions, there are of course diverse intermediate positions.

THREE QUESTIONS

This context raises three fundamental questions that will be at the center of our investigation:

1) **What are the respective benefits of home care and hospitalization?** The issue at stake is to articulate these two modes with the practice of personalized medicine. It requires a preliminary investigation that
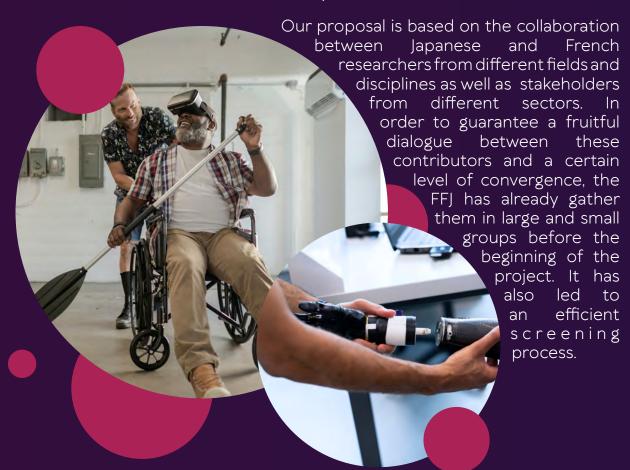
2) **How personalized medicine can contribute to a public policy of prevention?** From this perspective the key issue is to analyze under which conditions personalized medicine can contribute to the overall containment of healthcare expenses.

3) **How to conciliate the development of personal medicine and the protection of personal data?** From this perspective, the key issue is identifying the institutional, social, and political conditions to build trust between stakeholders.

OUR CONTRIBUTION

In this context, it is important to mobilize not only data scientists and engineers but also researchers in social sciences in order to discuss, criticize and compare the uses of data in healthcare, together with stakeholders, patients, medical doctors, policy makers, and the industry. Moreover, given the differences across countries, adopting an international and comparative perspective is essential. From this viewpoint, a dialogue between Japan and Europe is particularly relevant, the technological advances in this field are comparable, the ethical principal are similar, while there is a significant institutional, social, and cultural diversity.

Our proposal is based on the collaboration between Japanese and French researchers from different fields and disciplines as well as stakeholders from different sectors. In order to guarantee a fruitful dialogue between these contributors and a certain level of convergence, the FFJ has already gather them in large and small groups before the beginning of the project. It has also led to an efficient screening process.

>> PersMed Lab page - http://ffj.ehess.fr/lab_persmed.html

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Find out more about the project on FFJ website

ffj.ehess.fr/lab_persmed.html

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